



SCHOOL OF MEDICINE, DENTISTRY & BIOMEDICAL SCIENCE

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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

I welcome the opportunity to present views to the Committee for Health, Social Services and Public Safety on the Health & Social Care (Control of Data Processing) Bill. I support the proposal to introduce legislation to enable the Department to regulate the use of service user information for secondary purpose in controlled circumstances. I believe that access to patient data is essential for cancer research and to improve the outcomes including survival of cancer patients. The information held about patients in their medical records, in cancer registries and other datasets can be used to research the causes of cancer, monitor survival rates, study the effectiveness of treatments and interventions such as screening. The work of the Northern Ireland Cancer Registry is essential for the above, I appreciate that this legislation would protect the Registry's work from potential legal challenge.

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 are undertaking innovative and important work providing population based information for epidemiological research on disease causation and outcomes using Health & Care Data; an example is the Northern Ireland Cancer Registry. 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 previously collected eg 21 years of cancer incidence data for Northern Ireland in the Northern Ireland Cancer Registry.

I welcome this Bill as it will bring Northern Ireland into line with other areas. We are pleased to have clarification on this matter and not rely on an organisations ability to satisfy a public interest test.

Yours sincerely

A handwritten signature in dark ink, reading 'Roy Spence'. The signature is written in a cursive style, with a long horizontal stroke underlining the name.

Professor Roy Spence
Chair, Northern Ireland Cancer Registry Council
OBE, JP, MD, MA, LLD (Hon), FRCS (Edin, Ire), FRCS (Hon - Eng, Glas)