

NATIONAL CHILD MORTALITY DATABASE 2022

Specification

CONFIDENTIAL

Internal Ref: HQIP NCA 2148

Table of contents

1	Introducti	on	4				
	1.1 HQIP and the National Clinical Audit and Patient Outcomes Programme						
	1.2	1.2 Specification development					
	1.3	Contract opportunity	4				
		1.3.1 Potential future aspirational intent	4				
		1.3.2 Contract transitions	4				
	1.4	Aims and objectives of the National Child Mortality Database	5				
2	Scope of t	he project	5				
	2.1	Background and need for the work	5				
	2.2	Improvement aims and objectives of the programme	6				
	2.3	2.3 Population inclusion criteria					
	2.4	2.4 Population exclusion criteria					
	2.5 Use of routine data and data linkage						
	2.6	Selection of topics	8				
	2.7	7 Outputs					
	2.8	Target audience and settings	8				
	2.9	Alignment with health policy, standards and guidelines	9				
		2.9.1 Related processes	9				
		2.9.2 Related national initiatives	9				
	2.10	Assessment of equity and equality	9				
	2.11	Parity of esteem	10				
3	Organisat	ional structure, governance and management	10				
	3.1	Project governance structure and strategy	10				
	3.2	Project technical team	10				
		3.2.1 Clinical leadership	10				
		3.2.2 Healthcare improvement expertise	10				
		3.2.3 Methodology expertise	11				
		3.2.4 Statistical expertise	11				
		3.2.5 Programme and project management	11				
		3.2.6 Editor	11				
	3.3	Engaging and involving patients, families, carers and the public	12				
4	Dataset d	esign and performance metrics	12				
	4.1	Dataset	12				
	4.2	Data accessibility	13				
	4.3	Cause for concern	13				
5	Data colle	ction, IT systems and data analysis	13				

	5.1	Participatio	n and case ascertainment	13
	5.2	Data captur	e and data flows	14
	5.3	Data quality	/	14
	5.4	Exploitation	of existing data	14
	5.5	Data protec	tion and security	14
	5.6	Confidentia	lity and consent	15
6	Communi	cations, repo	rts and change initiatives	15
	6.1	Project info	rmation webpages	15
	6.2	Accessible o	digital content	15
	6.3	Communica	ition plan	16
	6.4	UPCORP too	lo	16
7	Uses of th	e data		16
	7.1	Incorporation	on in national outcomes/indicator frameworks and quality accounts .	16
	7.2	Synergies b	etween the project and other national initiatives	17
		7.2.1	Getting It Right First Time (GIRFT)	17
		7.2.2	NHS England Learning from Lives and Deaths programme (LeDeR)	17
		7.2.3	NHS England RightCare programme	17
	7.3	Revalidatio	n of professionals	17
	7.4	Internation	al comparisons	17
	7.5	Research		17
8	Sustainab	ility beyond r	national funding	17
9	Contract	deliverables		17
10	Dotontial	futuro acnira	tional intent	10

1 Introduction

1.1 HQIP and the National Clinical Audit and Patient Outcomes Programme

The Healthcare Quality Improvement Partnership (HQIP) is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement, and in particular to increase the impact that clinical audit and clinical outcome review programmes have on healthcare quality in England and Wales. HQIP holds the contract to manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising more than 30 clinical audits as well as a number of clinical outcome review programmes. These national projects cover care provided to people with a wide range of medical, surgical and mental health conditions. They are funded by NHS England, the Welsh Government and in some cases other devolved authorities.

1.2 Specification development

In order to develop a specification, HQIP consulted with key stakeholders through a specification development meeting (SDM) in July 2022. The resulting specification takes account of trends in the feedback, along with funder priorities.

1.3 Contract opportunity

The contract will initially be to deliver the National Child Mortality Database (NCMD) for England, for a period of three years, at a maximum total budget of up to £2,718,000 GBP excluding VAT. Bids exceeding this limit will be rejected. There is potential to extend the contract for up to two additional years. Any contract award will include payment linked deliverables.

The contract holder is responsible for all aspects of leadership, governance, stakeholder engagement, design and delivery of the specified project including scope development, data acquisition, analysis, reporting and stimulation of healthcare improvement. HQIP, and NHS England as funders contribute representatives to governance groups as described in Section 3.1, and the additional requirements of HQIP as commissioner are set out in the Provider Technical Manual. Whilst HQIP and the funders will support the project through sharing information and helping to integrate and promote the project, neither HQIP nor the funders provide resource required for any aspect of project delivery.

1.3.1 Potential future aspirational intent

The future aspirational intention of this opportunity includes the potential to modify the contract, without altering its overall nature. More information is included in section 10.

