

21 January 2026

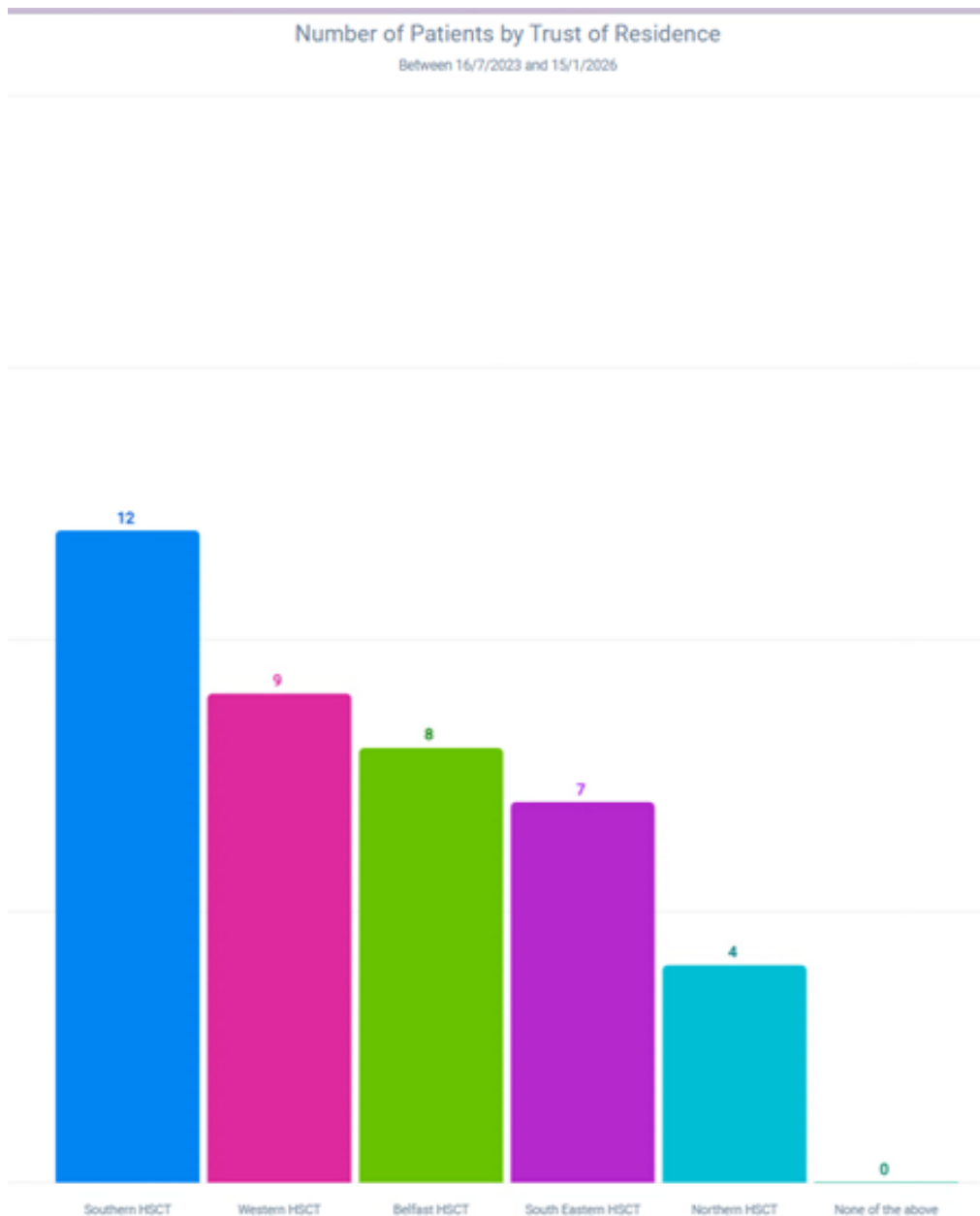
Prader-Willi Syndrome (PWS) Adults & Children

1. Please confirm the number of people currently living in Northern Ireland with a medical diagnosis of Prader-Willi Syndrome (PWS). If possible, I would also like to request an additional breakdown of the overall number by Trust, gender and age range i.e. children and adults.

