Necrotising enterocolitis

Study protocol – May 2026

Study Advisory Group Members

Ben Allin	Postdoctoral Clinical Research Fellow in Paediatric Surgery (National Perinatal Epidemiology Unit)
Josie Anderson	Policy, Research and Campaigns Manager, Bliss
Sarah Bates	Consultant Paediatrician and Neonatologist
Akshay Batra	Consultant Paediatric Gastroenterologist (British Association of Parenteral and Enteral Nutrition & British Society of Paediatric Gastroenterology, Hepatology and Nutrition)
Cheryl Battersby	Clinical Associate Professor in Neonatal Medicine and Consultant Neonatologist (British Association of Perinatal Medicine)
Cheryl Battersby	Consultant Neonatologist (British Association of Perinatal Medicine)
George Bethell	NIHR Doctoral Fellow and Registrar in Paediatric Surgery
Samantha Black	Consultant Paediatric and Perioperative Anaesthetist (Royal College of Anaesthetists)
Pamela Cairns	Consultant Neonatologist
Will Carroll	Consultant Paediatrician
Riddhika Chakravartty	Consultant Radiologist (British Society of Paediatric Radiology)
Sara Clarke	Lead Neonatal Network Dietitian (British Dietetic Association Neonatal Specialist Sub-Group)
Hilary Eadon	Lay Adviser
Alan Fenton	Consultant Neonatologist (Maternal Newborn and Infant Clinical Outcomes Review Programme (MBRRACE-UK))
Grenville Fox	Consultant Neonatologist (British Association of Perinatal Medicine – neonatal network representative)
Grenville Fox	(British Association of Perinatal Medicine – neonatal network representative)
Chris Gale	Professor of Neonatal Medicine and Consultant Neonatologist (Neonatal Medicine Research Group & Neonatal Society)
Jane Gill	Consultant Neonatologist
Nigel Hall	Consultant Paediatric Surgeon
Simon Hannam	Consultant Neonatologist (Children's Hospital Alliance)
Anoo Jain	Consultant Neonatologist (British Association of Perinatal Medicine)
Karen King	Lead Neonatal Dietitian
Nick Lansdale	Consultant Paediatric Surgeon (Neonatal Surgical Forum)
Matt Lee	Honorary Consultant/Clinical Scientist in Colorectal Surgeon (Association of Surgeons of Great Britain and Ireland)
Caroline Lee-Davey	Chief Executive, Bliss
Karen Luyt	Director (National Child Mortality Database)
Fiona Metcalfe	Lead Nurse in Neonatal Surgery (Neonatal Nurses Association & National Neonatal Surgical Interest Group)
Andrew Nyman	Consultant Paediatric Intensivist (Paediatric Critical Care Society)
Sam Oddie	Consultant Neonatologist (National Neonatal Audit Programme)
Sam O'Hare	Consultant Neonatologist & Neonatal Lead for the Paediatric and Neonatal Decision support and Retrieval service (PaNDR) (Neonatal Transport Group)
Rebekah Overend	Professional Lead for Children and Young People (Royal College of Nursing)
Lynne Paterson	Neonatal Nurse Consultant
Kathleen Rao	Parent/carer representative
Divya Saradhi	Parent/carer representative
Shailinder Singh	Consultant Paediatric Surgeon (Royal College of Surgeons)

Clare Skerritt	Consultant Paediatric Surgeon (Children's Hospital Alliance)
Marie Spruce	Chairperson & Research Liaison, NEC UK
Catalina Stendall	Consultant Paediatric Anaesthetist (Association of Paediatric Anaesthetists)
Hemanshoo Thakkar	Consultant Neonatal and Paediatric Surgeon (British Association of Paediatric Surgeons)
Alice Wygold-Munro	Parent/carer representative

Clinical Coordinators

Katie Malbon	Clinical Co-ordinator
David Wood	Clinical Co-ordinator

Non clinical staff

Heather Freeth	Senior Clinical Researcher
Paige Kolasinska	Research Assistant
Rachael Gomez	Senior Administrative Officer
Marisa Mason	Chief Executive