1.3.2 Contract transitions

HQIP's intention is to sustain continuous programme delivery, with efficient and seamless transition between contract periods. This means that all phases of the programme delivery will continue under the new contract including data collection, analysis, interpretation and delivery of outputs. If the contract is awarded to a new supplier, HQIP will engage with both the outgoing and incoming suppliers after contract award to identify and agree transition tasks. Transition between suppliers would be estimated to take place over a period of four to eight weeks immediately prior to 30/06/2023. Anticipated transition activities between suppliers are not listed in this specification. Suppliers are invited to explain clearly and

comprehensively how they would meet the scope of work described in this specification, excluding specific transition activities.

1.4 Aims and objectives of the National Child Mortality Database

A national database is designed to be a repository of data to enable detailed analysis and interpretation of that data. This provides a national picture and allow trends to be identified.

The NCMD is expected to:

- a. Ensure close alignment with relevant national guidance
- b. Enable improvements through the provision of timely, high quality data
- c. Engage young people, bereaved parents, carers and families in a meaningful way, achieving a strong voice which informs and contributes to the design, functioning, outputs and direction of the programme
- d. Link data at an individual child level to other relevant national datasets to improve data quality and completeness and enhance analysis
- e. Provide an electronic case management tool and ensure it is being used by partners to enter data
- f. Maintain and use surveillance functionality
- g. Ensure robust methodological and statistical input at all stages
- h. Identify from the outset the full range of audiences for reports and other outputs, and plan and tailor them accordingly
- i. Utilise strong and effective project and programme management to deliver outputs on time and within budget
- j. Develop and maintain strong engagement with partner bodies, NHS organisations, social care, police and law enforcement, education services, networks, commissioners, medical examiners, parents, families and carers and charity and community support groups in order to drive improvements and reduce future harm and deaths
- k. Influence national policy and priority setting by engaging with national agencies to ensure that learning is translated into actions.

2 Scope of the project

2.1 Background and need for the work

The National Child Mortality Database was first commissioned in 2018 following the Child Death Review Database Development Project. The Database was commissioned to identify how and why children die, and to make recommendations to reduce the number of children who die. It is part of the statutory Child Death Review process which applies to all children in England who die before their 18th birthday. It enables the identification and analysis of the wider social determinants of health including those factors in the child, social environment, parenting capacity and physical environment which may play a part in child death. The Database allows for the national analysis and use of data collected by local Child Death Overview Panels (CDOPs).

In the year ending 31st March 2022, there were 3,470 child deaths in England and the death of each child is a devastating loss that profoundly affects all those involved. The Royal College of Paediatrics and Child Health (RCPCH) 2020 report, State of Child Health, demonstrated that Progress in reducing child and adolescent

mortality has stalled in recent years. Of greater concern still is the <u>lack of progress in infant mortality (first year of life) in England from 2013 to 2018</u>. In addition, the Global Burden of Disease Study reported the 2019 under five mortality rate in the UK as 4.1 per 1000, the second highest amongst the 23 countries in Western Europe (average 3.4 per 1000), after Malta.

The National Child Mortality Database programme also provided vital rapid monitoring of trends in child deaths due to COVID-19 infection, as well as examining the effects of the vaccination and shielding policies. The Database continued to track surveillance of the changing patterns of child mortality and analyse the direct and indirect effects of COVID-19. The programme's versatility during the COVID-19 pandemic has demonstrated the usefulness of the system for responding to unknown future events.

Further details of the current work can be found here: www.ncmd.info

2.2 Improvement aims and objectives of the programme

The National Child Mortality Database is used to record a minimum set of comprehensive, standardised information collected by local Child Death Overview Panels (CDOPs) as part of the Child Death Review (CDR) process. This information is then combined with data from other sources, analysed and outputs produced. This information can be used by other organisations, providers of services, commissioners and policy makers to ensure that child deaths are learned from, that learning is widely shared and that actions are taken, locally and nationally, to prevent and to reduce the number of children who die.

