Understanding Practice in Clinical Outcome Review Programmes tool: UPCORP-tool guidance and checklist

A protocol to describe the key features of clinical outcome review programmes

FAQ

Who should complete the tool?

This tool is designed to be completed by individuals and organisations planning and implementing clinical outcome review programmes. It has been specifically designed for national clinical outcome review programmes commissioned by the Healthcare Quality Improvement Programme (HQIP) as part of the National Clinical Audit and Patient Outcome Programme (NCAPOP), but can be adapted and used by clinical outcome review programmes in other settings.

What is the tool for?

The tool provides a consistent approach, like a protocol, for describing the key features of clinical outcome review programmes. It consists of a standardised heading structure which can be completed to provide a "one-stop" summary of the key information about how clinical outcome review programmes have been designed and carried out. It is expected that this will be published openly for anyone to view, and help users and participants understand the methods, evaluate the quality and robustness of these confidential enquiries, and find information that is most relevant to them. For national clinical outcome review programmes commissioned by HQIP, the intention is that publishing this information openly will reduce the frequency of ad hoc requests for project information HQIP and other national agencies.

This tool is not intended to be used to formally "score" the quality of the responses. The design of this tool has been inspired by reporting checklists used for clinical guidelines (e.g. AGREE[1]) and in reporting research studies (e.g. STROBE[2], SQUIRE[3]).

What type of information is contained within UPCORP?

UPCORP enables structured information on the organisation, aims, governance, methods, information governance and outputs of each project. It is intended that the responses to the tool are factual and written concisely. Where possible, documents can be embedded and hyperlinks provided if information is published elsewhere. This document is intended to be a complete account of the information for the clinical outcome review programme. Please be vigilant about keeping any links included in the document up to date so readers can access full information about the clinical outcome review programme.

Who is the intended audience for the tool?

Examples of clinical outcome review programme stakeholders include:

- Patients / Carers / Public / Patient representative organisations
- Clinicians / Allied health professionals / Healthcare providers / Multi-disciplinary teams / Primary, secondary and tertiary care providers
- National agencies across the UK
- Commissioners
- Healthcare regulators

[1] AGREE stands for the Appraisal of Guidelines for Research & Evaluation. See https://www.agreetrust.org/about-the-agree-enterprise/introduction-to-agree-ii/, last accessed 24 April 2018.
[2] STROBE stands for Strengthening the Reporting of Observational Studies in Epidemiology. See https://www.strobe-statement.org/index.php?id=strobe-home, last accessed 24 April 2018.
[3] SQUIRE stands for Standards for Quality Improvement Reporting Excellence. See http://www.squire-statement.org/, last accessed 24 April 2018.

FAQ (con't)

How should the responses be written?

Responses should be clear, accessible and useful. Some tips and suggestions for writing clearly include:

- avoiding technical jargon where possible
- using short paragraphs and bullet points
- using the "active" voice rather than passive
- keeping sentences short

Where information is published openly elsewhere, links and references should be provided rather than duplicating information that is already available

When and how often should the tool be completed?

The tool is intended to provide accurate and up to date information about the clinical outcome review programme, and so can be updated whenever and however frequently it is relevant to do so. For programmes commissioned by HQIP it is intended that the tool is updated annually, although clinical outcome review programmes can update the tool more frequently if they wish to.

Each version of the tool should include a date of publication and version number.

Where should the completed UPCORP tool be published?

The completed tool should be published online e.g. on the website for the clinical outcome review programme.

How was UPCORP designed?

HQIP commission, manage and develop the NCAPOP (National Clinical Audit and Patient Outcomes Programme) under contract from NHS England and devolved nations. The work was led by HQIP who set up a Methodological Advisory Group (MAG) consisting of methodological, statistical and quality improvement experts who work with audits and registries. Meeting were held on a six monthly basis and the structure and content of the eight quality domains and their key items were agreed by the MAG. The tool was piloted by 5 audit and clinical outcome review programmes within the NCAPOP and re-edited in light of comments received. Other comments received by MAG members was also considered as part of the re-editing process. The final version of the UPCORP tool was signed off by the HQIP MAG working group and will be reviewed annually.