Introduction

Necrotising enterocolitis (NEC) is one of the most severe gastrointestinal emergencies affecting preterm and low-birthweight infants born before 32 weeks' gestation[1], with the most severe outcomes observed in babies born at 23 weeks[2]. NEC is characterised by intestinal inflammation and necrosis that may progress to perforation, sepsis, and death[3,4], with mortality commonly reported at 20-30%[5]. Despite advances in neonatal care, NEC remains a leading cause of neonatal morbidity, with long-term complications including intestinal failure, prolonged dependence on parenteral nutrition, and neurodevelopmental impairment[6,7,8].

Severe disease, typically defined as Bell stage II-III NEC or cases requiring surgery[9], carries the greatest risk of adverse outcomes[2]. Large cohort studies of low-birthweight infants demonstrate that NEC contributes substantially to mortality and serious complications within neonatal populations[10], while UK cohort data highlight significant early and long-term mortality following surgical NEC, particularly among infants requiring prolonged parenteral nutrition[11]. Outcomes are especially poor in infants presenting with intestinal perforation or advanced disease at the time of surgical assessment[12].

Early Recognition and Escalation

Early identification of NEC is inherently challenging. Initial symptoms may be subtle and overlap with sepsis or feeding intolerance, while radiological findings may evolve over time, creating diagnostic uncertainty[13,14,15]. Such ambiguity can influence thresholds for investigation, escalation, and referral for surgical review

Timely initiation of treatment, including bowel rest, antimicrobial therapy, supportive care, and surgical consultation where indicated, is widely considered critical for optimising outcomes[16]. However, variation has been reported in escalation practices and timing of surgical involvement[12,17]. Observational evidence suggests that infants classified as having failed medical management may experience the longest interval between diagnosis and surgery and poorer outcomes[18], highlighting the complexity of surgical decision-making and the importance of timely identification of infants requiring transfer or intervention. Even short delays in recognition, reassessment, referral, or transfer may therefore have significant consequences in rapidly evolving disease[19].

Organisational Context

Care for infants with NEC often spans multiple organisations and clinical teams. In the UK, neonatal services are delivered through managed clinical networks with centralised surgical provision[20]. These services are organised within a tiered system comprising Special Care Units (SCU), Local Neonatal Units (LNUs), and Neonatal Intensive Care Units (NICUs)[21,22].

While not all aspects of NEC management require intensive care, infants with severe disease are typically managed within a NICU. When surgical intervention is required, this is undertaken at specialist centres with either NICU- or Paediatric Intensive Care Unit (PICU)-based surgical provision[23]. However, not all NICU or PICUs have on-site surgical capability for NEC.

As a result, infants cared for in units without on-site surgical capability often require inter-hospital transfer for specialist review and operative management[24]. In some centres, particularly standalone children's hospitals, surgical care is delivered within a PICU setting, with pre-, peri-, and post-operative management occurring outside the traditional NICU environment.

Organisational factors, including location of care, availability of tertiary cots, transport capacity, workforce pressures, and access to senior decision-making, may influence the timing and sequence of clinical management[25]. Access to surgical review, particularly outside routine working hours, may also vary across settings[26]. Transfer processes themselves represent potential points of risk, particularly when clinical deterioration occurs while awaiting specialist review or cot availability[27]. Such structural factors suggest that NEC outcomes are shaped not only by disease severity and clinical decision-making but also by the configuration and responsiveness of healthcare systems.

Previous Research and Evidence Gap

While the epidemiology, risk factors, and preventative strategies for NEC are well described[28,29], comparatively limited work has examined process-of-care factors across the full clinical pathway. In particular, there is limited systematic evaluation of the timeliness of diagnosis, escalation of care, initiation of treatment, referral, surgical review, and inter-hospital transfer in cases of severe NEC. Although organisational variables, such as access to timely transfer, cot availability, location of care, and access to specialist expertise, are recognised as potential influences on the clinical trajectory of NEC, they remain poorly defined, with no standardised national framework for care pathways. Without structured evaluation of these pathway elements, opportunities to identify modifiable system factors and improve care delivery may be missed.