The improvement aims of the NCMD programme are to:

- a. Support the identification and notification of 100% of all eligible deaths to the NCMD
- b. Capture, analyse and disseminate appropriate data and learning from 100% of child death reviews
- c. Study and analyse the demographics, patterns, causes and associated risk factors of child mortality in England
- d. Provide information in a timely fashion that can be used by relevant NHS, health and social care organisations to make policy decisions and interventions with the aim of reducing the number of preventable child deaths
- e. Produce routine aggregate data tables and benchmarked child mortality data at the local level to support local response by NHS regions and Integrated Care Boards (ICBs)
- f. Provide information in a timely fashion that can be used by organisations in wider society to make policy decisions and interventions with the aim of reducing the number of preventable child deaths
- g. Support cross-system work to reduce the number of preventable child deaths, particularly in relation to groups with health inequalities, e.g. those who experience factors which impact on health determinants such as disability, socio-economic status, deprivation and poor housing
- h. Identify and issue relevant alerts for:
 - modifiable factors in child deaths, both related to the NHS and in wider society
 - clusters of deaths
 - newly emerging causes and risk factors for death

This may require working with external organisations to develop a shared view and to identify signals and patterns in the data.

i. Produce reports, briefings, present data, share case studies and make recommendations to relevant agencies for implementation

- j. Drive improvements in the quality of child death reviews, e.g. through training and support for the professionals involved
- k. Maximise the usefulness, impact and influence of the project findings (see also section 6.3)
- I. Make available in a timely manner (with permission from HQIP and any other relevant data controllers and in compliance with the relevant legal frameworks) pseudonymised or non-identifiable data to those with legitimate requests such as researchers (see section 7.5)
- m. Liaise with all other NHS England relevant workstreams for example the Maternal, Newborn and Infant Clinical Outcome Review Programme (MNI-CORP) surveillance, preventable neonatal deaths workstreams and the Learning from Lives and Deaths programme which focuses on people with a learning disability and autistic people (LeDeR)
- n. Share data with other relevant workstreams to ensure case ascertainment and accuracy, in addition to reducing risk of duplication
- Work closely with NHS England and government agencies in providing a prompt response to emerging trends in child mortality, which may include supporting decision making on risk escalation and appropriate actions.

2.3 Population inclusion criteria

- a. All live born children who die in England (including those normally resident abroad) at any time after birth and before their 18th birthday
- b. Children who die abroad but who are normally resident in England

2.4 Population exclusion criteria

- None
- National Data Opt out does not apply

2.5 Use of routine data and data linkage

Data sourced from existing national data sources for the purposes of this contract will require the contract holder to initiate and lead on data access applications to the relevant data controller. HQIP will review and authorise all data sharing agreements but takes no other role in data acquisition. All data access and processing costs are the responsibility of the contract holder and should be included in the cost schedule.

It is anticipated that the project will work with the following to enable linkage. This list may evolve over the period of the contract:

- BadgerNet
- Maternal, Newborn and Infant Clinical Outcome Review Programme
- National Neonatal Audit Programme
- National Maternal and Perinatal Audit
- Maternity Services Data Set
- Virology and vaccination data (UKHSA)
- National Congenital Anomaly and Rare Disease Registration Service
- National Cancer Registration and Analysis Service
- Death registration data (Office for National Statistics)
- Paediatric Intensive Care Audit Network
- Civil Registration Deaths Data

- Hospital Episodes Statistics (HES)
- Local authority data (serious incident data)
- LeDeR database
- Police and crime datasets

2.6 Selection of topics

The supplier will undertake a process to agree topics for the thematic reports listed in Section 2.7. This should be a proactive activity, with direct engagement with funders and stakeholders. Selection of topics will be approved by the funder.

2.7 Outputs

HQIP will work with the supplier to agree the final reporting dates and any subsequent alterations will be subject to HQIP approval. Outputs are anticipated to include the following:

- Annual data release (in line with the legal requirement) including when and where all child deaths
 occurred; the characteristics of the children who died, including sex and age group; and where
 modifiable factors were identified
- Two thematic reports per year, with a focus on modifiable factors (each with maximum 10 pages and 5 national recommendations)
- Monthly and ad hoc exception reporting based on real time surveillance for NHS England to facilitate monitoring of all child deaths
- The issuing of alerts relating to modifiable factors
- Routine reports, aggregate data tables and benchmarked child mortality data to be provided to Child Death Overview Panels (CDOPS), Integrated Care Systems (ICSs), the Learning from Lives and Deaths programme team (LeDeR) and NHS trusts.

This list is not exhaustive and HQIP will work with the successful bidder to agree the final list, granularity and frequency of reporting and the corresponding public accessibility. These will be developed and agreed in year 1 of the contract.

See sections 4.2 and 5.2 for further information.

2.8 Target audience and settings

The main audiences should be carefully targeted and may include:

- Child Death Overview Panels (CDOPS)
- Healthcare organisations (such as NHS Trusts)
- Integrated Care Boards (ICBs), particularly the executive leads for children and young people
- NHS Regional Medical Directors and children and young people leads
- Bereaved families and carers
- Public health bodies
- Care commissioners
- Social services
- Education services

- The police and wider law enforcement
- Local government
- National level NHS England, Office for Health Improvement and Disparities, and other areas of government including education and transport
- Relevant charities and voluntary organisations
- Companies offering goods and services
- Health and safety industry
- The Royal Society for the Prevention of Accidents (RoSPA)

2.9 Alignment with health policy, standards and guidelines

HQIP requires that all projects ensure their project design and data items remain aligned with, and responsive to, contemporary health policy directives. See section 7 for further information.

