



**Submission: Health and Social Care (Control of Data Processing) Bill**

The Huntington's Disease Association Northern Ireland works with professionals, family members, those at risk of and symptomatic with Huntington's across four strands- supporting, connecting, informing and campaigning. HD is a rare genetic disease which causes progressive loss of control in three areas- motor skills, cognitive ability and behaviour until people become entirely reliant on others for care and unable to communicate or swallow. HD is incurable and carries a 50% risk of inheritance though in many families the actual incidence of HD can be as many as 7 out of 8 siblings. Simply put, HD destroys not only individual lives but generation after generation of families.

HDANI are writing in support of the Health and Social Care (Control of Data Processing) Bill which we believe can radically improve the effectiveness of service provision. At present there is a barrier between the statutory and voluntary sector in supporting those affected by HD. At HDANI we have a secure database of all our clients and through them have commenced a family tree exercise whereby we can identify those affected and those at risk of the disease. In this way, existing members can reach out to family members who then get in touch with us for information about our support services. However the list of people we have is not aligned with the list of people having been diagnosed via the Regional Genetics Service for data protection reasons or those being seen at movement disorder or neuropsychiatric clinics. For this reason there is a gap not only in terms of our service provision but crucially in terms of where and how people are affected by HD meaning that there is also a grave imbalance in the availability and quality of statutory services. This impacts not only on the delivery of existing services but also in planning future service delivery as HD is a disease which will continue to manifest and multiply generation after generation. **We need a secure way to share patient information between those directly engaged in research and service provision to ensure the accessibility and quality of patient care.**

While there is no cure at present there are numerous advances taking place in drug trials to manage the condition and research in gene silencing to prevent or delay onset. At present studies are ongoing across the globe and several major pharmaceutical companies have invested billions of pounds in research. A number of studies have proceeded to human drug trials. However in the absence of a disease registry HD affected people in Northern Ireland are missing out on the opportunity to partake in trials and contribute to research. Most recently in the Republic an Enroll HD clinic has been established at Beaumont Hospital in Dublin with talks underway for further clinics in Cork and Galway. Enroll-HD is or will soon be up and running for HD families in North America, Europe, Latin America, Australia, New Zealand and some countries in Asia. It will eventually include more than 20,000 people.



Monitoring people over time in a real-world setting contributes to scientific knowledge. The study is designed to accelerate the discovery and development of new therapeutics for HD. At present the absence of legislation prevents the establishment of an Enroll centre in Northern Ireland which involves an annual review of symptoms, completion of simple cognitive tests and taking of blood samples to search for bio markers. All information is coded and maintained anonymously in a secure database which is accessible to anyone working on HD across the globe. Engaging in such trials, tests and registries is a way for those with a death sentence to help the next generation which usually includes their own family members. It instils hope. **HD patients in Northern Ireland are unable to contribute to and benefit from international research and best practice development.**

There is also the possibility of Pre-implantation Genetic Diagnosis which allows the disease to be essentially bred out of a family line through a form of IVF which only implants HD free embryos. However little information exists in Northern Ireland on such things meaning that we encounter families who have had children and passed on the gene without realising the possibility or being aware of any alternatives. A patient registry could ensure that childbearing women at risk are given this information and that options around family planning are distributed in a targeted manner. **Effective use of patient data could help eliminate inherited diseases.**

While we are broadly supportive of the Bill we are not without our concerns in light of the discovery of significant data breaches by statutory and private bodies in recent years. We know all too well the discrimination faced by those with disabilities and hereditary diseases in particular in the areas of finance, insurance and employment. This has led in the United States to specific pieces of anti discrimination legislation on genetic conditions. The gathering, collating, inputting, storage and use of patient data must be subject to a process of openness, transparency and stringent oversight. The entire process should be open to public scrutiny and undergo independent monitoring and review preferably by a means which engages patients and their advocates. **The security and appropriate use of patient data must be assured without compromising the valuable opportunities for collaborative cross sectoral work.**

In conclusion the establishment of disease registries and smarter use of patient data can contribute to genuinely evidence based commissioning, service planning and equitable service delivery across Northern Ireland which will lead to an improvement in the health and wellbeing of patients, their carers and families.

Please get in touch if you require further information,

Yours sincerely

**Sorcha McGuinness**  
Director