Rationale

NEC outcomes depend not only on treatment effectiveness but on how rapidly infants move through stages of recognition, escalation, referral, transfer, and definitive management. Understanding where delays occur, and whether these relate to clinical uncertainty, service configuration, or resource availability, is central to determining whether aspects of care could have been improved.

This study therefore aims to examine the clinical course of preterm infants diagnosed with NEC, including those requiring surgical intervention and/or who died, with a focus on the timeliness of diagnosis, initiation of treatment, referral and transfer processes, and organisational factors such as location of care, access to surgical assessment, bed availability, and number of transfers. In addition to case-note review, qualitative exploration of clinician and parental experiences through focus groups and surveys will provide contextual understanding of decision-making, escalation practices, and organisational barriers within NEC pathways. Integrating quantitative and qualitative insights will support identification of modifiable system factors and inform recommendations to improve NEC care delivery across neonatal networks.

Guidelines and standards

- National Neonatal Audit Programme (NNAP) Summary report on 2024 data. 2025. https://www.rcpch.ac.uk/sites/default/files/2025-10/091025_nnap_summary_report_2024_data.pdf
- The British Association of Perinatal Medicine Service and Quality Standards for Provision of Neonatal Care in the UK. 2022. https://hubble-live-assets.s3.eu-west-1.amazonaws.com/bapm/file_asset/file/3581/BAPM_Service_Quality_Standards_FINAL.pdf

- NICE Neonatal Infection: Antibiotics for prevention and treatment. 2021. https://www.nice.org.uk/guidance/ng195/resources/neonatal-infection-antibiotics-for-prevention-and-treatment-pdf-66142083827653
- GIRFT Neonatology GIFT Programme National Specialty Report. 2022. https://gettingitrightfirsttime.co.uk/wp-content/uploads/2025/01/Neonatology-national-report-09-12i-FINAL.pdf
- GIRFT and RCPCH. A snapshot of neonatal services and workforce in the UK. 2020. https://www.rcpch.ac.uk/sites/default/files/2020-09/a_snapshot_of_neonatal_services_and_workforce_in_the_uk_2.4.pdf
- NICE Neonatal parenteral nutrition. 2020. https://www.nice.org.uk/guidance/ng154/resources/neonatal-parenteral-nutrition-pdf-66141840283333
- Bliss. Necrotising enterocolitis (NEC). https://www.bliss.org.uk/parents/about-your-baby/medical-conditions/necrotising-entercolitis-nec
- NEC UK. What is NEC. https://www.necuk.org.uk/what-is-nec
- A UK wide cohort study describing management and outcomes for infants with surgical Necrotising Enterocolitis. 2017. Allin et al. https://pmc.ncbi.nlm.nih.gov/articles/PMC5269581/pdf/srep41149.pdf
- One-year outcomes following surgery for necrotising enterocolitis: a UK-wide cohort study. 2017. Allin et al. https://pmc.ncbi.nlm.nih.gov/articles/PMC6109245/pdf/fetalneonatal-2017-313113.pdf

Aim and objectives

Aim

- To improve the quality of acute care provided to babies born before 32 weeks gestation who develop necrotising enterocolitis (NEC)

Objectives

Organisational issues

Data to be collected from the organisational questionnaire

To review the organisation of services for babies with necrotising enterocolitis, including:

- The organisation of services (including type of organisation, access to NICU/NICU where surgery is undertaken, the size of the neonatal unit/capacity, access to paediatric surgeons and paediatric anaesthetists, criteria for referral to surgery and access to theatre)
- Protocols, pathways of care, and the use of guidelines (including for the escalation of care, standardised feeding pathways, and access to donor human milk (DHM) and probiotics)
- Networks of care
- Transfer arrangements (including transport arrangements, distance to nearest NICU where surgery is undertaken/PICU)
- The availability of appropriately trained, skilled and experienced staff, taking into account case exposure and the whole MDT including but not exclusively anaesthetists, surgeons, allied health professionals, specialist nurses including in stoma and palliative care.
- Feeding and nutritional support arrangements (including access to parenteral nutrition (PN) and DHM)
- The availability of information and support for parent/carers
- Equity of access to care across the whole pathway

Clinical issues

Data collected from the clinical questionnaire, the reviewer assessment form and surveys.

To explore:

- The recognition of deterioration (including the time to and frequency of clinical reviews, the seniority of clinical reviewer and the timeliness of making a diagnosis)
- The appropriateness of the escalation of care (including delays to referral)
- The decision-making process and the timeliness of initiating appropriate treatment (including medical/surgical management, anaesthetic and surgical risk discussion, antibiotics, time to surgical assessment, and time to procedure where applicable)
- The availability of and timeliness of PN provision
- Staffing arrangements and MDT working (including discussion with a NICU and/or surgical team and surgical review, and access to paediatric anaesthetists, paediatric surgeons, neonatal nurses and surgical clinical nurse specialists, psychologists, paediatric/neonatal pharmacists, neonatal dietitians and paediatric palliative care teams)
- Transfer arrangements (including which babies were transferred, how they were transferred, why they were transferred, the timing of and the appropriateness of the transfer)
- Parent/carer involvement in care (including the identification of early warning signs in their babies) and in decision-making

Methods

Inclusion criteria

Babies born at <32 weeks gestation who develop NEC at <40 weeks of gestation and were discharged/died between 1st January 2024 – 31st December 2025. Babies will be identified for inclusion in two ways:

1. Via the National Neonatal Audit Programme (NNAP) or via a study contact where a Trust/Health Board doesn't return data to NNAP
2. Via local reporters using hospital patient administration systems (PAS).

Via NNAP

Babies with a diagnosis of NEC who were discharged/died between 1st January 2024 – 31st December 2025 will be identified for inclusion via NNAP, using data already returned as part of the audit.

Via a study contact

Where a Trust/Health Board does not return data to NNAP via BadgerNet they will be asked to set up a study contact in the neonatal department who will be asked to populate the patient identification spreadsheet with the details of babies who fit the study criteria. This study contact could be the neonatal clinical lead or head of service; the Perinatal Mortality Review Tool (PMRT) lead, or the Child Death Review (CDR) lead.

Via local reporters

Local reporters will be asked to populate a patient identification spreadsheet with the details of babies with an ICD10 code for NEC, who were discharged/died between 1st January 2024 – 31st December 2025. This data will be cross referenced with the NNAP data as part of a coding improvement message.

The code used for **patient identification** will be:

- Necrotising enterocolitis (P77) in any position

The codes used for **sampling** (where required) will be based on the NNAP definitions of NEC:

- Necrotising enterocolitis (P77) in any position

AND

- At least one clinical feature from:
    - Bilious gastric aspirate or emesis (P92.0)
    - Abdominal distension (R14.0, P76.9, P78.8)
    - Occult or gross blood in stool (no fissure) (R19.5)

  AND

  - At least one radiographic feature from:
    - Pneumatosis (K63.8)
    - Hepato-biliary gas (K63.8)
    - Pneumoperitoneum (P78.2)

Exclusions

Babies with both an ICD10 code for NEC (P77) and volvulus (K56.2, P76) will not be sampled for inclusion in the peer review process

Data sampling time frames

The timeframe from which data will be sampled will be babies who were discharged/died between the 1st January 2024 – 31st December 2025.

Participating providers of healthcare
All acute hospital providers with a neonatal intensive care unit (NICU), local neonatal unit (LNU), a special care unit (SCU) or a Paediatric Intensive Care Unit (PICU) on site across England, Wales, Northern Ireland and Jersey will be asked to participate in the study.

