

# 4 Nations rapid review of iGAS deaths in children

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Mae'r ddogfen yma ar gael yn y Gymraeg/This document is available in  
Welsh

Produced by Public Health Wales (Communicable Disease Surveillance Centre & Child Death Review Programme), UK Health Security Agency, National Child Mortality Database England, Public Health Scotland (Respiratory Bacterial Pathogens Team), National Hub for Reviewing and Learning from the Deaths of Children and Young People (Healthcare Improvement Scotland / Care Inspectorate), Public Health Agency, Northern Ireland (Health Protection Surveillance & Child Death Review Programme).



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## Executive Summary

### Background

- An increase in child deaths from invasive Group A Streptococcus (iGAS) was observed in the UK in the 2022/3 season.
- A collaborative approach between public health and Child Death Review (CDR) teams across each of the four nations facilitated a rapid qualitative review of community deaths relating to iGAS, with the aim of identifying key themes, patterns and mitigations which may ultimately lead to a reduction in child deaths due to iGAS.
- The intended audience of the report includes those involved in planning, financing and delivery of child health services.

### Findings

- Across the four nations, 28 child deaths were identified which met the case definition during this five-month period. Twenty of these children were residents of England, eight were residents of Wales or Scotland. No child deaths meeting the case definition were identified in Northern Ireland.
- The majority of children had no recorded co-morbidities or that information was unknown. Nine had developmental impairment and/or health complexities.
- A small number of children (less than five) were known to social services due to neglect concerns.
- Time between onset of symptoms and death varied between less than 1 day to 20 days.
- Viral/mild symptoms were recorded prior to rapid collapse for 10 children; more severe symptoms such as vomiting, high fever, shortness of breath, lethargy, muscle cramps or irritability, with or without preceding viral/ mild symptoms, were recorded for 11 children. For the remaining seven children, there was either no information available on symptoms, or the description 'generally unwell' was recorded.
- Co-infection was identified in 15 children.
- Most children had some form of interaction recorded with healthcare services prior to deterioration, in some instances more than once. For a small number of children there was no identified contact with healthcare, despite developing more severe symptoms.
- A small number of children were found to have had antibiotic treatment initiated, though this may reflect that clinicians had initially suspected an alternative diagnosis. None completed a course of antibiotics.
- Rapid clinical deterioration occurred in 16 of the 20 children for whom information indicating speed of deterioration prior to collapse was available.
- For a small number of children, records indicated either actual or anticipated delays in provision of emergency ambulance response.

## Themes

Initial mild presentation followed by deterioration was often too rapid to enable transferring the child to secondary care for definitive management:

- Initial presentation often led to a clinical diagnosis of viral illness.
- Ongoing clinical course included:
  - rapid collapse, with or without developing more severe symptoms
  - apparent recovery following viral-like illness before collapse – ('biphasic' presentation)
  - development of more severe symptoms.

Earlier diagnosis of viral illness may have affected parent and clinician behaviour, this may be particularly important during winter

- Where more severe symptoms were present prior to collapse, the following factors may have been relevant:
  - Further assessment was not always sought by parent (or care giver), possibly due to false reassurance taken from earlier diagnosis of viral infection
  - Confirmed or suspected respiratory infection with different viral pathogens may have deterred health professionals from considering a diagnosis of GAS, even after clear clinical deterioration:
    - the potential for co-infection, and its risk of more severe disease, may not have been considered
    - suspicion of a viral cause may also have led healthcare professionals to specify the number of days within which parents and carers might expect to see improvement.

Some groups of children may be more at risk of severe outcomes:

- Children with developmental impairment and health complexities are likely to be more at risk of severe outcomes.
- Children known to social services with neglect concerns may also be more at risk of poor outcomes after serious infections. Contact with healthcare in the early stages of infection may present an opportunity for prevention.

Delays in ambulance service provision may affect timely provision of emergency acute care.

Other

- In a small number of children there was no report of contact with healthcare, or this information is unknown, despite developing more severe symptoms.

## Limitations

- This review was limited by a lack of access to full clinical records meaning that complete, time-bound information on clinical presentations was not available.
- The rapid nature of the review meant that the final outcome of child death review processes were not available (at the time of review) and therefore some information may have been missing which could have affected the final findings.
- There may have been further deaths that occurred during the period of the review which were not identified at the time.
- The aim of this work was to identify any potentially modifiable factors, it is not a clinical audit of management of iGAS and therefore conclusions cannot be drawn on whether appropriate actions were taken for individual children.
- Similarly, it was not possible to quantify the frequency of the identified modifiable factors, in part due to missing information but also due to the overall small sample size.
- The review aimed to identify themes which are relevant, rather than generalisable.