IPR and copyright

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Domain 1: Organisational information

1.1. The name of the programme

Child Health Clinical Outcome Review Programme (Confidential Enquiry)

1.2. The name of the organisation carrying out the programme

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

1.3. Main website for the programme

www.ncepod.org.uk

1.4. Version number and date of publication of the tool on your website

V1. January 2021

Domain 2: Aims and objectives

2.1. Overall aim

The aim of the child health clinical outcome review programme is to assess the quality of healthcare being provided to patients across the UK.

The programme makes recommendations, generated by clinicians, for clinicians and stakeholder groups that will improve the care provided to future patients.

The emphasis of the programme is on quality rather than causation of incidents or measuring outcomes.

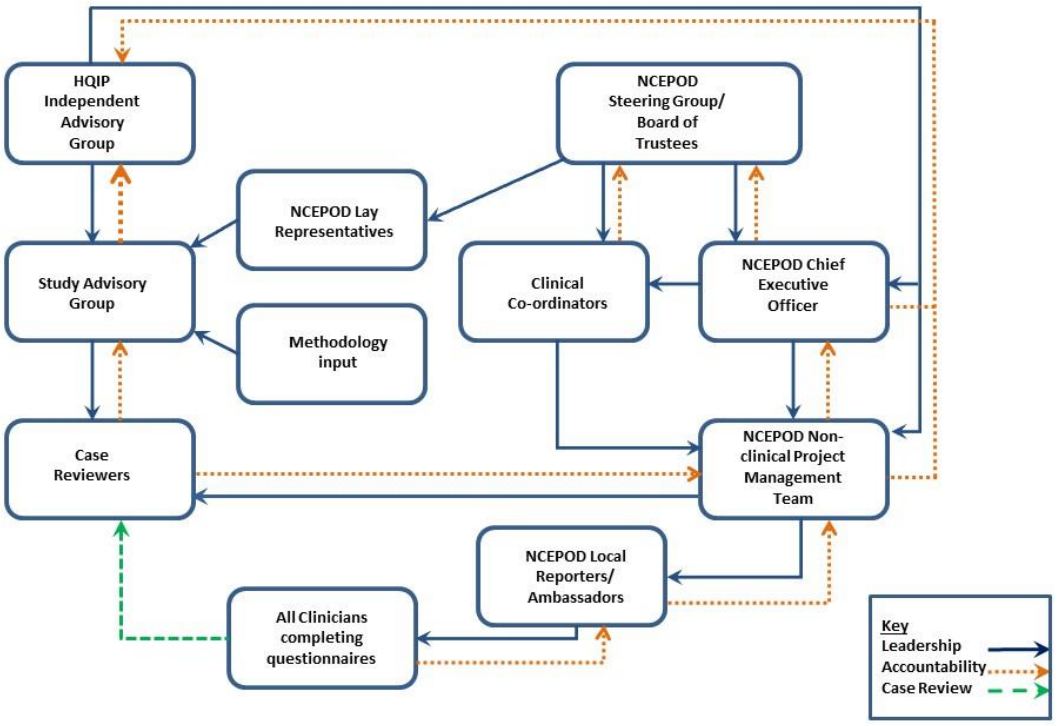
2.2. Objectives to achieve overall aim

The main objectives of the programme are to:

1) Undertake a robust topic selection process
2) Work with relevant healthcare stakeholders, including patients as part of a study advisory group to agree the aims and objectives of the topic that will be reviewed
3) Undertake the data collection
4) Appoint case reviewers and facilitate peer review of the data being returned
5) Produce a final report with clear and actionable recommendations targeted at relevant groups
6) Provide tools to enable local clinical audit/QI against the recommendations
7) Provide tools for patients, such as infographics and patient information/questions to ask of service providers

Domain 3: Governance, programme delivery and stakeholder involvement

3.1. Organogram and governance arrangements



The clinical outcome review programme is governed by a Steering Group, chaired by the NCEPOD Chair. The Steering Group is responsible for overseeing the programme and providing oversight and clinical advice to the programme. The board is the guarantor of the findings from the programme. The Steering Group meets twice a year and decisions are only taken at meetings where meetings are quorate. There is a process for reviewing membership of the group, which comprises nominated members from:

