

29 July 2015

Ms Austin
Senior Assistant Clerk
Committee for Health, Social Services and Public Safety
Room B32
Parliament Buildings
Ballymiscaw
Stormont
Belfast
BT4 3XX

Dear Ms Austin

Please find below my views/comments on the health and Social Care Bill which is going through the legislative process at present. I have general remarks and some later specific to the Bill's content. I feel this Bill is crucial for the ongoing assessment and improvement of health services in N. Ireland. Let me give an example.

The N. Ireland Cancer Registry (NICR) which is funded by the Public Health Agency and located in Queen's University, Belfast has provided many outputs over the past 21 years using data which has been collected in the course of patient care. These data have allowed us to measure the numbers of cancers occurring in the population, this allows us to quickly assess if there are more cancers in one area than another, it also allows us to monitor the care that cancer patients receive and answer questions about survival and the total numbers of cancer patients living here after a diagnosis of cancer.

Health service planners, charities, the media, clinicians and patients all use this data.

The NICR has documented a 40% increase in cases since 1993 and predict a further 66% over the next twenty years.

It provides information to Trusts to enable them and the Department monitor the care of patients in each hospital.

It provides information to help monitor the accuracy and quality of the cancer screening services (Cervix, Breast and Bowel).

It has surveyed men to see how their treatment of prostate cancer has affected their lives and this information is leading to improvements in service for these men.

It provides information to help the clinical genetics service when advising family members of cancer patients.

Registry staff have researched conditions that might lead to cancer and also the care of patients as they approach death.

This is all completed without disclosure of personal identifiable information. See NICR website www.qub.ac.uk/nicr

These outputs have directly improved the management of cancer patients and their outcomes including survival.

The NICR could not undertake this work with anonymised data as we need to count every case separately and also link using names etc for clinical genetics and other work. It would also be too difficult to achieve patient consent due to logistics of when this would be sought and how it would be recorded during the interactions of patients with the clinical service at a very traumatic time for patients. NICR does however have an 'opt' out for patients who do not want to be registered or contacted for surveys etc. This and the registry's work are advertised via a patient leaflet and also through a video available from NICR website.

Without this proposed legislation the work of the N. Ireland Cancer Registry would likely have to cease.

The NICR is currently unable to provide already collated anonymised data for national audits of patient care due to lack of a legislative framework. This means that we cannot compare the care of Northern Ireland patients with lung, colorectal, upper Gut or urology tumours with that of patients from England, Wales or Scotland. Such comparisons are important for benchmarking and improving clinical practice and ultimately patient care and survival. It is important that this proposed legislation would also apply to historic data held in existing disease registries and also facilitate work undertaken outside of the Health Service such as in a secure area of the University where the N. Ireland Cancer Registry is currently located.

Specifically relating to the contents of the Bill:

Section 3(1) page 4 – I welcome the plan to develop and publish a Code of Practice with regular revisions.

Section 3(4)-3(6) page 4 – This and several sections of the proposed Bill refers to Health and Social Care Bodies. Some organisations eg Queen's University Belfast is undertaking innovative and important work providing population based information for epidemiological research on disease causation and outcomes using Health & Care Data. Two examples of this are the N. Ireland Cancer Registry and the Cerebral Palsy Register. The legislation should be phrased in such a way as to ensure it does not exclude such work.

There is a need for this legislation to apply retrospectively to Health & Social Care data already collected eg 21 years of cancer incidence data for N. Ireland in the N. Ireland Cancer Registry.

Section 2(3)a page 3&4 – The establishment of a committee to authorise processing of confidential information is welcome. I consider that it should have some representation of patients.

Section 11(a)ii page 3 – It is good to see prevention included as NICR registers premalignant disease eg Barrett's Oesophagus, colorectal polyps and this has yielded important information on disease risks at population level and factors for prevention of progression.

Section 10 page 2 – re Information – The definition of information should also include basic sociodemographic facts such a name, date of birth, postcode, ethnic group, gender and marital status to enable comprehensive monitoring of disease at population level.

Is there a complaint process in case of breaches or perhaps that is not necessary to define at this stage.

I welcome this Bill as it will bring N. Ireland into line with other areas. It is good to have clarification on this matter and not rely on an organisations ability to satisfy a public interest test.

Please contact me if you require any additional information.

Yours sincerely



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