## Considerations

Early non-specific symptoms followed by rapid deterioration make prevention challenging, however there may be opportunities to:

- explore producing timely bulletins to clinicians (at start of winter viral illness season) which highlight that:
  - initial clinical presentation consistent with viral infection and/or a positive test result for a different infection may provide false reassurance about absence of iGAS infection. In addition, co-infection may increase risk of poor outcomes;
  - children with developmental impairment and/or other health or social complexities may be at risk of poorer outcomes from infection, and therefore may require careful safety netting / clinical review as appropriate;
- identify a forum / mechanism to engage with relevant clinical bodies and leaders to explore how to reinforce:
  - responding appropriately to concerns raised by parents or carers when re-presenting after an earlier mild episode;
  - safety netting in a way which empowers parents and carers to seek timely help (based on traffic light advice) and avoids discourse which may deter parents and carers from using their own judgement faced with an evolving clinical picture;
- explore how 'concerns about neglect' which is a potential risk factor for poorer outcomes from infectious disease, could be categorised, defined and recorded on clinical information systems. For example, ensuring that if a child is on a child protection register, this is documented on their clinical record;



- consider further research and evaluation into the value of point of care testing for GAS and its integration into clinical assessments;
- explore developing pro-active and reactive messaging for parents and carers about how and where to access the most appropriate service, based on symptom-checkers, as part of multiagency, multidisciplinary winter planning, working with relevant clinical bodies.

## Introduction

### Background

An increase in child deaths from invasive Group A Streptococcus (iGAS) was observed in the UK in the 2022/3 season, which runs from week 37 to week 36 each year (mid-September to mid-September). This coincided with higher notifications of iGAS and scarlet fever, and also Group A Streptococcus (GAS) from upper respiratory tract samples in Scotland, where scarlet fever is not notifiable, as a proxy. Whilst an increase in cases was seen in all ages, the highest percentage increase was in under 15-year-olds. A UK national incident management team (IMT) was set up with aims that included minimising the impact of iGAS infection on the paediatric UK population and providing intelligence related to changes in scarlet fever and iGAS incidence.

Previous evidence has identified that deaths from iGAS infection are most likely to occur close in time to diagnosis,<sup>1,2</sup> a pattern observed in the 2022/23 season. It is important to understand these trends and identify opportunities to facilitate early identification, responsive assessment, and treatment. Best practice guidance emphasises the importance of early transfer to hospital.<sup>3</sup>

Alongside quantitative description and analysis of deaths from iGAS infection, a more detailed case review of deaths in children may identify patterns and themes which could inform prevention. More specifically, in reviewing out of hospital deaths to provide important insights and information leading to actions which could be taken in a community setting. Given the small numbers of deaths in children, relative to the number of cases overall, a UK-wide approach was used to increase the likelihood of being able to identify themes.

A collaborative approach between public health and Child Death Review (CDR) teams across each of the four nations facilitated a rapid review of community deaths relating to iGAS infection, with the aim of identifying key themes, patterns and mitigations which may ultimately lead to a reduction in child deaths due to iGAS infection.

The intended audience of the report includes those involved in planning, financing and delivery of child health services.

### Aims and objectives

The aim of this review was to identify modifiable factors relating to child deaths occurring in the community which could be used to inform public health action and the prevention of deaths due to iGAS.



The objectives were to:

- reconcile numbers of iGAS deaths in children across public health and CDR teams
- identify deaths meeting the case definition
- extract data at individual nation level using a common template
- identify themes from the information available on child deaths across the UK

## Methods

### Type of study design

Qualitative case review.

### Case definition(s)

- iGAS cases who died in the community, were defined as those who:
  - died outside of hospital or;
  - were declared dead on arrival at hospital or;
  - were declared dead within an hour of arrival at hospital, including those who collapsed outside of hospital and had resuscitation attempts that started or continued in the emergency department (ED);
- in children aged under 15;
- with a date of death between 01/10/2022 and 28/02/2023;
- where either:
  - iGAS was identified post-mortem
  - GAS had been isolated in a normally sterile site +/- 7days of death (based on the sample date and the date of death) or any time post-mortem
  - or a death certificate had been issued and the underlying or other cause of death has a relevant ICD-10 code (see below).

