

Reference:	FOI.21407.26
Subject:	Systematized Nomenclature of Medicine Clinical Terms (SNOMED-CT) codes
Date of Request:	1 August 2026

Requested:

I am interested in understanding whether SNOMED codes can be used to estimate the number of rare disease patients in Wales. I have been advised by DHCW, as they do not hold this data for secondary care, to contact you for support in pursuing this.

Attached is a spreadsheet with three fields:

Orphacode: Number assigned by [Orphanet](#) representing a rare condition.

Condition: The rare condition represented by the Orphacode and SNOMED.

SNOMED: SNOMED-CT code representing a rare condition.

The output I would like is a count of patients who have a recorded SNOMED code in the provided list and, where it is present, the associated Orphacode and Condition and the data source used for the count to be reported. Descriptions of the data source, including patient coverage (e.g. inpatient, outpatient), total number of patients in data source, and years covered would also be very valuable. Please use the table below as a template for providing this output.

Orphacode	Condition	SNOMED	Count	Data source name	Patient coverage	Total patient number	Years coverage

Response:

Hywel Dda University Health Board (UHB) does not hold the requested information as it does not use SNOMED-CT codes.