2.9.1 Related processes

Regular review of the relevant national standards and guidance must be considered for aspects which fall within the scope of the project including the project's datasets. The following list captures some of the relevant processes / organisations which may inform the work (please note this list is not exhaustive):

- Child Death Review process
- Medical Examiner's process
- Coroner's process
- Healthcare Safety Investigation Branch
- The Special Health Authority for independent maternity investigations which will be established from 2022-23

2.9.2 Related national initiatives

It is anticipated that the Provider will, where relevant, either liaise with and / or take into account the outputs of the:

- NHS Long Term Plan
- Paediatric Early Warning Score (PEWS) implementation
- National Perinatal Mortality Review Tool (PMRT)
- Paediatric Intensive Care Audit Network (PICANet)
- National Asthma and COPD Audit Programme
- LeDeR Learning from Lives and Deaths People with a learning disability and autistic people
- National Confidential Inquiry into Suicide and Safety in Mental Health
- National Neonatal Audit Programme
- National Maternal and Perinatal Audit
- Maternal, Newborn and Infant Clinical Outcome Review Programme
- The Saving Babies Lives Care Bundle

2.10 Assessment of equity and equality

HQIP promotes equality, paying particular attention to groups or sections of society where improvements in health and care and other outcomes are not keeping pace with the rest of the population. The project plan and outputs should support local and national initiatives to reduce inequalities and promote parity of care.

2.11 Parity of esteem

Parity of esteem is best described as: 'valuing mental health equally with physical health' and it is expected that the project will promote this equity through conscious design under the contract to ensure there is a holistic approach.

3 Organisational structure, governance and management

3.1 Project governance structure and strategy

The project must be governed by a robust management structure with defined governance groups, designed to maximise effectiveness. The decision making, reporting, and accountability hierarchies must be explicit. HQIP must be included in the membership of the supplier's highest level project governance group, normally the programme/project board. An approved representative from each funder (usually NHS England) should sit on the group which decides on the dataset, definitions and topics for thematic reports, and the ratification of the dataset and topics for thematic reports will be by the funders. Details of the structure should be included in the tender along with any other proposed mechanisms for achieving project governance.

Typical governance structures include:

- Accountable host senior responsible officer
- Programme/project board
- Project steering group/clinical reference group
- Project technical team
- Funder monitoring meeting
- Stakeholder group representing bereaved families and voluntary groups, supported by charities

3.2 Project technical team

3.2.1 Clinical leadership

Effective clinical leadership must be integral to the planning and delivery. In this context, clinical leadership means that individual(s) have relevant clinical expertise, appropriate experience of national project delivery, and demonstrably high professional peer authority, in order to be integral to the project's governance to lead the project. It is required that the suppliers will include resourced, dedicated clinical time in the costings for the bid. The time and costs allocated to clinical leadership should reflect sufficient time commitment and expertise of the individual(s).

3.2.2 Healthcare improvement expertise

Expertise and leadership in healthcare improvement must be available to the project from the outset and throughout the duration of the contract. This expertise may be provided by an individual who is a member of the project team or sourced through a subcontract with an individual or organisation expert in healthcare improvement. Expertise should also include effecting improvement through regional and national approaches as well as through meaningful public and family involvement.

3.2.3 Methodology expertise

Appropriate methodological input must be integral to the planning and delivery from the outset. Projects pose various challenges related to the definition of the inclusion criteria, the definition of the dataset and the robust collection of the data, including the linkage of project data to information from other databases. Methodological input is also required during the analysis and interpretation of the project findings. These individuals will have a key role in the design of the project, ensuring that it meets the requirements of the project aims and objectives. HQIP's Provider methodology manual should be consulted throughout the contract to ensure all aspects of methodology are in line with the requirements set out by HQIP.

3.2.4 Statistical expertise

Appropriate statistical input is integral to the successful delivery of the project. Statistician input will be essential to the drafting and delivery of a comprehensive analysis plan which should be developed jointly with the clinical lead(s), the methodologist(s) and other experts on the team. The HQIP Provider methodology manual should be consulted to ensure alignment with requirements set out by HQIP.

The analysis plan must be designed to support the specific improvement goals and anticipated published comparisons, which have been identified for the project during development. The approach to managing missing data or variability in the quality of data submitted must be explicit in the analysis plan and adhered to.