Based on the available Regional Molecular Diagnostic Services Laboratory Information Management System (StarLIMS) information:

17 PWS probands were diagnosed from late 2010 to end of 2025 (15 years)

The Trust EPIC system shows that:

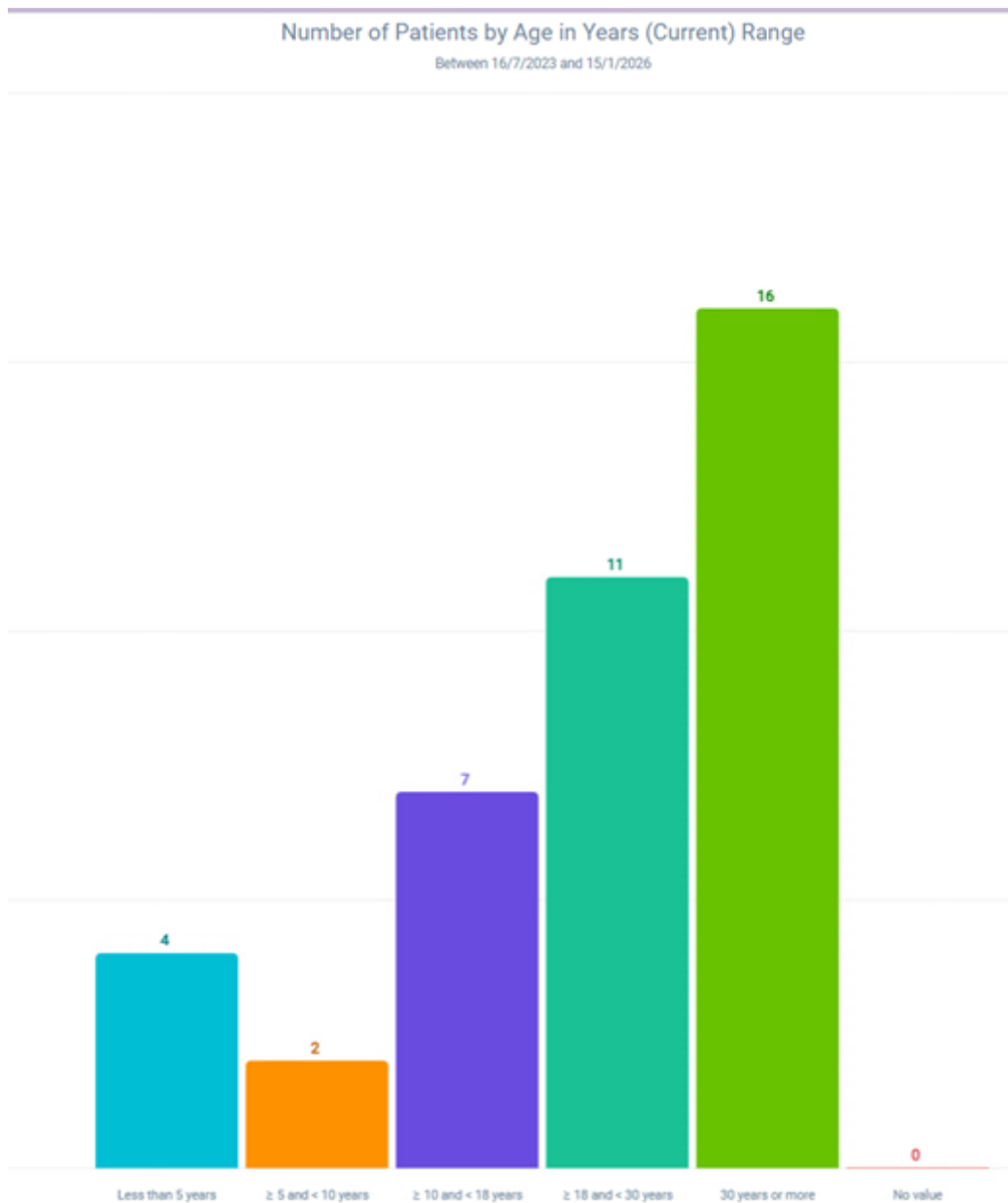


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Trust breakdown above: Total 40 (all diagnoses on Epic from go-live, hence 2023 cut-off). Diagnosis: Prader Willi syndrome in Problem List or Medical History.

Sex: 24 Female: 16 Male.

Age distribution:



The StarLIMS data will be the confirmed minimum level of Prader-Willi Syndrome patients; the Laboratory information will not capture some patients that may have been diagnosed out of area and some patients in the Epic group are of an older age group, where we will not have LIMS data.

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Therefore, the figure of 40 is probably more accurate; there is a caveat in relation to the Epic information in that the Epic results may be where the diagnosis is queried.

The incidence of Prader-Willi Syndrome is said to be approximately 1:22,000, so we would expect ~1 per year in Northern Ireland, which would correlate well with these figures.

- 2. Please also advise if PWS is currently red flagged on patient records on admission to A&E and/or other hospital services in NI to both support patients and inform medical professionals treating individuals with PWS?**

Patients with PWS are not red flagged by Belfast Trust.