

18 November 2025

Care of Newborn Infants with Down's syndrome (trisomy 21) and Congenital Heart Defects

Under the Freedom of Information Act 2000, I am requesting information relating to the care of newborn infants with Down's syndrome (trisomy 21) and congenital heart defects at the Royal Belfast Hospital for Sick Children / Belfast Health and Social Care Trust between 1 January 1970 and 31 December 1995.

- 1. Copies of any written policies, guidelines, memos or internal documents relating to:**
 - a. Parental disclosure of congenital defects in infants with Down's syndrome, including communication of surgically treatable heart defects.**
 - b. Decisions to withhold information or treatment, including any discussion framed as "kindness" or "not escalating care".**
 - c. Referral pathways to paediatric cardiology or paediatric cardiac surgery for infants with Down's syndrome and heart defects.**
 - d. Any guidance or minutes from ethics committees, mortality/morbidity meetings, or clinical governance committees discussing the above.**

There were no documents, letters or reports imported into the HeartSuite system when it went live in Belfast in 2004. Therefore, there is no information for 1 January 1970 to 31 December 1995 stored digitally within HeartSuite, i.e. no written policies, guidelines, memos or internal documents relating to care of newborn infants with Down syndrome (trisomy 21) and congenital heart defects. Therefore, Belfast Trust is unable to answer Question 1, points a to d, as the information is not held.

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2. Aggregate, non-identifiable counts for the period 1970 – 1995 of:

- a. Infants born with Down’s syndrome at the hospital.**
- b. Of those, infants diagnosed with congenital heart defects (if recorded)**
- c. Number referred to paediatric cardiology / cardiac surgery.**

Please see table below setting out data pulled from HeartSuite system. Unfortunately, this is all the information Belfast Trust has available. The data has been pulled into a summary and shows:

- 1. The number of children recorded on HeartSuite with a diagnosis of Down Syndrome
- 2. The number of children from this total who are recorded with a cardiology diagnosis
- 3. The number of children from this total who required a cardiac procedure.

Year	Number of Children with a confirmed Diagnosis of Down Syndrome on HeartSuite	Number of Children with a confirmed Diagnosis of Down Syndrome on HeartSuite who had a cardiology diagnosis	Number of Children with a confirmed Diagnosis of Down Syndrome on HeartSuite who had a cardiology procedure
1970	<5	<5	
1976	<5		
1977	<5		7
1978	<5		
1979	5		
1980	6		
1981	14	<5	
1982	12	<5	
1983	<5		<5

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Year	Number of Children with a confirmed Diagnosis of Down Syndrome on HeartSuite	Number of Children with a confirmed Diagnosis of Down Syndrome on HeartSuite who had a cardiology diagnosis	Number of Children with a confirmed Diagnosis of Down Syndrome on HeartSuite who had a cardiology procedure
1984	5		<5
1985	8		
1986	11		9
1987	12		5
1988	17	<5	<5
1989	41	<5	8
1990	31	5	13
1991	29	<5	23
1992	46	5	13
1993	57	9	5
1994	29	<5	10
1995	17		8
Grand Total	351	33	108

Use of <5 (less than five): We are unable to provide an exact figure - exempt from release under Section 40(2) of the Freedom of Information Act, as the small numbers involved could make patients personally identifiable. Disclosure would constitute a breach of the principles of the General Data Protection Regulation 2018.

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- d. Number discharged without surgical intervention or without parents being informed of the defect (if recorded).**
- e. In-hospital or early neonatal deaths among infants with Down's syndrome, with a note if death occurred without treatment being offered.**

There were no documents, letters or reports imported into the HeartSuite system when it went live in Belfast in 2004. Therefore, Belfast Trust is unable to provide a response to Question 2, points d and e, as no information is held.