The analysis plan must include the use of risk adjustment as appropriate. Adjustment must be achieved using a validated method and applied by a person or group with the appropriate statistical expertise. A validated model must already be available or be able to be developed within the available resources.

HQIP will review the analysis plan alongside the project plan throughout the contract.

3.2.5 Programme and project management

There should be robust programme and project management throughout the contract, ensuring that all deliverables are met on time, on budget and to high quality. HQIP's Provider technical manual and Provider methodology manual should be consulted throughout the contract to ensure all aspects of delivery are in line with the requirements set out by HQIP. This must include development and maintenance of a project plan.

Suppliers are also required to appropriately manage risks and issues in the programme, including monitoring risks, highlighting and managing risks and issues appropriately, and supplying an updated risk/issue log.

Suppliers are invited to include a programme of staff welfare in their submissions.

3.2.6 Editor

All outputs must be reviewed by an individual with editorial expertise, fully quality assured and corrections made. Before any report is submitted into the Standard Reporting Procedure (SRP) for review by HQIP and funders it should be fully edited and quality assured. Timelines for report production should include an allowance for the time required to complete these tasks.

Editorial review and quality assurance includes, but is not limited to:

- Overall output structure flows clearly and logically and all references to the findings are consistent across different report sections
- Proofreading of outputs has been completed to a high standard and errors corrected
- Other requirements set out in the Provider technical manual and Provider methodology manual have been complied with..

3.3 Engaging and involving patients, families, carers and the public

Engagement should include, but not be limited to parents, families, young people and charities. Refer to HQIP's Patient and Carer Engagement Strategy.

HQIP adheres to seven principles of patient and carer engagement:

- Representation
- Inclusivity
- Early and continuous involvement
- Transparency
- Clarity of purpose
- Cost effectiveness
- Feedback

Engaging families effectively and meaningfully in the governance structure is required and the above principles should be integrated appropriately throughout every stage of the design and delivery of the work including:

- a. Representation on relevant governance groups throughout the project lifetime including the project board; resources are defined to support this
- b. Involvement in developing the tender response and when defining specific project improvement goals and audit measures
- c. An agreed role and purpose for families in contributing to different stages of the project
- d. A process that sets out how families can contribute to the development of all project resources and co-produce accessible outputs and key messages that are aimed at families
- e. An inclusive communication and dissemination plan to support wider engagement of diverse people and communities, including neuro-diverse people and people with a learning disability, those for whom English is a second language and deaf British Sign Language users
- f. Transparent evidence of how family involvement will influence project activity with demonstrated planning in place to measure impact of engagement.

4 Dataset design and performance metrics

The dataset should align to current and where possible forthcoming national guidance and quality standards of best practice.

4.1 Dataset

The dataset should be comprehensive enough to support quality improvement and assurance, allow for

adequate risk adjustment, while balancing the need to minimise local burden. Relevant patient protected characteristics (e.g. ethnicity and disability) and other information (such as socioeconomic deprivation) must be collected, analysed and reported to permit evaluation of access to services, health inequality and inequity. The reporting of findings should include a breakdown of analysis by ethnicity and socioeconomic deprivation and disability.

The supplier will be expected to engage in appropriate stakeholder consultations during dataset development and review, including, but not limited to:

- Families
- Commissioners (local and national)
- Clinicians
- Third sector organisations
- Other users of the data

All datasets and associated measures will be subject to review and sign off by HQIP and funders on an annual basis.

4.2 Data accessibility

Outputs should be tailored to meet different audience needs to best support local, regional and national quality improvement and:

- a. Made accessible, for example through infographics and interactive web tools
- b. Allow users to choose services or other comparisons as benchmarks relevant to them
- c. Some or all outputs to be available via a data visualisation platform which is freely accessible in the public domain
- d. Online improvement resources must be available to accompany the data and support audiences to make best use of the data. These may include improvement toolkits, case studies, vignettes, useful links and outputs.

4.3 Cause for concern

For all NCAPOP projects, it is expected that the latest <u>HQIP guidance</u> on the identification and management of cause for concern in National Clinical Projects and Clinical Outcome Review Programmes in England and Wales will be followed and the projects will each produce and apply their own policies in line with this.

5 Data collection, IT systems and data analysis

5.1 Participation and case ascertainment

It is expected that the programme strives for 100% participation across all elements. To influence and drive increases in participation the supplier should engage with key stakeholders. The supplier is expected, where possible, to utilise routine national data sources to ensure case ascertainment is complete.

Participation must be included in the analysis plan for each topic, and reported publicly alongside the metrics results.