Incidence and prevalence of the exemplar conditions
The National Neonatal Audit Programme (NNAP) summary report on 2024 data identified 351 babies with NEC over a one-year period. (https://www.rcpch.ac.uk/resources/NNAP-summary-report-2024-data)

Based on this, data will be collected over a two-year period to ensure babies are identified from centres where a smaller number of babies are admitted.

Study promotion
Prior to data collection, NCEPOD will contact all hospitals providing care to this group of babies. The study will also be promoted via NCEPOD local reporters (sending the study poster on to the relevant departments), the relevant Colleges and Associations, and any relevant patient groups and third sector organisations.

Study method test
The data collection methods and data collection tools will be tested to ensure they are robust before the full study is run.

Methods of data collection

There will be five main methods of collecting data for the study:

1. Parent/carer views will be collected through focus groups and an online anonymous survey. We will work with local reporters, and relevant charities (e.g. NEC UK, Bliss) to encourage involvement.

2. Clinician views will be collected through an online anonymous survey. We will work with local reporters and study contacts to encourage involvement from clinicians.

3. An organisational questionnaire will be sent to all hospitals with a NICU, LNU, SCU or PICU on site.

4. Clinical data collection – retrospective data collection: For a sample of babies, questionnaires will be sent to the clinician responsible for the baby at the time of admission to the neonatal unit where the baby was being cared for 48 hours before the diagnosis of NEC was made (neonatology questionnaire), and to the clinician responsible for the baby at the time of admission to a NICU or PICU for surgical assessment (surgical questionnaire). If a baby is transferred between hospitals within the 48 hours prior to diagnosis, or for an increase in medical care following diagnosis, separate neonatal questionnaires will be sent for each admission, where appropriate.

5. Case note review: Copies of selected extracts of case notes will be collected for peer review.

Further details on the methods of each method of data collection are given below.

1. Anonymous online parent/carer surveys and focus group interviews

The survey and focus group interviews will gather data on the parent/carer views of the services available to them when they had a baby with NEC. It will also collect information around support services and information, feeding arrangements (including breast feeding arrangements and access to DHM) and follow-up. The data will not be linked to any other aspects of data collection.

2. Anonymous online clinician survey

The survey will gather data on clinician views of the services available for them to provide to babies with NEC. It will also collect information around confidence, competency, training and what clinicians consider the definition of NEC to be. The data will not be linked to any other aspects of data collection.

3. Organisational questionnaire

Data will be collected at a hospital level and will collect information around the organisation of services, protocols and pathways, networks of care and transfer arrangements, the availability of staff, feeding arrangements, the availability of information and support for parent/carers, training and the retention of skills and equity of care. Questionnaires will be sent to all hospitals participating in the study via the online questionnaire system.

4. Clinical data collection – retrospective data collection

Patient identification

Two patient identification spreadsheets will be used to collect data for this study; one which identifies babies for inclusion via NNAP or a study contact, and one which identifies babies via local reporters using PAS.

Via NNAP/study contact

- NNAP/the study contact will provide the data on babies with a diagnosis of NEC who were discharged/died between the 1st January 2024 – 31st December 2025

Via local reporters

- The local reporter will be asked to complete the patient identification spreadsheet with the details of all babies with NEC (ICD10 code P77) who were discharged/ died between the 1st January 2024 – 31st December 2025

The data fields requested across both spreadsheets will include:

- Patient identifiers (date of birth, gestation at birth, sex, NHS number, hospital number, sex, mothers' postcode, baby's ethnicity)
- Admission details (date of arrival, admission, source of admission, ward level of care)
- Transfer details (name of transferring Trust/Health Board)
- NEC details (NEC diagnosis, clinical features, radiographical features, NEC diagnosis based on) *NNAP data only*
- Coding details (primary ICD10 code, all ICD10 codes, all OPCS codes) *PAS data only*
- Surgical procedure information (If OPCS code T341 (peritoneal drain) or T340 (laparotomy), date of procedure) *PAS data only*
- Discharge information (date of discharge, discharge destination, transfer details where applicable)
- Clinician details (admitting SCU/LNU/NICU clinician, operating clinician (for NEC procedure) where available) *Local reporter data only*

