National Hub for Reviewing and Learning from the Deaths of Children and Young People – How we use data

What data we process and why?

Healthcare Improvement Scotland is collecting data on behalf of the National Hub for Reviewing and Learning from the Deaths of Children and Young People (National Hub).

The National Hub will seek to gather data from reviews carried out into the deaths of children and young people. These reviews aim to identify trends that could alert professionals of possible areas of risk and look to establish a minimum standard for carrying out reviews into the deaths of children and young people.

All NHS boards and local authorities will be asked to complete the information set out in the core review data set in relation to reviews into the deaths of children and young people using a secure online portal. This process will support the collection of consistent data nationally.

Identifiable data will only be collected to check completeness of data and ensure consistency in correspondence between the National Hub and the reporting organisation.

The only identifiable data requested by the core review data set relates to the deceased child or young person and are therefore outside the scope of data protection law. We have developed the core review data set to minimise this possibility and tried to focus on the experiences of the child or young person. Any additional information that gives details about anyone other than the child or young person will be immediately deleted and alert the reporting organisation that only anonymised documents will be accepted.

Lawful basis

We will carry out very limited processing of personal data to fulfil our public tasks under the Public Services Reform (Scotland) Act 2010 and the National Health Service (Scotland) Act 1978 (UK GDPR article 6(1)e) and for the provision and management of health care (UK GDPR article 9(2)h).
Participants in our research and policy work

We may ask whether you wish to take part in a research project, consultation or survey. Participation is voluntary and any information is collected with your consent.

Where possible we will avoid collecting personal information about you, when collecting this information. Where this cannot be avoided, we delete your personal data as soon as we have collated the information into an anonymised format.

We will inform you that external researchers with whom we are working may hold research-related information.

If you choose to provide us with information that identifies you, this will not be published in any reports.

Sharing your information

Identifiable data will not be shared with anyone outside the National Hub team.

Aggregated, anonymised learning from reviews will be themed and shared with Scottish Government, NHS boards, local authorities and identified key stakeholders.

How long we retain data

Any identifiable data received about the child or young person will be kept for 7 years for the purposes of communication with NHS boards and local authorities in relation to ongoing audit and thematic analyses.

Anonymised data will be kept permanently as part of the remit of the National Hub for national learning.

For more information or to raise concerns about how Healthcare Improvement Scotland processes personal data, please see our main privacy notice: Healthcare Improvement Scotland privacy statement.