

FOI DOF/2025-0490

Request

I am writing to request information under the Freedom of Information Act 2000.

Please provide the number of recorded deaths in Northern Ireland where the cause of death was classified as *sudden unexpected death in epilepsy (SUDEP)*, broken down by year, for each of the last five calendar years (2019–2023).

If available, please also confirm the coding or classification used to record SUDEP in mortality data.

I would prefer to receive the information electronically, in tabular format if possible.

Response

I can confirm that the Department holds the information requested. We can provide the information from the last five calendar years (2019-2023).

The Northern Ireland Statistics and Research Agency (NISRA) produces statistics based on the cause of death information recorded on death certificates and collected by the General Register Office (GRO) during the death registration process. NISRA collates data on registrations of death.

There is no specific International Classification of Diseases (ICD10) code for Sudden Unexpected Death in Epilepsy (SUDEP), it is therefore not possible to identify where this is the underlying cause of death using this method. To obtain data, deaths that mentioned epilepsy on the death certificate, i.e. cases where the list of causes of death included the ICD10 code 'G40' (epilepsy), either as a contributory cause of death or underlying cause of death were identified for each year. These cases were then further filtered by a search of the cause of death text fields to identify those cases where 'sudden' was mentioned on the death certificate. A supplementary search was also conducted based only on key words ('sudden' and 'epilepsy'). All identified cases were then reviewed manually. All relevant cases were found to have the term 'Sudden Unexpected Death in Epilepsy' mentioned in one of the causes of death text fields.

The table below provides the information requested.

1. Total Deaths from Sudden Unexpected Death in Epilepsy (SUDEP), 2019 to 2023

Year	Total Deaths
2019	4
2020	5
2021	7
2022	2
2023	5