Tracking healthcare across multiple organisations
Babies may be transferred between units; therefore, care will be tracked across multiple organisations to identify this. To enable us to identify whether a baby was transferred, transfer details will be requested in the patient identification spreadsheets, and the neonatology questionnaire. If a baby is identified as being transferred and is not included on one of the original patient identification spreadsheets returned to NCEPOD, we will contact the local reporter to confirm whether the baby is known to their organisation for that episode of care using the NHS number and date of birth, prior to uploading the relevant questionnaire.

Clinician questionnaires
Two clinician questionnaires will be used to collect clinical data for this study:

1) Neonatal questionnaire
2) Surgical questionnaire

Neonatal questionnaire
The neonatal questionnaire will be sent to the clinician responsible for the baby at the time of admission to the neonatal unit where the baby was being cared for 48 hours before the diagnosis of NEC was made (SCU, LNU, or NICU). If a baby is transferred between hospitals within the 48 hours prior to diagnosis, or for an increase in medical care following diagnosis, separate neonatal questionnaires will be sent for each admission, where appropriate. Questionnaires will be sent to the NCEPOD local reporter for dissemination via the online questionnaire system. A reminder will be sent at six weeks and ten weeks where the data is outstanding. Up to 8 babies per hospital will be sampled for inclusion in the study.

Surgical questionnaire
Where applicable, the surgical questionnaire will be sent to the surgeon responsible for the baby at the time of admission to the neonatal unit where surgery on neonates is undertaken on site (this may be in NICU or PICU). This questionnaire will be sent to the NCEPOD local reporter for dissemination via the online questionnaire system. A reminder will be sent at six weeks and ten weeks where the data is outstanding.

5. Case note review
Photocopied case note extracts will be requested for each baby included in the study sample.

Notes requested will include:
From admission to the neonatal unit where the baby was being care for 48 hours prior to diagnosis to the end of the first 4 weeks of treatment following diagnosis. If the baby had a long hospital admission prior to developing NEC, the notes can be limited to the 48 hours prior to symptoms starting. If the baby was transferred between hospitals, notes will be requested from all hospitals.

- Medical and nursing notes
- NICU/critical care notes
- Transfer arrangement notes and transfer documentation
- Imaging reports
- Operation notes
- Anaesthetic charts
- Consent forms
- Drug charts – including any PN prescriptions
- Dietetic notes separate to the main medical notes

- PEWs charts
- Blood culture results, histology reports and any other laboratory/point of care results
- Parent/carer communication sheets
- BadgerNet notes (where available)

In relation to the whole admission

- The completed Perinatal Mortality Review Tool (PMRT) (where available)
- The completed Child Death Overview Panel form (CDOP) (where available)
- Discharge summary

Upon receipt at NCEPOD the case notes will be redacted if not already done so prior to sending.

Reviewer assessment form

A multidisciplinary group of reviewers (detailed below) will be recruited to assess the case notes and questionnaires and provide their opinion on what went well and what did not go well during the process of care via the reviewer assessment form.

The table below summarises the data sources for significant points along the pathway.