- Association of Anaesthetists of Great Britain and Ireland
- Association of Surgeons of Great Britain and Ireland
- Coroners' Society of England and Wales
- Faculty of Dental Surgery of the Royal College of Surgeons of England
- Faculty of Intensive Care Medicine
- Lay Representatives
- Royal College of Anaesthetists
- Royal College of Emergency Medicine
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Obstetricians and Gynaecologists
- Royal College of Ophthalmologists
- Royal College of Paediatrics and Child Health
- Royal College of Pathologists
- Royal College of Physicians of Edinburgh
- Royal College of Physicians of London
- Royal College of Physicians and Surgeons of Glasgow

- Royal College of Psychiatrists
- Royal College of Radiologists
- Royal College of Surgeons of England
- Royal College of Surgeons of Edinburgh

Individual Study Advisory Groups are formed to steer specific topics. These groups are responsible for overseeing the content of each study, and sign-off of the final recommendations. Each group includes:

- The study proposer
- Healthcare professionals with an interest in the topic – including
- Nominated members from relevant Royal Colleges and specialist associations
- At least one patient representative
- At least one lay representative from NCEPOD's panel of lay members
- A Steering Group member
- Two NCEPOD Clinical Co-ordinators
- NCEPOD research team members covering project management, thematic and data analysis.

During formation of this group we ensure that there are representatives from:

- Each participating country
- All relevant service providers, e.g. primary, secondary and tertiary care, acute hospitals as well as district general hospitals, community care etc.

For commissioning oversight, the programme reports twice a year to an Independent Advisory group formed by HQIP. This group is responsible for commissioning the programme and ensuring it is delivered.

3.2. Organisations involved in delivering the programme and approaches to stakeholder involvement

NCEPOD is solely responsible for delivering the programme, but draws on a wide group of stakeholders to guide the development and dissemination of the findings.

There will be specific stakeholder groups for each of the topics reviewed, who will act in an advisory capacity as a Study Advisory Group member:

- Patients with the condition under review and/or carers
- Representatives from Medical and Surgical Royal Colleges and Specialty Associations
- Clinical teams (this covers all clinical input, not just doctors/surgeons) providing care for people with the condition under review

In addition there are stakeholders who need to be kept up to date with the existence, progress and outputs of the study but who will not be directly involved in it:

- NHS England
- Welsh Government
- NI Government
- Commissioners of healthcare services
- Regulators
- GIRFT
- Academic Health Sciences Networks
- National charity/patient groups for patients with the condition under review

3.3. Declarations of interest and Conflicts of interest

The policy and register of declaration and conflicts of interest for the programme is held at NCEPOD. All interests are collected in advance of meetings and decisions regarding whether a conflict exists and appropriate actions are made by the Chair.

Any new declarations of interest are also requested at each meeting as a standing agenda item and noted on the minutes of all meetings.

Domain 4: Methods

4. Data flow diagrams

Our data flow diagram can be found here: **DATA FLOW DIAGRAM**

4.1. The population cohort for data collection

The study population vary on a study by study basis - an example of the cohorts is summarised here and more detail can be found in each of the study protocols found on our website: **CURRENT STUDIES**

Population Sampled	
Inclusion and Exclusion criteria	Patients aged up to their 25th birthday Each study will have specific inclusion/exclusion criteria listed on study website page and in the associated protocol
Define patient population	Patients will be included if they have one of the ICD10 or OPCS codes included in the study, or, if no code exists then the population will be determined by pre-agreed clinical criteria
Case selection	All patients meeting the inclusion criteria during a pre-set sampling period are notified to NCEPOD. Patients are then randomly selected to ensure there is no bias introduced from 'chosen' cases. The number of cases per hospital are frequently capped at 10 and the number of questionnaires per clinician, capped at 3.
Cohort dates	For each topic, a sampling period is defined based on the prevalence of a condition or procedure.

4.2. Geographical coverage of data collection

Healthcare services in England, Wales, Northern Ireland, the Isle of Man, Guernsey and Jersey are expected to participate. Within each participating organisation, a named contact, referred to as the NCEPOD Local Reporter, acts as a link between NCEPOD and the healthcare staff, facilitating case identification, dissemination of questionnaires and data collation.