5.2 Data capture and data flows

Suppliers should plan how data items will submitted locally and the data flows which will enable central analysis (by the supplier and/or their sub-contractors). The project design must take into account the workload anticipated locally during participation in the project and minimise this wherever possible. The dataset size should be the minimum required to effectively meet the requirements of the project and the supplier must not introduce a data capture mechanism that duplicates those already in use, although a new mechanism which accepts uploads from existing systems would be acceptable.

Functional and efficient IT provision is essential. This should facilitate:

- Simple data entry, potentially on a variety of devices to maximise usability
- Support local data providers in entering complete and good quality data; automated validation should be designed into the system as far as possible
- Minimisation of local burden through use of existing data sources, importing data from other sources
- Responsiveness to changes if the dataset requires revision, such as removing data items that are no longer clinically relevant
- Meaningful data are able to be extracted by local providers, for purposes of local quality improvement, quality assurance and benchmarking. This includes the provision of online reports that present results, in graphical, tabular or other usable format. These reports should enable providers to determine if they are an outlier when compared to their peers
- Data extraction at different health geographies to meet the needs of different stakeholders
- The merger of NHS Digital into NHS England is likely to impact on the design of many aspects of national NHS data capture and processing, potentially also including databases, registries and audits. The supplier would be expected to work with funders and HQIP to help develop and deliver future changes where possible.

5.3 Data quality

The supplier must ensure the highest standards of data quality and completeness, including mechanisms to check inter-rater reliability and identify missing data. Data completeness and quality must be actively monitored and reported. The levels of completeness required to support the subsequent analyses should be identified at the outset and all efforts made to support participants to achieve these.

5.4 Exploitation of existing data

Suppliers are expected to identify any existing data collections of relevance. Unnecessary duplication of data entry must be avoided and the provision of upload facilities from local databases or hospital patient administration systems should be considered. All efforts must be made to locate any pre-existing national data collections with overlapping datasets that might provide an appropriate source of data for the project.

5.5 Data protection and security

Comprehensive measures must be developed and implemented to mitigate the risk of loss of data. The future project supplier will be required to undertake Data Protection Impact Assessments (DPIA) on behalf of HQIP. Suppliers must be able to show a full understanding of the Data protection act (2018), UK General Data Protection Regulation (UK GDPR), Common law duty of confidentiality (and any other relevant data

protection legislation) and its relevance to project processes, as well as all other relevant security policies and legislation, and illustrate their future approach by completing a provisional DPIA prior to contract start date. The confidentiality, integrity, availability, and resilience of processing systems and services must be ensured and so suppliers are also expected to carefully review the data security and data processing requirements reflected in HQIP's standard contractual terms and conditions and demonstrate in their tender how these will be met.

Suppliers should note that all data processors delivering projects on behalf of HQIP are required to demonstrate appropriate security arrangements by maintaining accreditation against the Data Security and Protection Toolkit, achieving a minimum 'standards met' against all requirements, (or demonstrate compliance equivalence). Future project suppliers will be required to comply with data subject rights and to manage data subject requests (such as, but not limited to, access, rectification, erasure and portability) on behalf of HQIP and in accordance with HQIP policy and processes.

5.6 Confidentiality and consent

A comprehensive information governance policy must be developed for this project. Suppliers must state whether any patient-identifiers will be extracted for central processing or linkage purposes and the proposed mechanism for gaining the required permissions. Where any processing is to be based on consent this must meet standards of active, informed consent, and that such consents are recorded and auditable. A data flow map is required, illustrating all planned data flows anticipated for the delivery of the project. It must include the source and destination of each dataset, the data controller, the level of patient anonymity of the dataset (personally identifiable/de-identified/anonymous) and the legal basis for each data processing activity. This must be updated and shared with HQIP throughout the contract).

6 Communications, reports and change initiatives

6.1 Project information webpages

Comprehensive information about the project including the commissioning body, project aims and objectives, design, geographical cover, timelines, and project tools/data set (including terms and conditions of their use) must be publicly accessible via a dedicated section of the supplier's website, with links wherever possible from relevant stakeholders' websites.

6.2 Accessible digital content

It is expected that HQIP suppliers commit to making their digital content accessible. This means making content and design clear and simple enough so most people can use it without adaptation, while supporting others as needed. We expect suppliers to comply with UK government requirements for public sector organisations. More information is available online at: www.gov.uk/guidance/accessibility-requirements-for-public-sector-websites-and-apps.