### Case finding

In Wales, the following codes were used for an initial screening search as underlying or other cause of death codes: A40.0, A49.1 (if additional information stated that type was A), B95.0, and G00.2.<sup>4</sup> Further review of the case record helped ascertain whether the definition of Group A Streptococcus isolated from a normally sterile site was met. In the absence of ICD-10 codes, information was shared between the CDR team and the Communicable Disease Surveillance Centre (CDSC) team (using the

case management system, Tarian) to identify deaths which might fit the case definition.

In England, iGAS cases were identified using the laboratory surveillance system SGSS, to which local laboratories are required to submit records of microbiologically-confirmed cases. National reference laboratory specimen referrals were also interrogated. Deaths in this group were identified by linkage with NHS death records, and location of death was established by cross-referencing with case-management records held by UKHSA (HPZone) and records held by the National Child Mortality Database.

In Scotland iGAS cases were identified from the laboratory surveillance system ECOSS (Electronic Communication of Surveillance in Scotland) to which all local laboratories are required to submit records of microbiologically-confirmed cases and from enhanced surveillance forms, completed and submitted by local health protection teams for each laboratory confirmed notification. Deaths were notified via enhanced surveillance. Additional information for the review that was not available from the enhanced surveillance system was obtained from the CDR team for Scotland.

In Northern Ireland, iGAS cases were identified using the NI regional case-management system (HPZone). All iGAS cases reported to the NI Public Health Agency were recorded on the system for both case-management and surveillance purposes. Once cases were initially identified, information about deaths including location of death was taken from case-management notes on the HPZone system. Additionally, the CDR database was interrogated, and further assurance gained directly from Trusts to identify if there were any cases that met the case definition.

## Methods

In-depth qualitative review of records were conducted by CDR and epidemiology and clinical leads for each of the four nations, with a focus on the circumstances of the deaths, interaction with healthcare, and role of known risk factors. Sources included:

- information available from the local multiagency child death review process and national CDR programmes for each nation
- information available from health protection case management systems on presentation (not on management of contacts or other public health actions)
- additional microbiological test data were obtained through patient level data linkage, to enhance assessment of potential respiratory virus co-infections.

A depersonalised data collection Excel spreadsheet template was used for consistency between the four nations. No personally identifiable information apart from date of death was included in the spreadsheet.



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Iechyd Cyhoeddus  
Cymru  
Public Health  
Wales

## UK Thematic analysis

Public Health Wales carried out the synthesis of completed data collection grids on behalf of UK nations. Themes were identified in the data through immersion to identify emergent themes, and any relationships between themes agreed by consensus with four nations colleagues following review.

## Output

The report was presented to the UK iGAS incident management team (IMT), the four nations CDR group, and will be shared with key health and government stakeholders in each nation. A four-nation steering group will consider any further outputs/ distribution.

## Legal basis, ethics and data handling

This review is part of the public health response; as such, and in accordance with legislative frameworks (see [Appendix](#)), patient consent for collection and collation of data was not required. In this report, the results have been combined at UK level and all information has been aggregated so that no results on fewer than five children are presented. A dissemination strategy was agreed across the four nations, including key stakeholders.

## Findings

Across the four nations, we identified 28 child deaths meeting the case definition during this five-month period. Twenty of these children were residents of England,<sup>a</sup> eight were residents of Wales or Scotland. No child deaths meeting the case definition were identified in Northern Ireland. The ages of children ranged between age categories 'under 1 year' and 10 to 14 years.

## Co-morbidities and social circumstances

Thirteen children had no recorded co-morbidities and nine children had developmental impairment and/or other health complexities\*. This information was unknown for 6 children.

\*In this report, the term 'Developmental impairment' is used to describe conditions known to cause global developmental impairment; the term 'health complexities' is used to describe other long-term conditions, health states known to be risk factors for long term conditions, and other impairments not meeting the definition of 'developmental impairment'.

A small number of children (less than five) were either known to social services due to concerns of neglect or had a previous history of an adverse childhood experience.

## Emm type

There were a range of emm types, with emm type 1.0 being predominant, which reflected iGAS cases generally during the season. However, emm typing was not available for all children.

