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11th October 2022

PQ 47209/22: To ask the Minister for Health if he will provide a report on waiting lists for a genetic test for BRCA1; the number of persons who are waiting; the average waiting times per hospital in tabular form; and if he will make a statement on the matter.

PQ 47210/22: To ask the Minister for Health the supports that are in place for someone who tests positive for BRCA1; and the frequency with which they receive these supports

Dear Mark Ward,

Specialist cancer genetics services are provided at St James's Hospital (SJH) Cancer Genetics Service and at the Department of Clinical Genetics, Children's Health Ireland (CHI) at Crumlin. Please note that the waiting times and numbers provided by the hospitals below are for any cancer genetics appointment, not specifically for an assessment and testing in relation to a genetic test for BRCA1 as that would not be possible to separate out.

There are currently 2,749 patients on the cancer genetics waiting list awaiting a cancer genetics appointment in SJH and 142 patients (adult and children) on the cancer genetics waiting list in CHI at Crumlin.

The current average waiting times for a cancer genetics appointment in SJH are listed in the table below. There are broken down by triage category (Urgent, ASAP, Routine, Re-referral) and relate to January to July 2022.

SJH waiting times for a cancer genetics appointment	
Visit Type	Average Days - Referral to Appointment
New-Re-referral	881
New-Routine	502
New-ASAP	41
New-Urgent	26
Overall Average	340

The data for BRCA1 patients on the waiting list is not available. However, the SJH service did see 20 patients for BRCA1 predictive testing (i.e. cascade testing in relatives) from January to July 2022, i.e. 3% of all new patients seen in clinic during this period

The Department of Clinical Genetics in CHI at Crumlin has over 2021/2 reduced the waiting list for genetic testing with regard to cancer genes from over 24 months to predominately under 12 months. This is due in large part to a targeted blitz of Consultant and Genetic Counsellor cancer waiting lists during COVID by maximising virtual appointments. The introduction, in May 2022, of a dedicated paediatric cancer genetics multidisciplinary monthly meeting is proving hugely successful in streamlining the diagnostic process for these children. Children Health Ireland is actively recruiting to an additional Genetic Consultant post in Oct 2022 to help improve access to genetic testing.

CHI at Crumlin waiting times for cancer genetics appointment	
0-3 months	48 (33%)
3 -6 months	70 (50%)
6-9 months	12 (8.5%)
9-12 months	8 (5.5%)
over 12 months	<5 (<3%)

Those who carry a BRCA1 gene variant are at increased risk of a number of cancers, most commonly breast cancer and ovarian cancer. The range of associated complex needs have been identified by the National Cancer Control Programme in a Health Needs Assessment for Persons Diagnosed with a Cancer-Predisposing Variant of BRCA1 and BRCA2 in Ireland, conducted in early 2022 with patients and healthcare providers. These include

The need for accessible, inclusive and jargon-free information resources for carriers

Access to suitably qualified specialist genetics healthcare professionals after diagnosis, to include family planning supports and specialist fertility services

Adequate access to risk-reducing measures, such as breast and ovarian prophylactic surgery, breast cancer surveillance and chemoprevention

The need for access to psychological support throughout the patient journey and

Specialist services relating to the adverse effects of risk-reducing measures, in this case the management of surgical menopause

Significant investment is required to establish a comprehensive service, which can meet these needs in a structured and timely way and to ensure equal access to a high quality service for all.

In May 2022, the HSE constituted a National Genetic and Genomic Steering Group to guide the development of a National Genetic and Genomic Strategy for Ireland. This will strive to improve access to genetic testing for patients and to a number of specialist genetics services. However, it is also essential that the necessary 'downstream' services for people with an inherited cancer predisposition (as outlined above) are appropriately resourced, to ensure the benefits to patients are realised.

Yours sincerely



Professor Risteárd Ó Laoide
National Director
National Cancer Control Programme