Area of enquiry	**Method of data collection**	**Confidentiality**
Acute care	Case notes, clinician questionnaire, organisational questionnaire	Identifiable
	Online surveys	Anonymous

Sample Size

Data source	**Target number**
Organisational questionnaire	~200
Neonatal questionnaires	Up to a maximum of 8 per initially admitting hospital
Surgical questionnaires	Up to a maximum of 8 per initially admitting hospital, and up to a maximum of 20 per Trust/Health Board to account for transfers in
Case note review	Up to a maximum of 20 per Trust/Health Board
Parent/carer surveys (non-identifiable)	50
Clinician online survey (non-identifiable)	300

Analysis and Review of Data

Reviewers

A multidisciplinary group of reviewers will be recruited to assess the case notes and questionnaires and provide their opinion on what went well and what did not go well. The reviewer group will comprise neonatologists, paediatric surgeons, paediatricians, paediatric critical care clinicians, anaesthetists, anaesthetists with regular paediatric sessions, neonatal nurses, advanced neonatal nurse practitioners, neonatal transport team members, and neonatal dietitians.

An advert will be sent to the relevant Royal Colleges, Associations and professional bodies, and to local reporters to disseminate throughout the relevant departments. It will also be placed on the NCEPOD website and social media channels. Successful applicants will be

asked to attend a training day where they will each assess the same two cases to ensure consistent assessment. A number of meeting dates will be arranged, and each reviewer will then be asked to attend a minimum of a further 4 meetings. NCEPOD staff will ensure there is a mix of specialties at each meeting from across the UK. Each meeting will be chaired by an NCEPOD clinical coordinator who will lead discussion around the cases under review. The meetings will either be held in person in the NCEPOD office, or over Microsoft Teams with secure and temporary access to the case notes for review (not downloadable or printable by the case reviewer). Towards the end of the study the reviewers will be invited to attend a meeting where the data will be presented to and discussed with them. The reviewers will also be sent two copies of the draft report for their comment as this is developed.

Confidentiality and data protection

All data held by NCEPOD are held securely and protected by NCEPOD.

In order to carry out this work in England and Wales, we have been given 'section 251' support to collect and use this information under very strict conditions of confidentiality and data security by the Secretary of State for Health and Social Care, on advice from the Confidentiality Advisory Group (CAG).

In addition, in England, the National Data Opt-Out (NDOO) is a process that allows individuals to opt-out of their confidential patient information being used for purposes other than medical care. To ensure that NCEPOD recommendations are not affected by reported variations in who is opting-out, we will not be excluding the data of individuals who have opted out via the NDOO. We have been granted this exemption by the Secretary of State for Health and Social Care, on advice from the Confidentiality Advisory Group (CAG). However, individuals still have the right to contact NCEPOD and ask for their data to be removed and permanently erased.

Ethical approval will not be required to undertake this study. Duty of candour is covered by the NCEPOD Cause for Concern policy, which ensure that any cases reviewed as less that satisfactory and as a cause for concern are discussed and action taken where required.

Study outputs

On completion of the study a report will be published and widely disseminated to all stakeholders to encourage local quality improvement (QI) (further details available in the communication plan). In addition to the report, supporting tools will be made available including:

- A summary report and summary sheet
- A parent/carer information leaflet
- Infographics
- The recommendation checklist
- An audit tool
- A slide set
- A guide for commissioners
- Quality improvement tools
- Useful links for parent/carers