Your website or app will meet these public sector requirements if it:

a. Complies with the <u>Web Content Accessibility Guidelines</u> (known as WCAG 2.1). These are an internationally-recognised set of recommendations for improving web accessibility. They explain

how to make digital services, websites, and apps accessible to everyone, including users with impairments to their:

- Vision like severely sight impaired (blind), sight impaired (partially sighted) or colour blind people
- o Hearing like people who are deaf or hard of hearing
- o Mobility like those who find it difficult to use a mouse or keyboard
- o Thinking and understanding like people with dyslexia, autism or learning difficulties
- b. Works on the most commonly used assistive technologies, including screen magnifiers, screen readers and speech recognition tools
- c. Includes people with disabilities in user research.

6.3 Communication plan

A comprehensive communication plan will form part of the project delivery and must be provided for review by HQIP during the early stages of the contract. Dissemination of project outputs are expected to be to the full range of interested parties listed above (see section 2.8). The communications strategy should have as an aim increasing the impact of the findings of the programme. We invite bidders to include a focus on communications and influencing policy as part of their submission. The building of networks that has been established to date should continue.

Dissemination should take place through a variety of formats and activities appropriate to the needs of the target audience. The interpretation of the project results for all reports must reflect the same integral clinical leadership, methodological/statistical input and patient and public involvement as other stages of the project.

All summative / descriptive reports produced under this contract must be publicly accessible unless they are reporting pilot or developmental work. Findings and recommendations should be accessible to all relevant audiences.

All national comparative reports will be subject to HQIP's Standard Reporting Procedure (SRP). Early in the contract, a progress report may be relevant rather than publication of comparative data, and in this case the requirement to follow the SRP may be waived.

6.4 UPCORP tool

The Understanding Practice in Clinical Outcome Review Programmes (UPCORP) tool is a protocol to describe the key features of clinical outcome review programmes. Project suppliers are expected to maintain a publicly available, dynamic and regularly refreshed UPCORP document online.

7 Uses of the data

7.1 Incorporation in national outcomes/indicator frameworks and quality accounts

The programme is expected to align where appropriate with any national outcomes/indicator frameworks including the collection of data for relevant for framework indicators and/or contributing to the development of new framework indicators if required.

Where relevant, projects may be requested to flow data to support other publicly funded reporting mechanisms, such as data dashboards, to support commissioning and to gather information on quality and outcomes from a variety of sources.

7.2 Synergies between the project and other national initiatives

Through the provision of analysed data, information and support, and in accordance with any relevant IG permissions, it is expected that the project will also directly contribute to:

7.2.1 Getting It Right First Time (GIRFT)

Where the topic is also included in <u>Getting It Right First Time (GIRFT)</u>, the supplier is expected to work collaboratively to help align improvement approaches and enable sharing of relevant data for GIRFT reports (sharing of data subject to HQIP approval).

7.2.2 NHS England Learning from Lives and Deaths programme (LeDeR)

The supplier is expected to work collaboratively to enable sharing of relevant data with <u>LeDeR</u> academic partners (subject to data sharing protocols).

7.2.3 NHS England RightCare programme

In addition to the above initiatives, the Project should engage, where requested and agreed, with the <u>NHS</u> <u>England RightCare programme</u>.

7.3 Revalidation of professionals

HQIP supports the expectation that individual clinicians can use project data as part of their revalidation portfolios.

7.4 International comparisons

It is expected that the supplier will take into account the potential for ongoing international comparisons of care quality and form appropriate links with those developing and leading relevant overseas projects if appropriate.

7.5 Research

HQIP encourages the use of the data for epidemiological studies and health services research. Such requests must be submitted to HQIP data access request group process (DARG) for approval and the subject of an appropriate data sharing agreement and information governance support.

8 Sustainability beyond national funding

The project supplier must give consideration to self-sustainability and explore methods, processes, and solutions to ensure the continuation of the project after national funding has ceased.

9 Contract deliverables

Contract deliverables will be agreed between HQIP and the successful bidder following contract award. These deliverables are based on a standard template which is then adjusted as needed after contract award and at the point of contracting. This ensures the final, agreed deliverables are fully aligned with the requirements of this specification as well as the detailed timelines of the project plan submitted by the successful bidder. Some deliverables will be payment-linked. The standard specification template, and information on how payment linked deliverables are applied in practice, are provided as tender documents for information via HQIP's eTendering portal.

