

FOI - 2037

16th May 2024

FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST

1. What is the population of people within the Trust?

Response:

This information is obtained in “ANNUAL REPORT AND ACCOUNTS FOR 2022-2023”.

[Annual Reports | Southern Health & Social Care Trust \(hscni.net\)](https://www.hscni.net/annual-reports)

Page 10 of the document confirms the following:- “We serve a population of approximately 388,700.

2. How many people living within the Trust have either a predictive or symptomatic diagnosis of Huntington’s disease?

Response:

This information is not held in an accessible format. We can provide the number of inpatient consultant episodes with a diagnosis of Huntingtons Disease

NUMBER OF INPATIENT FINISHED CONSULTANT EPISODES & DAYCASES WITH DIAGNOSIS OF *HUNTINGTONS DISEASE BASED ON END DATE BETWEEN 01/01/2021 TO 31/12/2023
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Notes:

*Information relating to Huntingtons Disease Diagnosis is based on Primary or Secondary Diagnosis Codes 1-15: G10.X (as confirmed by SHSCT Clinical Coding)

Clinical Coding Position for 2023 = 91.89 % complete; this means that information that has yet to be clinically coded will be EXCLUDED from these figures

Please note that a Patient may have attended hospital on a number of occasions either within the same calendar year or within any of the other calendar years (noted in column B and C); the number of Patients this equates to within each year is noted in column D.

Calendar Year	Inpatient Finished Consultant Episodes	Day Cases	Number of Patients Equates to
2021	6	0	<5
2022	21	<5	7
2023	22	0	6

The Trust has a legal duty to protect patient confidentiality and, in line with this duty, the figure <5 has been provided where figures are very low. This is because of the potential risk of identification of an individual. In reaching this decision the Trust has taken into account the small geographical area which the Trust serves and the sensitivity of the information requested. In addition the Trust has taken into account the fact that all information disclosed in response to an FOI is disclosed to the 'world at large' and is published on the Trust website.

Section 40 (2) (third party information) of the Freedom of Information Act 2000 has been applied to exempt the information from disclosure. The Trust does not consider the disclosure of the information to be fair to the individuals concerned as there is the potential risk of identification of an individual(s) which they would not expect, and which would therefore breach the fairness element of the first principle of the Data Protection Act 2018

3. How many people living within the Trust are at 25/50 or 75% risk of developing Huntington's disease?

Response:

This information is not held.

4. How many people within the Trust have received funding for PGD within the last 5 years?

Response:

PGD is not carried out in SHSCT and patients are referred to BHSCT.

5. Do you offer any services specific to people with Huntington's Disease e.g. outpatient, dedicated bed space, HD nurse specialist?

Response:

This information is not held.

6. Are there any business cases pending for the development of any services specific to people with Huntington's Disease?

Response:

No

7. In the past 5 years has the Trust funded anyone with Huntingtons' Disease to access special services, other than PGD, in

a) Another Trust

b) An area outside of Northern Ireland

Response:

This information is not held

8. How many neurologists are currently employed by the Trust?

Response:

SHSCT currently employs 4 Neurologists

9. What is the average waiting time for a first appointment with a neurologist within the Trust?

Response:

Rf 1 week

Urgent 25 weeks

Routine 170 weeks

10. How many neuropsychologists are currently employed by the Trust?

Response:

SHSCT currently employs 3 Psychologists in Neuropsychology, with 1 member on the Specialist Register with the Division of Neuropsychology

11. What is the average waiting time for a first appointment with a neuropsychologist within the Trust?

Response:

Currently Neuropsychologists are only employed within the Acquired Brain Injury Rehabilitation Service where the average waiting time for a first appointment is 4 weeks

12. How many neuropsychiatrists are currently employed by the Trust?

Response:

SHSCT does not currently employ any neuropsychiatrists

13. What is the average waiting time for a first appointment with a neuropsychiatrist within the Trust?

Response:

N/A

14. How many neuro-physiotherapists are currently employed by the Trust?

Response:

SHSCT do not currently employ neuro-physiotherapists who currently work with patients with Huntington's

15. What is the average waiting time for a first appointment with a neuro-physiotherapist within the Trust?

Response:

N/A

16. How many adult occupational therapists are currently employed by the Trust?

Response:

There are 244 staff employed as Adult Occupational Therapists in SHSCT.