## Presentation and clinical course

As clinical notes were not assessed, the available data could not be reviewed for completeness and thus should be treated with a degree of caution.

There was no information available or the description 'generally unwell' was recorded for seven children. For the remaining 21 children:

- viral\*\*/mild symptoms were recorded prior to rapid collapse for 10 children
- more severe symptoms such as vomiting, high fever\*\*\*, shortness of breath, lethargy, muscle cramps or irritability, with or without preceding viral/ mild symptoms, were recorded for 11 children.

(\*\*viral/mild symptoms refers to coryza, cough, and low fever\*\*\*)

(\*\*\*this was a descriptive term specified in records, without a recorded observed temperature)

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<sup>a</sup> This number does not represent the total number of iGAS deaths in England during this period but is the number identified at the time of data collection for the purposes of this review.



Time between onset of symptoms and death varied between less than 1 day to 20 days (median 4 days), although identifying the onset of symptoms can be challenging in the context of possible co-infection and initial non-specific presentation.

Six children appeared to have biphasic presentation. Each child displayed first symptoms from five to seven days prior to death. It was either recorded that they had showed signs of improvement before a subsequent rapid deterioration or that they were seemingly well the evening before death, then were found unresponsive.

Of the small number of children where the family were known to social services, there were instances where the child had been seen by a health care professional in the week before death. However, the signs they had presented with were of unknown relevance to their subsequent collapse.

## Co-infection

Co-infection (a laboratory confirmed bacterial or viral infection detected between seven days before and one day after the iGAS sample date) was identified in 15 children. It is likely that most of these results were only available post-mortem. It is not known how many children were tested. Co-infection included with viruses and/or bacteria, sometimes with multiple organisms in addition to the detection of iGAS.

## Healthcare use and experience

### Healthcare interactions

Information was not available for two children. Where information was available, children had varying patterns of engaging with healthcare services. Most (17/26) had some form of interaction recorded in the period following onset of symptoms and prior to collapse/onset of resuscitation, including with NHS 111, primary care, urgent care centre or ED:

- for six children there was more than one contact made with a healthcare provider (including NHS 111)
- eight children were seen acutely in secondary care (ED or urgent care centre). Fewer than five children were subsequently admitted to hospital, each of whom were diagnosed with a respiratory viral illness and subsequently discharged prior to collapse.

### Assessment

In all of the instances where a diagnosis had been made and a healthcare interaction completed (i.e. excluding instances where the child was in the process of being referred for further assessment at the point of collapse), records suggested that a diagnosis of a viral illness had been made. As notes were not accessed, it was not always clear whether the diagnosis was made based on signs and symptoms alone or with the results of rapid point of care or laboratory testing.

## Treatment

A small number of children (less than five) were found to have had antibiotic treatment initiated, though this may reflect variability in clinical suspicion and diagnosis. None completed a course of antibiotics.

## Clinical progression

Where information was available to indicate speed of deterioration prior to collapse (available for 20/28 children), rapid clinical deterioration occurred in 16/20 children, defined as:

- death within 12 hours of deterioration;
- records stated “found unresponsive”;
- or records stated “rapid deterioration”.

Some of the remaining children for whom records were available deteriorated within 48 hours of experiencing mild symptoms.

Where healthcare advice was sought on a subsequent occasion, the presence of an earlier diagnosis of viral illness may have deterred health professionals from considering a diagnosis of GAS even after clear clinical deterioration (for example reassuring parents reporting worsening symptoms that these were consistent with the initial diagnosis).

For a small number of children, multiple attempts had been made to access additional advice and included instances where a specified number of days was indicated to parents after which they might expect to see improvement, but death occurred before that time period elapsed.

Where deterioration occurred, there was some evidence of parents being unaware of how best to re-access the system, for example trying to access broader primary care services despite continued clinical decline, rather than feeling able to present directly to ED. Further examples suggested parents may not have recognised the worsening of symptoms as indicating a deterioration, such as worsening breathlessness, lethargy or fever; and/or took false reassurance from an earlier clinical encounter despite symptoms worsening.

For a small number of children, records indicated either actual or anticipated delays in provision of emergency ambulance response. Additionally, amongst the records that were reviewed, a small number mentioned long wait times in ED.

## Location where death pronounced

Death was pronounced outside of hospital in 12/28 children, on arrival at ED in 5/28 children and within an hour of arrival at ED for 11/28.

## Themes

The following themes and sub-themes were identified from the data.

