NCEPOD Data Burden Reduction Strategy

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)
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Purpose

The purpose of this strategy is to reduce the burden associated with NCEPOD data collection across all stages of the review process while maintaining the quality, completeness and integrity of the data required to support confidential enquiries and improve patient care.

This strategy recognises that healthcare professionals and audit departments are operating within increasingly constrained resources. Data collection should therefore be proportionate, minimise duplication, make best use of existing information, and focus on information that directly contributes to answering the clinical questions of each study.

HQIP definition: data burden impact refers to the time, effort and costs required for a healthcare provider to participate in NCEPOD (i.e. the collection and submission of data). Data burden excludes the work required by a healthcare provider to internally disseminate the outputs of the audit or outcome review programme, develop associated action plans and take forward quality improvement (QI) activities.[HQIP]

Strategic principles

1. Collect only essential data

Each data item included within questionnaires or case note requests has a clearly defined purpose, detailed in the analysis plan.
Questions should be included only where they:

- answer a specific study objective;
- support peer review;
- contribute directly to recommendations.

Questions with limited analytical value are removed.

2. Keep questionnaires as short as practicable

Clinical questionnaires are as concise and proportionate as possible. NCEPOD recognises that there is one chance to get all the information need for a study as the enquiry method is not a routine data collection, but every effort is made to exclude extraneous questions.
Each questionnaire undergoes thorough review by the project team and study advisory group before data collection starts to ensure that:

- duplicate questions are removed;
- free-text responses are minimised;
- conditional logic is used where appropriate;
- questionnaires are tested by the study advisory group and their clinical contacts to assess completion time and content;
- questions are understandable and clinically relevant;
- clinician input is encouraged to form part of their CPD.

3. Request relevant case notes only

Case note requests are proportionate to study objectives.

Where appropriate we:

- request only relevant episodes of care;
- avoid requesting duplicate records;
- prefer the transfer of electronic records;
- provide clear guidance on required documentation.

4. Use existing data before requesting new data

Where possible, NCEPOD will obtain information from existing national datasets rather than requesting hospitals to reproduce information already available. This is limited due to financial and information governance restraints, along with the time to access data when each enquiry has a fixed delivery time, but existing audits have been used existing audits have been used in the past, and when all these constraints are able to be addressed, these are the best potential source of data.

Other potential sources include:

- Electronic patient record exports
- Governmental and national data sets (HES/PEDW/NISRA)
- Office for National Statistics mortality data
- National clinical audits
- Disease registries

5. Align with NHS workflows

Study timelines recognise operational pressures.

Where feasible we:

- avoid major NHS winter pressures;
- provide adequate notice before data collection;
- allow flexible submission periods;
- space studies across the NCEPOD work programmes to coordinate requests for data;
- coordinate requests with other national programmes.

6. Support local reporters, ambassadors and the clinicians completing questionnaires

Local reporters, ambassadors and the clinicians completing questionnaires, play a critical role in study success. Learning from their feedback informs continuous improvement of NCEPOD's methods and processes. NCEPOD provides:

- standard procedures as a baseline while recognising every hospital works differently;
- training days;
- frequently asked questions;
- very responsive helpdesk support;
- long and flexible submission deadlines;
- S.251 approval means that local reporters do not have to anonymise data prior to submission
- capping of the number of questionnaires per clinician and the requested sets of case notes per hospital.

7. Continuous improvement

Following each study, NCEPOD evaluates:

- user feedback;
- enquiries;
- unnecessary questions identified during analysis.

Lessons learned are incorporated into subsequent studies wherever possible.

Measuring success

Success is measured using the following indicators:

- Reduced requests for clarification from the NCEPOD office;
- A reduction in in the number of negative comments about the volume of data collected, either through questionnaire length or case notes requested;
- Positive participant feedback regarding ease of data collection;
- Maintenance or improvement in the overall data completeness and quality.

Governance

The Data Burden Reduction Strategy is overseen by NCEPOD's senior management and embedded within study design, questionnaire development and project governance.

For every new study:

- each data item has documented justification laid out in the analysis plan;
- questionnaire burden is assessed before a study starts by testing it through the study advisory group and their contacts;
- feedback from previous studies is considered;
- opportunities for routine data use are considered during protocol development.

Progress against this strategy is reviewed annually and reported through NCEPOD's governance framework.

Estimated time spent on tasks based on feedback from those involved.

Local reporters:

- Return of patient identification spreadsheets - *approximately three hours - the total time will be spread over several days.*
- Facilitating the completion of an online organisational questionnaire - a*pproximately two hours, spread over several weeks to gather input from different people.*

Healthcare professionals:

- Completion of questionnaires through an online platform which can be saved and revisited - *approximately 1-1.5 hours to complete.*
- Return extracts of the case notes for peer review – *approximately two hours per case.*
- Participation in study advisory groups or as a case reviewer - *although this does not occur locally, healthcare professionals are released from their local clinical commitments for three to ten days over the course of the study.*