Geographical Coverage	
England	☑
Wales	☑
Scotland	☒
Northern Ireland	☑
Crown Dependencies (please list/delete as appropriate) • Jersey • Guernsey • Isle of Man	☑ ☑ ☑ ☑
Other (please specify) _____	☒
Type Funded Care	
NHS healthcare	☑
Independent sector healthcare	☑
Social care	☑

4.3. Proforma/questionnaire for data collection

Each study will have a mix of different questionnaires depending on the nature of the topic. In general though the questionnaires comprise the following, with linked examples from the Long-Term Ventilation Study:

LEAD CLINICIAN QUESTIONNAIRE
COMMUNITY TEAM CLINICAL QUESTIONNAIRE
ORGANISATIONAL QUESTIONNAIRE(S)
REVIEWER ASSESSMENT FORM
PATIENT AND PARENT CARER SURVEY

The questionnaires associated with specific studies can be found on the report page once the study is published: see the examples **HERE**

4.4. Methods of data collection and sources of data

Case identification
Patients will be identified within each community, general practice or hospital by a Local Reporter or named contact who will be asked to complete a spreadsheet listing all patients who meet the relevant study criteria for the study period. Patient identifiers including the hospital and NHS number, alongside the details of the consultants who cared for the patients.

From the large pool of case data supplied, patients will be selected randomly for inclusion.

Different questionnaires are used to collect data for a study; primarily a clinician questionnaire(s) for each included patient and an organisational questionnaire for each clinical site participating in the study.

Clinician questionnaire(s)
This is sent to the consultant/GP responsible for the care of the patient at the time of their inclusion in the study. This might be their lead clinician, or a specialty clinician caring for them for a particular purpose. However if this is not the most suitable person to complete the questionnaire they are asked to identify a more appropriate consultant. The clinician questionnaire collects information on the patient's presenting features/comorbid conditions, management plan, investigations, treatments, complications, escalation in care, discharge planning and follow-up.

Organisational questionnaire
This questionnaire is completed by person/persons with knowledge of the staff, service locations (e.g. critical care, mental health services, specialist wards etc.), equipment, guidelines and standard operating procedures, network arrangements and follow-up clinics for the area of study.

Case notes
In addition to the questionnaires, copies of case note extracts are requested for each included patient. Where applicable these might include sections of:

- Inpatient annotations/medical notes
- Nursing notes
- Critical care notes
- Operation/procedure notes
- Anaesthetic charts
- Observation charts
- Haematology/biochemistry results
- Fluid balance charts
- Blood transfusion records
- Drug charts
- Nutrition/dietitian notes
- Consent forms
- Discharge letter/summary
- Autopsy report if applicable

See page 18 of the **LONG-TERM VENTILATION** report for an example.

Data Source	
Acute care	☑
Primary care	☑
Community care	☑
Mental health	☑
Independent healthcare providers	☑
Other (please specify) _____	☒

4.5. Time period of data collection from organisations

Once a sampling of included cases has been done and questionnaires and case notes requested, data return is open for approximately 6 months to receive and review case notes.

4.6. Time lag between data collection and feedback

Feedback is provided via the report for each study, which are published within 18 months of the start of data collection.

4.7. Evidence base included in feedback, recommendations, key findings

All recommendations are supported by key data points from the report and, where possible, are linked to other relevant guidelines. The example below is taken from the long-term ventilation report:

Suggested target audiences to action the recommendations are listed in italics under each one. The primary target audience/audiences are in bold. *The term 'healthcare professionals' includes, but is not limited to, doctors, surgeons, nurses, general practitioners, physiotherapists, speech and language therapists and occupational therapists*		# is the number of the supporting key data in the report	Associated guidelines and other related evidence
1	**Ensure service planning/commissioning of integrated care pathways for long-term ventilation services includes formal contract arrangements and local standardisation where possible.** These arrangements should bridge child and adult health as well as social care services, respite care and any other partnerships relevant to the local network. Networks should map commissioning arrangements to ensure integration and consistent standards of care and national commissioners should provide a forum to ensure that long-term ventilation provision is considered collectively and delivered to agreed standards. ***Target audiences*** ***Service Planners/Commissioners (National and Local)*** *with support from Trust/Health Board Executive Committees, Social Care, Primary Care, Education, Respite/Hospice Care, Healthcare Professionals in all hospitals (including those that are not LTV centres) and Third Sector Organisations*	**CHAPTER 2 – PAGE 29** #3. Health and social care survey data highlighted a number of improvements that could be made to LTV services, as well as areas of good care, which were often similar – Table 2.3 including: • Access to the wider multidisciplinary team - worked well 138/219 (63.0%) and could be improved 115/219 (52.5%) • Access to services - worked well 35/219 (16.0%) and could be improved 70/219 (32.0%) • Improved clinical knowledge and skills about LTV - worked well 26/219 (11.9%) and could be improved 48/219 (21.9%) • Respite/hospice care - worked well 21/219 (9.6%) and could be improved 15/219 (6.8%) **CHAPTER 3 – PAGE 37** #18. Commissioning of LTV services was rated 5-7 on a seven point scale by 68/167 (40.7%) health and social care professionals – *Figure 3.2* **CHAPTER 3 – PAGE 38/39** #19. Data from the LTV community team clinical questionnaire showed that healthcare was commonly the primary source of funding (73/85; 85.9%). There were 36/85 (42.4%) people who received social care funding, and only 15/85 (17.6%) people had a personal healthcare budget in place – *Table 3.2*	The Quality Review Service (formerly West Midlands Quality Review Service) LTV Quality Standards: https://qualityreviewservicewm.nhs.uk/standards/page/2/ NHSE E07 – Service specification- Level 3 - Paediatric Critical Care (PCC) https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/e07-sa-paed-inten-care.pdf NHSE Paediatric Critical Care and Surgery in Children Review https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2FPaedreview%2FjoinGroup – register to access

4.8. Data analysis

The data are analysed using a mix of quantitative and qualitative summary data to underpin the narrative as follows:

- Clinical questionnaire data are analysed using descriptive tables and figures to underpin the clinical narrative that will be drawn out from the case reviewer data
- All quantitative data are analysed against a pre-defined analysis plan, in Excel, by an NCEPOD Clinical Researcher. It is developed by linking the data being requested to each of the objectives for the study. This also ensures that questions are not being asked just because it is interesting
- Qualitative data are assessed and coded to identify a saturation of themes by the Clinical Researcher and Clinical Co-ordinators involved. Furthermore themes from cases reviewed are merged to form anonymous case vignettes in the report highlighting example of good practice and care/processes that could have been better
- Data from the organisational questionnaire are linked to the clinical data where applicable, but it is used primarily to highlight variation in service provision across the UK and by hospital type
- The data are reviewed at a meeting of the SAG and case reviewers to agree or raise concerns with the data emerging. A summary of the data is also presented to the NCEPOD Steering Group. The SAG, case reviewers and NCEPOD Steering Group then receive two drafts of the report to comment on – the comments are themed with only the consensus view being included to prevent extreme views guiding the analysis
- No individual patient, healthcare professional or hospital is named with regard to the quality of care provided in any of the outputs. However, where a case is flagged as a 'cause for concern' this will be discussed with the Lead Clinical Co-ordinator and the Chief Executive. If it is a concern then the Chief Executive will write to the Medical Director in that hospital, highlighting the issues. Acknowledgement of receipt of the letter is requested, but no further action taken. This process follows HQIPs guidance and has previously been ratified by the NCEPOD Steering Group and the GMC

A confidential enquiry does not lend itself to conventional statistical analysis as only a sample of case are included for the peer review. For this reason it is not possible to identify outliers or provide summary of data at an individual or organisational level.

The findings are quality assured by the Study Advisory Group, Reviewers, NCEPOD Steering Group including Clinical Co-ordinators, Trustees and Lay representatives prior to publication.