Initial mild presentation followed by deterioration was often too rapid to enable transferring the child to secondary care for definitive management:

- Initial presentation often led to a clinical diagnosis of viral illness.
- Ongoing clinical course included:
  - rapid collapse, with or without developing more severe symptoms
  - apparent recovery following viral-like illness before collapse – ('biphasic' presentation)
  - development of more severe symptoms.

Earlier diagnosis of viral illness may have affected parent and clinician behaviour, this may be particularly important during winter

- Where more severe symptoms were present prior to collapse, the following factors may have been relevant:
  - Further assessment was not always sought by parent (or care giver), possibly due to false reassurance taken from earlier diagnosis of viral infection
  - Confirmed or suspected respiratory infection with different viral pathogens may have deterred health professionals from considering a diagnosis of GAS, even after clear clinical deterioration:
    - the potential for co-infection, and its risk of more severe disease, may not have been considered
    - suspicion of a viral cause may also have led healthcare professionals to specify the number of days within which parents and carers might expect to see improvement.

Some groups of children may be more at risk of severe outcomes:

- Children with developmental impairment and health complexities are likely to be more at risk of severe outcomes.
- Children known to social services with neglect concerns may also be more at risk of poor outcomes after serious infections. Contact with healthcare in the early stages of infection may present an opportunity for prevention.



Delays in ambulance service provision may affect timely provision of emergency acute care.

#### Other

- In a small number of children there was no report of contact with healthcare, or this information is unknown, despite developing more severe symptoms.





## Conclusion

### Summary

Clinical presentations which were often initially mild and non-specific, combined with rapid deterioration (sometimes with apparent improvement prior to decline) meant that children were unable to access sufficiently timely emergency care to potentially prevent death, despite often best attempts by caregivers and health services. An earlier diagnosis of viral infection (based on clinical symptoms, laboratory testing or point of care testing) may have provided false reassurance to both parents and clinicians. Children with health and social complexities may be particularly at risk of poor outcomes.

### Limitations

Lack of access to full clinical records and means that complete, time-bound information on clinical presentations was not available. The rapid nature of the review meant that the final outcome of child death review processes were not available (at the time of review) and therefore some information may have been missing which could have affected the final findings. Additionally, there may have been further deaths that occurred during the period of the review which were not identified at the time. The aim of this work was to identify any potentially modifiable factors, it is not a clinical audit of management of iGAS and therefore conclusions cannot be drawn on whether appropriate actions were taken for individual children.

Similarly, it was not possible to quantify the frequency of the identified modifiable factors, in part due to missing information but also due to the overall small sample size. The review aimed to identify themes which are relevant, rather than generalisable.

### Considerations

Early non-specific symptoms followed by rapid deterioration make prevention challenging, however there may be opportunities to:

- explore producing timely bulletins to clinicians (at start of winter viral illness season) which highlight that:
  - initial clinical presentation consistent with viral infection and/or a positive test result for a different infection may provide false reassurance about absence of iGAS infection. In addition, co-infection may increase risk of poor outcomes;
  - children with developmental impairment and/or other health or social complexities may be at risk of poorer outcomes from infection, and therefore may require careful safety netting / clinical review as appropriate;

- identify a forum / mechanism to engage with relevant clinical bodies and leaders to explore how to reinforce:
  - responding appropriately to concerns raised by parents or carers when re-presenting after an earlier mild episode;
  - safety netting in a way which empowers parents and carers to seek timely help (based on traffic light advice<sup>5</sup>) and avoids discourse which may deter parents and carers from using their own judgement faced with an evolving clinical picture;<sup>6,7</sup>
- explore how 'concerns about neglect' which is a potential risk factor for poorer outcomes from infectious disease, could be categorised, defined and recorded on clinical information systems. For example, ensuring that if a child is on a child protection register, this is documented on their clinical record;
- consider further research and evaluation into the value of point of care testing for GAS and its integration into clinical assessments;
- explore developing pro-active and reactive messaging for parents and carers about how and where to access the most appropriate service, based on symptom-checkers, as part of multiagency, multidisciplinary winter planning, working with relevant clinical bodies.

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## Appendix: legislative basis

### UKHSA

The sharing of confidential patient information without patient consent is covered by the statutory exemption under Section 251, the National Health Services Act 2006, for the purposes set out under Regulation 3 (Communicable disease and other risks to public health) of the Health Service (Control of Patient Information) Regulations 2002.

