



## Department of Children and Youth Affairs

### Inventory of Data Sources on Children's Lives

#### A35 National Paediatric Mortality Register (NPMR) (formerly National Sudden Infant Death Register)

|                                      |   |
|--------------------------------------|---|
| <b>Data owner</b>                    | The National Paediatric Mortality Register (NPMR) is currently owned by the Irish Sudden Infant Death Association ( <a href="http://www.sidsireland.ie">www.sidsireland.ie</a> ). The future placement and ownership of the NPMR is currently under consideration by a development group representing the HSE, the Department of Health/Children and Youth Affairs, NPMR and the Temple St Children's University Hospital.  |
| <b>Brief description</b>             | The National Paediatric Mortality Register (NPMR; formerly the National Sudden Infant Death Register) obtains accurate, up-to-date information on unexpected/unexplained deaths in infants and young children. Between 1992 and 2011, 726 cases of SIDS were registered on the NPMR. The register also conducts research into the identification of causes and prevention of sudden infant death, as well as formulating childcare guidelines for parents on how best to reduce an infant's risk of SIDS. From 2010, the NPMR has been providing accurate data on the incidence and categories of all paediatric deaths under 15 years of age on an annual basis. |
| <b>Primary function of data</b>      | Register of all sudden, unexpected/unexplained deaths in infants and young children in Ireland. Currently extending to establish a register of all paediatric deaths in children aged 29 days to 18 years of age.   |
| <b>Key classificatory variables</b>  | ID Other; DOB; Gender; County   |
| <b>Themes/domains</b>                | Health; Demographics  |
| <b>Unit of observation</b>           | Individual case   |
| <b>Start date of data collection</b> | 1992 for children under 2 years of age. Data collection relating to children aged 2-14 years was initiated in the last quarter of 2009 and backdated to 2006.   |
| <b>Frequency of data collection</b>  | Continuous for data relating to children under 2 years of age. On a quarterly basis for children aged 2-14 years.   |
| <b>Data format</b>                   | Separate record for each individual case. Only aggregate data published.  |
| <b>Method of data collection</b>     | Paper-based form containing maternity, GP and post-mortem data. All data anonymised and then entered into a computerised dataset. Cause of death information on all paediatric deaths in children 0-14 years obtained from CSO in form of encrypted microdata files. Autopsy reports on all deaths in children under 15 of age obtained in paper format.  |
| <b>Access/further information</b>    | National Paediatric Mortality Register ( <a href="http://www.sidsireland.ie">www.sidsireland.ie</a> )   |

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### Notes

The NPMR's strength lies in the size and continuity of the dataset, now comprising approximately 400 SIDS cases and 1,700 controls, allowing trends in variables (such as smoking rates, breastfeeding rates and use of medical services) to be tracked on an annual basis. Ongoing annual surveillance means that effects and changes in sudden infant death are monitored as they occur, with social and demographic factors documented alongside, enabling significant issues and needs to be identified. The success of the SIDS Register led to the development of the NPMR, where it is hoped that additional reductions in the number of preventable deaths in older children will be achieved.