An example of a data return flow diagram is shown here – taken from the long-term ventilation report:

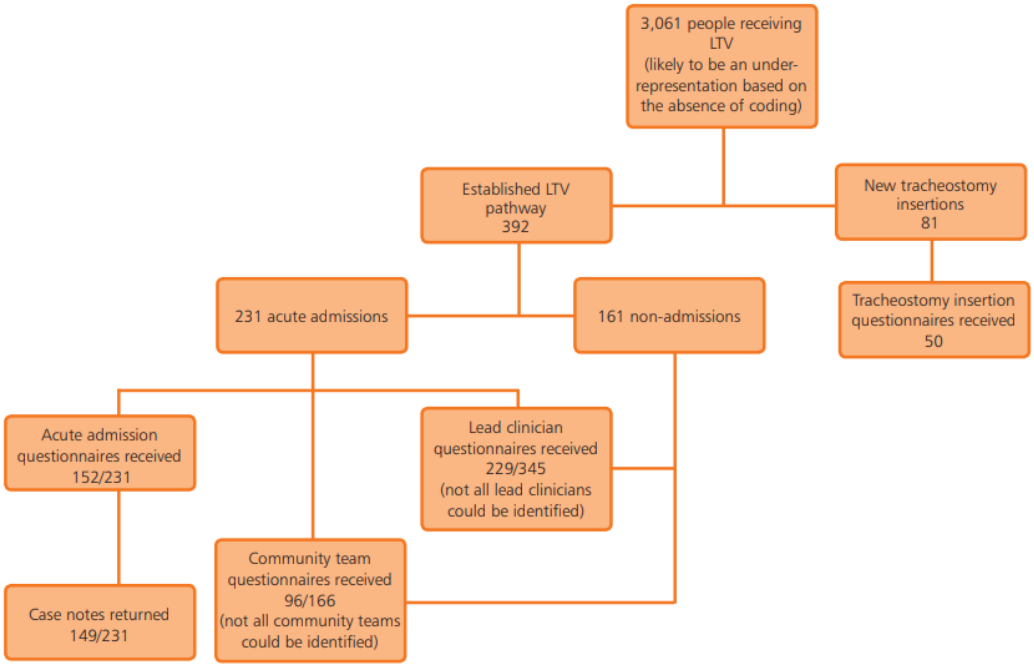


Figure 1.4 Study sample for inclusion in the clinical questionnaire and peer review

4.9. Data linkage (only if appropriate and/or applicable)

No data linkage performed.

4.10. Validation and data quality

All case identification processes are checked prior to running the full study.
All questionnaires are tested with the study advisory group.
All data analysis are reviewed by the case reviewers, the study advisory group then the NCEPOD Steering Group
The draft report is sent out for review and comment to the above groups twice and the recommendations sent out for a final consensus agreement prior to submitting to HQIP.

Domain 5: General Data Protection Regulation (GDPR)

5.1. Information governance, information security and ethics

The programme has approval under section 251 of the NHS Health and Social Care Act 2006 to collect identifiable data without consent. The current status of all applications can be viewed on online at http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/cag-advice-and-approval-decisions/

Patients can opt out of data collection by contacting their local clinical team or notifying the NCEPOD directly details can be found here: https://www.ncepod.org.uk/igovernance.html

Details of the programme's information governance can be found here:
https://www.ncepod.org.uk/confidentiality.html

The DSTP status for NCEPOD can be found here:
https://www.dsptoolkit.nhs.uk/OrganisationSearch/8HH01
This indicates that the programme can be trusted to handle personal information securely.

Domain 6: Outputs

6.1. The intended users or audience for the outputs (including modalities of feedback and outputs)

Study outputs are produced to maximise impact. The outputs can be downloaded from the NCEPOD website. At publication a link to the report and associated outputs will be tweeted and emailed to all Local Reporters/Ambassadors/clinical and patient stakeholders for forwarding - this equates to approximately 2000 initial contacts:

The study outputs are listed here and links have been made to examples on our website:

- **A FULL REPORT** with a strong narrative, anonymous case vignettes, key findings and recommendations targeted at owners ensuring leverage at various points in the healthcare service e.g. colleges/policymakers/healthcare professionals/clinical leads/commissioners/health executive boards/service user organisations/regulators
  AUDIENCES – People who deliver care, receive care, commission care and regulate care

- **A SUMMARY REPORT** with an overview of the study including key findings and recommendations
  AUDIENCES – People who deliver care, receive care, commission care and regulate care