Collection and processing of such data fall within the uses set out in the UKHSA Privacy Notice:

<https://www.gov.uk/government/publications/ukhsa-privacy-notice/ukhsa-privacy-notice>

### NCMD England

The NCMD legal basis to collect confidential and personal level data under the Common Law Duty of Confidentiality has been established through the Children Act 2004 Sections M-N, Working Together to Safeguard Children 2018 (<https://consult.education.gov.uk/child-protection-safeguarding-and-family-law/working-together-to-safeguard-children-revisions-supporting-documents/WorkingTogethertoSafeguardChildren.pdf>) and associated Child Death Review Statutory & Operational Guidance ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/859302/child-death-review-statutory-and-operational-guidance-england.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/859302/child-death-review-statutory-and-operational-guidance-england.pdf)).

The NCMD legal basis to collect personal data under the General Data Protection Regulation (GDPR) without consent is defined by GDPR Article 6 (e) Public task and 9 (h) Health or social care (with a basis in law).

### Public Health Wales

The processing of confidential patient information without consent in the Child Death Review Programme is covered by Section 251 approval (CAG reference 19/CAG/0177). The activities of the Child Death Review Programme can be justified under paragraphs 3(b) and 3(c) of the Public Health Wales NHS Trust (Establishment) Order 2009. The activities of the Communicable Disease Surveillance Centre can be justified under paragraphs 3(a) and 3(b) of the Public Health Wales NHS Trust (Establishment) Order 2009.

Paragraph 3 of the Public Health Wales National Health Service Trust (Establishment) Order 2009 states the nature and functions of the trust. These functions are:

Paragraph 3(a) 'to provide to or in relation to the health service in Wales and manage a range of public health, health protection, healthcare improvement, health advisory, child protection and microbiological laboratory services and services relating to the surveillance, prevention and control of communicable diseases'.

Paragraph 3(b) 'to develop and maintain arrangements for making information about matters related

to the protection and improvement of health in Wales available to the public in Wales; to undertake and commission research into such matters and to contribute to the provision and development of training in such matters’

Paragraph 3(c) ‘to undertake the systematic collection, analysis and dissemination of information about the health of the people of Wales in particular including cancer incidence, mortality and survival; and prevalence of congenital anomalies’.

### **Public Health Scotland (Respiratory Bacterial Pathogens Team) & National Hub for Reviewing and Learning from the Deaths of Children and Young People (Healthcare Improvement Scotland / Care Inspectorate)**

The Scottish National Hub for Reviewing and Learning from the Deaths of Children and Young People are responsible for ensuring reviews are conducted on all deaths of live born children up to the date of their 18th birthday, or 26th birthday for care leavers who are in receipt of continuing care or aftercare at the time of their death. The aim is to reduce deaths and harm to children and young people.

Under UKGDPR Article 6(1)(e), processing personal identifiable data (of the child or young person only) is necessary for the performance this task which is carried out in the public interest, or in the exercise of official authority vested in the controller. Information concerning deceased persons is not directly covered by the Data Protection Act 2018 (DPA) however, it is still subject to the duty of confidentiality and the provision of information to the National Hub from the NHS boards and local authorities constitutes a public interest disclosure for health and social care purposes. (See GMC Ethical Guidance – Confidentiality <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/confidentiality>). The CLO advises organisations should apply the principles of data protection provided by the DPA when handling these data.

In support of the HIS “general duty of furthering improvement in the quality of health care” under s10A(1)b of the National Health Service (Scotland) Act 1978 as amended by the Public Services Reform (Scotland) Act 2010. All data only pertains to the deceased child – no other identifiable information is stored.

Parental consent for CDR reviews and data collection is not explicitly sought, but an information booklet is provided to ensure families and carers are aware of the work of the National Hub and its purpose as part of good practice.

### **Public Health Agency, Northern Ireland (Health Protection Surveillance & Child Death Review Programme)**

Processing of confidential patient information without patient consent is covered by the UK General

Data Protection Regulation (UKGDPR) under Article 6(e)- Public task: the processing is necessary for you to perform a task in the public interest or for your official functions and the task or function has a clear basis in law, and under Article 9(i) Public health (with a basis in law).

For more information, please refer to the NI Public Health Agency Privacy Notice: [PHA Privacy notice | HSC Public Health Agency \(hscni.net\)](#).



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