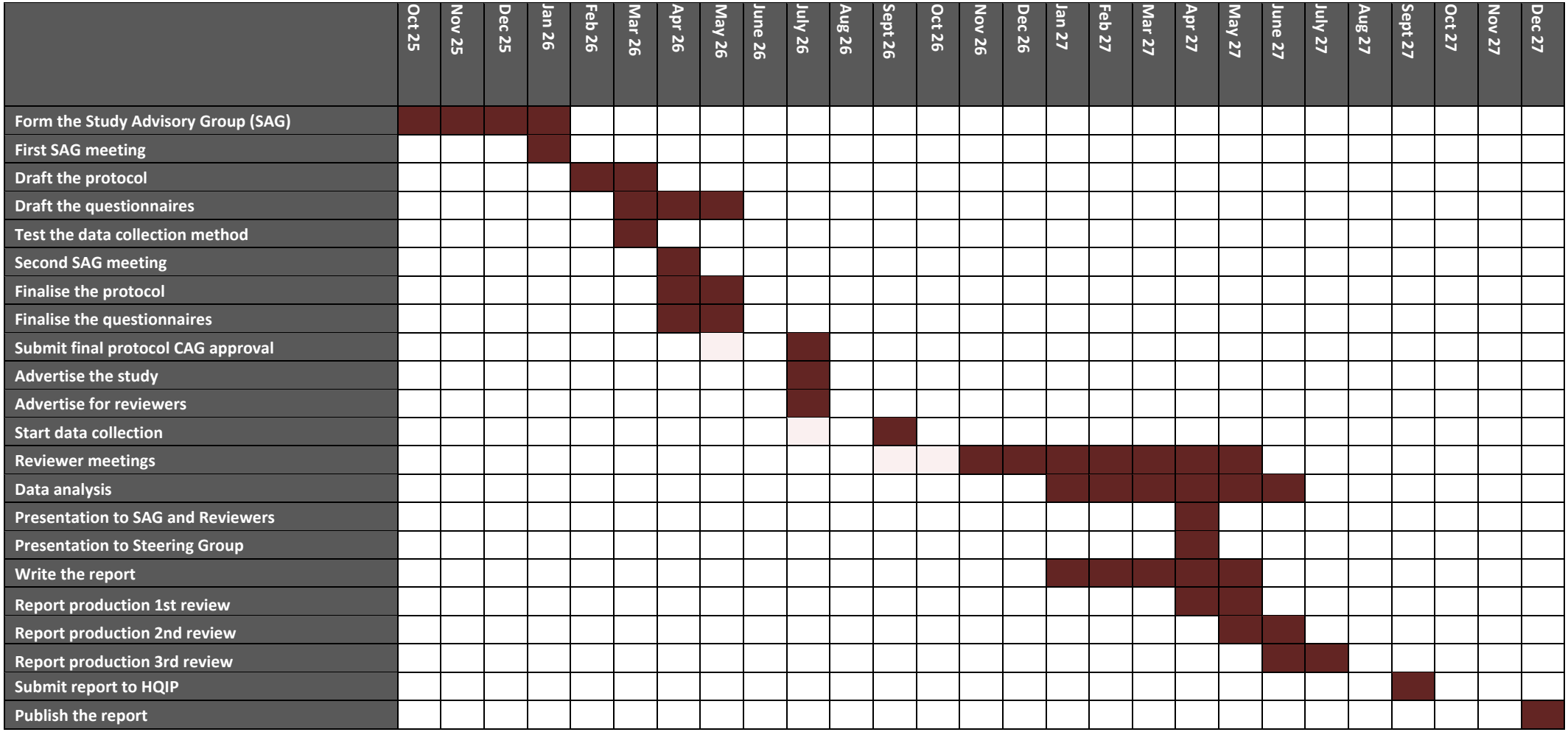
Examples of good practice will be shared, and additional QI tools will be developed where appropriate. Key messages from the report will be shared via social media.

Following publication, the report findings will be shared at national and local conferences, study days and other events; and papers submitted to journal for consideration for publication.

Data sharing

Post publication of the study there is the potential to share anonymised data sets with interested parties working in the same field. This will be undertaken following a strict process and will ensure the data does not become identifiable in their nature due to small numbers.

Timescale


Oct 25
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Dec 26
Jan 27
Feb 27
Mar 27
Apr 27
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June 27
July 27
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Sept 27
Oct 27
Nov 27
Dec 27
Form the Study Advisory Group (SAG)
First SAG meeting
Draft the protocol
Draft the questionnaires
Test the data collection method
Second SAG meeting
Finalise the protocol
Finalise the questionnaires
Submit final protocol CAG approval
Advertise the study
Advertise for reviewers
Start data collection
Reviewer meetings
Data analysis
Presentation to SAG and Reviewers
Presentation to Steering Group
Write the report
Report production 1st review
Report production 2nd review
Report production 3rd review
Submit report to HQIP
Publish the report

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