- **A SUMMARY SHEET** providing the key messages and recommendations
  AUDIENCES – People who deliver care and people who receive care

- **AN INFOGRAPHIC** aimed at, and developed with, clinicians and patients to provide the key report messages and what needs to be done to improve care in straight-forward steps
  AUDIENCES – People who deliver care and people who receive care

- **A PATIENT QUESTION SHEET** aimed at, and developed with, patients to provide the key questions to ask when being treated for the topic under review
  AUDIENCE – People who receive care

ADDITIONAL RESOURCES to help stimulate QI and change at a local level include:

- **A RECOMMENDATION CHECKLIST** - a gap analysis tool pre-populated with the recommendations and owners, allowing easy filtering
  AUDIENCE – People who deliver care, commission care and regulate care

- **A SLIDE SET** of findings with comments in the notes section so that the findings can be presented locally
  AUDIENCE – People who deliver care

- **AUDIT TOOLKITS** that generate a summary indicating how recommendations are being adhered to, highlighting where future focus needs to be
  AUDIENCE – People who deliver care

- **A FISHBONE DIAGRAM** template to help users locally determine what will lead to improved care
  AUDIENCE – People who deliver care

- **A COMMISSIONER'S GUIDE** explaining what the findings mean for them
  AUDIENCE – People who commission care

On an ongoing and more direct level we:

- **Present the study findings** at national conferences and local hospital meetings
- Use **social media** to stimulate discussions
- Provide **YouTube videos** aimed at patients and healthcare professionals summarising the findings

6.2. Editorial independence

As an independently commissioned programme, the contents of the outputs are written by NCEPOD Clinical Co-ordinators and quality assured by the Study Advisory Group, Case Reviewers and NCCEPOD Steering Group through the governance processes described in previous sections.

6.3. Recommendations and/or key findings

The reports published under the programme list recommendations specific to each topic Recommendations are:

- Specific, action oriented, and tailored to the intended audience
- Targeted at specific groups to action
- Agreed and signed off through an agreed process
- Supported by data collected by the programme
- Designed to have impact

Examples from the LONG-TERM VENTILATION report – see pages 12-15

Suggested target audiences to action the recommendations are listed in italics under each one. The primary target audience/audiences are in bold. *The term 'healthcare professionals' includes, but is not limited to, doctors, surgeons, nurses, general practitioners, physiotherapists, speech and language therapists and occupational therapists*	
RECOMMENDATIONS RELATED TO SERVICE PLANNING AND COMMISSIONING	
1	**Ensure service planning/commissioning of integrated care pathways for long-term ventilation services includes formal contract arrangements and local standardisation where possible.** These arrangements should bridge child and adult health as well as social care services, respite care and any other partnerships relevant to the local network. Networks should map commissioning arrangements to ensure integration and consistent standards of care and national commissioners should provide a forum to ensure that long-term ventilation provision is considered collectively and delivered to agreed standards. ***Target audiences*** ***Service Planners/Commissioners (National and Local)*** *with support from Trust/Health Board Executive Committees, Social Care, Primary Care, Education, Respite/Hospice Care, Healthcare Professionals in all hospitals (including those that are not LTV centres) and Third Sector Organisations*
2	**Ensure that it is possible to identify all people who are receiving long-term ventilation.** a) Locally this should be achieved by implementing/maintaining a database as soon as possible b) Nationally this should be achieved by developing procedure codes for long-term ventilation to bring together the local data collection and support a national database to quantify service provision and facilitate quality improvement ***Target audiences*** ***LTV Services and NHS Digital, NHS England, NHS Improvement, NHS Scotland, NHS Wales Informatics Service, Northern Ireland Statistics and Research Agency*** *with support from Trust/Health Board Executive Committees, Social Care and Service Planners/Commissioners*

6.4. Comparators and benchmarking (only if applicable)

Not applicable.

6.5. Planning and stimulating quality improvement

The programme supports participants in QI by:

- Providing a self-assessment checklist with each report to measure local compliance against the recommendations.
- Providing an audit tool
- Providing QI tools as requested
- Providing a guide to the report for Commissioners

See the **LONG-TERM VENTILATION** webpage for examples