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29th April, 2022

Deputy David Cullinane
Dáil Eireann,
Leinster House,
Kildare Street,
Dublin 2.

Dear Deputy Cullinane,

The Health Service Executive (HSE) has been requested to reply directly to you in the context of the following Parliamentary Question, which was submitted to this Department for response.

PQ 19212_22

To ask the Minister for Health the number of persons with Huntington's disease that were seen at memory assessment services and clinics in each of the years 2016 to 2021 and to date in 2022, in tabular form; the current waiting list for same; and if he will make a statement on the matter.

The HSE funds a range of community services and supports to enable each individual with a disability, including persons with Huntington's disease, to achieve his or her full potential and maximise independence, including living as independently as possible. Services are provided in a variety of community and residential settings in partnership with service users, their families and carers and a range of statutory, non-statutory, voluntary and community groups. Services are provided either directly by the HSE or through a range of voluntary service providers. Voluntary agencies provide the majority of services in partnership with and on behalf of the Health Service Executive.

There are a large number of rarer types of dementias for example Huntington's disease, identified in people under the age of 65. There is a challenge from the point of view of accurate diagnosis (Fadil et al., 2009). The Clinical Care Programme is working on the development of a pathway for Huntington's disease. This is focused on the clinical design aspect of a pathway of care for Huntington's disease.

Information on the number of people with Huntington's disease being seen at memory assessment services and clinics between 2016 and 2021 is not currently available. However, a system is being developed to support reporting through the dementia registry implementation programme which has funding to commence later this year. This is a project funded under the National Service Plan 2022 and includes a programme of work following publication of the report 'A feasibility Study for a National Dementia Registry for Ireland' (Hopper, 2021) commissioned by the National Dementia Office.

Implementation of the dementia registry will be undertaken on a phased basis and will include the use of a minimum dementia dataset across specialist services to support standard recording and collation of data including diagnosis and sub-typing of dementia.

Regards,

A handwritten signature in cursive script, appearing to read "Janette Dwyer", is written over a horizontal line.

Ms. Janette Dwyer
Assistant National Director,
Services for Older People, Change & Innovation