10 Potential future aspirational intent

The future aspirational intention of this opportunity is to potentially modify the contract, without altering its overall nature, by including the following potential options:

Table 1: Aspirational intent					
Options	Description/Specification	Amount ¹	Mechanism for Invoking		
1. Up to 24-month	Potential total of 24- months	£906,000-	HQIP may propose an		
extension that	extension to the contract for a	£1,812,000	extension if there is evidence		
mirrors the	maximum term of five years		that the provider has met the		
NCAPOP headline			requirements of the		
contract			specification, deliverables are		
			met in line with requirements		
			(section 9) and the funder		
			agrees with an extension. If		
			the provider agrees to the		
			extension the contract shall be		
			so amended provided that		
			such amendment will not		
			change the overall nature and		
			balance of risk of the contract,		
			and on the basis that any		
			increase in costs is on an		
			open-book basis, or uses the		
			same pricing profile as in the		
			initial contract, so as to		
			achieve best value.		
2. Transition to	Section 5 of this specification	£0-£500,000	In these circumstances, HQIP		
different models of	outlines the known data		will propose amending the		
data collection /	models. As the programme		contract further for		
outputs & / or	evolves, it may become relevant		programme evolution, and if		
operational	to adjust the way in which this		the provider agrees the		
methods /	data is collected and adjust the		contract will be so amended		
processes	methods/processes for routine		provided that such		

¹ Potential Value Range and resultant increase to the contract value

-

Table 1: Aspirational intent				
Options	Description/Specification	Amount ¹	Mechanism for Invoking	
3. Additions or enhancements to the service delivery of the project	Under section 2 of this specification, the funder may require non-material changes to the scope of the project to enhance the service provision	£0-£3,333,333	amendment will not change the overall nature and balance of risk of the contract, and on the basis that any increase in costs is on an open-book basis, or uses the same pricing profile as in the initial contract, so as to achieve best value. Funder request to be discussed with the provider. In these circumstances, HQIP will propose amending the contract further to the funder's required non-material changes, and if the provider agrees the contract will be so amended provided that such amendment will not change the overall nature and balance of risk of the contract, and on the basis that any increase in costs is on an open-book basis, or uses the same pricing profile as in the initial	
4. Additional thematic review on deaths of children with a learning disability and autistic children	Under section 2 of this specification, the funder may require non-material changes to the scope of the project to produce an additional specific thematic review on this topic in 2023/24	£75,000- £150,000	value. Funder request to be discussed with the provider. In these circumstances, HQIP will propose amending the contract further to the funder's required non-material changes, and if the provider agrees the contract will be so amended provided that such amendment will not change the overall nature and balance of risk of the contract, and on the basis that any increase in costs is on an open-book basis, or uses the same pricing profile as in the initial	

Table 1: Aspirational intent				
Options	Description/Specification	Amount ¹	Mechanism for Invoking	
			contract, so as to achieve best	
			value.	
5. Inclusion of	HQIP may amend the contract	0-£1,076,360	Request of Devolved Nations,	
additional national	to include the addition of		Crown Dependencies or other	
or international	further Devolved Nations /		international countries.	
funders	Crown Dependencies /		If the provider agrees to the	
	international funders and		extension, the contract shall	
	participants in the programme		be so amended provided that	
	commissioned. The thresholds		such amendment will not	
	in table 2 are indicative ranges		change the overall nature and	
	of the percentage proportion		balance of risk of the contract,	
	that a Devolved Nation / Crown		and on the basis that any	
	Dependencies would add		increase in costs is on an	
	financially to the contract value.		open-book basis, or uses the	
	The minimum value range		same pricing profile as in the	
	would relate to no aspirational		initial contract, so as to	
	intent being invoked, the higher		achieve best value.	
	value range would relate to all			
	aspirational intent being			
	invoked including a 2 year			
	extension. This % has been			
	calculated based upon the			
	Barnett Formula.			
	See table 2 for Devolved			
	Nations and Crown			
	Dependencies.			
	No formula, similar to the			
	Barnet Formula, exists for			
	calculating international %			
	funding. International funding			
	is currently unknown. This will			
	be assessed on a case by case			
	basis.			

Table 2: Devolved Nations Aspirational Intent			
Devolved Nation	Indicative Percentage Contribution	Potential Value Range and resultant increase to the contract value	Mechanism for Inclusion
Scotland	8.37 – 9.11%	0 to £761,899.64	Further to a request from the

Northern Ireland	2.89 – 3.34%	0 to £279,335.32	devolved nation HQIP shall
Guernsey	0.10 - 0.11%	0 to £9,199.67	propose amending the
Jersey	0.15 - 0.16%	0 to £13,381.33	contract, and if the provider agrees the contract will be so
Isle of Man	0.13 - 0.15%	0 to £12,545.00	amended.

Please note, there is no commitment by the Authority at this stage to include any of the above aspirational intent. Taking this aspirational intent into account, including the possibility that a contract extension may be offered for an additional 24 months, the **potential** ceiling value is £9,589,694 GBP excluding VAT.