17. What is the average waiting time for a first appointment with an adult occupational therapist within the Trust?

Response:

PROFESSION	Adult	Child	Average days (child & adult)
Occupational Therapists	252	276	259
Average days (child & adult)	252	276	259
*Average days waiting as at 31/12/2023			

18. How many adult speech and language therapists are currently employed by the Trust?

Response:

There are 53 staff employed as Adult Speech & Language Therapists in SHSCT, however not all of these staff work with people with Huntington's.

19. What is the average waiting time for a first appointment with an adult speech and language therapist within the Trust?

Response:

PROFESSION	Adult	Child	Average days (child & adult)
Speech and Language Therapy	130	160	147
Average days (child & adult)	130	160	147
*Average days waiting as at 31/12/2023			

20. How many adult dieticians are currently employed by the Trust?

Response:

There are 52 staff employed as Adult Dietitians in SHSCT.

21. What is the average waiting time for a first appointment with an adult dietician within the Trust?

Response:

PROFESSION	Adult	Child	Average days (child & adult)
Dietetics	119	145	125
Average days (child & adult)	119	145	125
*Average days waiting as at 31/12/2023			

22. Under which directorate(s)/service area(s) does Huntington's disease sit within the Trust?

Response:

Acute and Community Adult Social Work, AHPs, Neurology, Primary health care (GP surgeries/health centres), Mental Health & Disability Services, Community pharmacy, Palliative care, District nursing, Genetics, Carer Support

23. Who are the HD relevant service leads within the Trust?

Response:

There is no designated HD lead. Each consultant see their own patients.

In an effort to build condition specific awareness and help reach affected family members we would like to establish links with front line staff via their team leads;

Could you provide the name and email address for relevant team/service leads

- 1. Adult social work**
- 2. Occupational therapy**
- 3. Physiotherapy**
- 4. Primary health care (GP surgeries/health centres)**
- 5. Speech and language therapy**
- 6. Community mental health**
- 7. Community pharmacy**
- 8. Dieticians**
- 9. Palliative care**
- 10. District nursing**
- 11. Neurology**
- 12. Genetics**
- 13. Carer Support**

Response:

Service	Director	Department Contact Details
Adult Social Work	Director of Medicine & Unscheduled Care	Hospital Social Work
	Director Adult Community Services	Directorate Lead for Social Work, Bannvale House, 10 Moyallan Road, Gilford, Craigavon, BT63 5JX
Occupational Therapy	Director Adult Community Services	ACS.Admin@southerntrust.hscni.net
Physiotherapy	Director of Surgery & Clinical Services	Physiotherapy Lead, Cherrytrees Resource Centre, 1A Edenderry Gardens, Portadown, Armagh Northern Ireland, BT63 5EA,

	Director Adult Community Services	ICT Physiotherapy Manager, Kilkeel Primary Care Centre, Newry St, Kilkeel, BT34 4DP
Primary health care (GP surgeries/health centres)	Please contact the Strategic Planning and Performance Group for contact details. Please note Mullaghbawn GP Surgery and Kilkeel Medical Practice are the only practices currently managed by SHSCT (temporary contractor until 31st March 2024) (contact is Primary Care Multidisciplinary Team Project Manager,)	
Speech and language therapy	Director of Adult Community Services	Professional Head of Adult SLT Services.
Mental Health & Disability Services	Director of Mental Health & Disability Services	physical.disability@southerntrust.hscni.net
Community pharmacy	Please contact the Strategic Planning and Performance Group (Head of Pharmacy and Medicines Management) for contact information	
Dietetics	Director of Adult Community Services	community.dietitian@southerntrust.hscni.net
Palliative care*	Director of Surgery & Clinical Services	Lead Nurse, Cancer Services
	Director of Adult Community Services	Community.mdpallcare@southerntrust.hscni.net Any specific enquiries for the attention of; Specialist Palliative Care Service Lead (Macmillan) Community Specialist Palliative Care Team or the Head of Service Specialist Primary Care.
District nursing	Director of Adult Community Services	Head of Service for Integrated Care Teams; and Consultant District Nurse Bannvale House, 10 Moyallan Road, Gilford, Craigavon, BT63 5JX
Neurology	Director of Medicine & Unscheduled Care	Neurology Centre, Craigavon Hospital, 68 Lurgan Road, Portadown, BT63 5QQ.
Genetics	N/A	
Carer Support	Director Adult Community services	carers.coordinator@southerntrust.hscni.net

Email: foi.team@southerntrust.hscni.net