Genetic Alliance UK
Supporting. Campaigning. Uniting.

Control of Data Processing Bill

Committee for Health, Social Services and Public Safety
Northern Ireland Assembly

Response to call for evidence, from Genetic Alliance UK, 7th August 2015

Introduction

1. Genetic Alliance UK is the national charity working to improve the lives of patients and families affected by all types of genetic conditions. We are an alliance of over 180 patient organisations. Our aim is to ensure that high quality services, information and support are provided to all who need them. We actively support research and innovation across the field of genetic medicine.

2. Rare Disease UK (RDUK) is a multi-stakeholder campaign run by Genetic Alliance UK, working towards the delivery and implementation of the *UK Strategy for Rare Diseases*[1], signed by all four health departments in the UK and published by the Department of Health in November 2013.

3. In 2011, we collaborated in the establishment of the Northern Ireland Rare Disease Partnership, with which we maintain strong links.

4. Data use, sharing and governance are critical issues in the rare and genetic disease arena. In this document we seek to inform the Committee of the value of secondary use of data to the rare disease community and of the rare disease committee's attitude to this.

5. We are grateful for the opportunity to submit evidence.

Clause 1: Control of information of a relevant person

1.—(1) The Department may by regulations make such provision for and in connection with requiring or regulating the processing of prescribed information of a relevant person for medical or social care purposes as it considers necessary or expedient—
(a) in the interests of improving health and social care, or
(b) in the public interest.

6. From the perspective of the rare disease community, there is much value to be had from such provisions. The scale of the challenge to the NHS that rare, genetic and undiagnosed conditions present is difficult to ascertain. It is not currently feasible to find how many citizens are affected by almost any rare or genetic condition without proper implementation of these provisions. (Where it is possible, it is usually due to independent data collection by a patient organisation or research project.)

[1] UK Strategy for Rare Diseases. Department of Health, published November 2013, available at: www.gov.uk/government/uploads/system/uploads/attachment_data/file/260562/UK_Strategy_for_Rare_Diseases.pdf

Unit 4D, Leroy House, 436 Essex Road, London, N1 3QP
+44 (0) 20 7704 3141
contactus@geneticalliance.org.uk
www.geneticalliance.org.uk

Registered charity numbers: 1114195 and SC039299
Registered company number: 05772999

7. Without this basic information it is impossible for the NHS in Northern Ireland to plan effectively and evolve the healthcare system into one optimised for delivering healthcare for the patients that Genetic Alliance UK and its Rare Disease UK campaign represent.

8. Many rare diseases are severe and life-limiting. For individuals or families affected by most rare diseases, the day-to-day challenges of managing a severe condition are made worse by the absence of an effective treatment or cure. These patients look to research as the source of new therapies to address their unmet health need. In order for progress to be made, patients recognise that the rarity of their conditions means that research relies on the effective sharing and use of their medical data, nationally and internationally.

9. Patients in the rare disease community therefore tend to be familiar with the need for their data to be shared and used widely. Given the small number of individuals affected by these conditions, patients recognise that collecting as much data as possible is vital to help research into the prevention, cause and treatment of rare conditions. Indeed we have anecdotal evidence of patients' and patient organisations' frustration at not having their information shared with researchers due to overly restrictive consent requirements.

10. Rare disease patients recognise that there is an inherent risk that they could be identified personally from some of their data. Despite this, rare disease patients are willing to share their medical data in order to support research[2]. For these patients, not sharing data would be detrimental to research efforts and as a result, to potential scientific advancements that could improve their quality of life.

Clause 2: Establishment of committee to authorise processing of confidential information

2.—(1) For the purposes of subsection (2), the Department may by regulations establish a committee.

11. There has been significant public debate about the sharing of medical data for research in recent years with concerns over data security, privacy and access discussed. It is essential that there are clear, functional systems in place to transparently govern the sharing of data whilst reassuring the public that their data will be stored and shared safely and accountably. The establishment of a committee to authorise processing of confidential information will be necessary to ensure such regulation is governed effectively and transparently.

12. We support the Chairperson of the Committee's assertion on the 17th June 2015 that the formation of such a committee is essential, and support amendments to achieve this.

13. Clause 2 does not discuss the membership of this committee. We would recommend that the committee should include at least one member from the patient community, particularly to ensure that the views outlined in paragraphs 8-10 of our response are represented

Conclusion

14. Patient data is of critical importance to quality improvement, service design, public health and medical research in the NHS. Genetic Alliance UK supports an approach to empower the release of these benefits to the patient community with appropriate use of such data.

Alastair Kent OBE
Director

---

[2]'Genome sequencing: What do patients think?', February 2015, available at: http://www.geneticalliance.org.uk/docs/patient-charter-genome-sequencing-what-do-patients-think.pdf