

| CLINICAL DATA  |  |   |   |   |   |
|--|--|---|---|---|---|
| Data source  | Data type  | Internal controls   | Storage   | Data preparation  | Analysis  |
| <p>Data Controller: If the data comes from healthcare providers: Healthcare provider organisations<br/>           Data Processor: Healthcare providers<br/>           Data Controller: If the data come from an NCAPOP provider: HQIP and NHS England are joint controllers for the English NCAPOP data. HQIP and Digital Health and Care Wales are joint controllers for the Welsh NCAPOP data.<br/>           Data Processor: NCAPOP provider issuing the data</p> <p>Data Controller: HQIP and NHS England are joint controllers for the English NCAPOP data. HQIP and Digital Health and Care Wales are joint controllers for the Welsh NCAPOP data.<br/>           Data Processor: NCAPOP</p> |  |   |   |   |   |
| CASE IDENTIFIER SPREADSHEETS   |  |   |   |   |   |
| All healthcare providers via local contacts /clinicians or data from another NCAPOP programme such as a national clinical audit  | Case identifier spreadsheets/pre-agreed data fields are transferred using data sharing platforms like SharePoint or by email to the NCEPOD nhs.net address   | Data from the NCAPOP provider checked to ensure it is correct<br><br>Spreadsheets from healthcare providers checked for completeness<br><br>Incomplete spreadsheets are returned password protected to the local contact at the hospital                                  | Complete data are entered into a database   | Each patient case is allocated a unique 'NCEPOD number' linked to organisation providing data<br><br>Data sampled for patients to be included and crosschecked for other healthcare providers involved who need contacting                    |   |
|  | identifiable   | identifiable  | identifiable  | pseudonymised   |   |
| CLINICAL QUESTIONNAIRES  |  |   |   |   |   |
| All healthcare providers via local contacts /clinicians  | Clinical questionnaires submitted by a clinician using a unique log-in to an online application housed in NCEPOD or via hard copy if online is not possible<br><br>Blank or partially completed ones are notified to the local reporter using the NCEPOD number only so that | Checked for completeness and if other healthcare providers have been involved   | Electronic data held on a protected standalone server. Paper questionnaires are entered into a database and the hard copy destroyed   | 'NCEPOD number' only is used as a case identifier<br><br>Check with the additional healthcare providers if the patient is known them, if so add their details to  |   |
|  | pseudonymised  | pseudonymised   | pseudonymised   | pseudonymised   |   |
|  | pseudonymised  |   |   | identifiable  |   |
| CASE NOTES   |  |   |   |   |   |
| All healthcare providers via local contacts /clinicians  | Case notes<br><br>Local contacts asked to return the outstanding items   | Case notes checked for completeness   | Secure server/locked cupboards  | Anonymised  | Peer reviewed in NCEPOD office or using secure remote access  |
|  | identifiable   | identifiable  | identifiable  | anonymous   | anonymous   |
| ORGANISATIONAL DATA  |  |   |   |   |   |
| All healthcare providers via local contacts /clinicians  | Organisational questionnaires submitted by the Local Reporter using a unique log-in to an online application housed  | Checked for completeness<br><br>Blank or partially completed ones are notified to the local reporter  | Database  | Stored on the standalone server   | A 'SITE ID' only is used as an identifier   |
|  | non-sensitive data   | non-sensitive data  | non-sensitive data  | non-sensitive data  | non-sensitive data  |
| LINKED SURVEYS/INTERVIEWS  |  |   |   |   |   |
| Data source - all UK   | Data type  | Internal controls   | Storage   | Data preparation  | Analysis  |
| Data Controller: PARTICIPANT<br>Data Processor: NCEPOD   | Data Controller: HQIP and NHS England are joint controllers for the English NCAPOP data. HQIP and Digital Health and Care Wales are joint controllers for the Welsh NCAPOP data<br>Data Processor: NCEPOD  | Data Controller: HQIP and NHS England are joint controllers for the English NCAPOP data. HQIP and Digital Health and Care Wales are joint controllers for the Welsh NCAPOP data<br>Data Processor: NCEPOD   | Data Controller: HQIP and NHS England are joint controllers for the English NCAPOP data. HQIP and Digital Health and Care Wales are joint controllers for the Welsh NCAPOP data<br>Data Processor: NCEPOD   | Data Controller: HQIP and NHS England are joint controllers for the English NCAPOP data. HQIP and Digital Health and Care Wales are joint controllers for the Welsh NCAPOP data<br>Data Processor: NCEPOD                                     | Data Controller: HQIP and NHS England are joint controllers for the English NCAPOP data. HQIP and Digital Health and Care Wales are joint controllers for the Welsh NCAPOP data<br>Data Processor: NCEPOD |
| Clinicians   | Online clinician survey about a particular procedure<br><br>Clinician data are anonymous, or their name provided with their consent<br>Patient data are pseudonymised using partial NHS number/Hospital number for linkage purposes only                                     | Surveys checked for completeness<br><br>Clinician data are anonymous, or their name provided with their consent<br>Patient data are pseudonymised using partial NHS number/Hospital number for linkage purposes only<br><br>Incomplete surveys are deleted from the table | Complete surveys are exported and stored in Excel on a protected stand alone server<br><br>Clinician data are anonymous, or their name provided with their consent<br>Patient data are pseudonymised using partial NHS number/Hospital number for linkage purposes only | Each response will be checked for a matching NHS/hospital number and linked to the case data where possible with the same unique NCEPOD number. If no case data are matched the NHS number will be replaced with a new unique 'NCEPOD number' | Unique number only is used as a case identifier - both for the linked and unlinked data   |
|  |  | anonymous   |   | pseudonymised   | anonymous   |
| UNLINKED SURVEYS/INTERVIEWS  |  |   |   |   |   |
| Data source - all UK   | Data type  | Internal controls   | Storage   | Data preparation  | Analysis  |
| Data Controller: PARTICIPANT<br>Data Processor: NCEPOD   | Data Controller: HQIP and NHS England are joint controllers for the English NCAPOP data. HQIP and Digital Health and Care Wales are joint controllers for the Welsh NCAPOP data<br>Data Processor: NCEPOD  | Data Controller: HQIP and NHS England are joint controllers for the English NCAPOP data. HQIP and Digital Health and Care Wales are joint controllers for the Welsh NCAPOP data<br>Data Processor: NCEPOD   | Data Controller: HQIP and NHS England are joint controllers for the English NCAPOP data. HQIP and Digital Health and Care Wales are joint controllers for the Welsh NCAPOP data<br>Data Processor: NCEPOD   | Data Controller: HQIP and NHS England are joint controllers for the English NCAPOP data. HQIP and Digital Health and Care Wales are joint controllers for the Welsh NCAPOP data<br>Data Processor: NCEPOD                                     | Data Controller: HQIP and NHS England are joint controllers for the English NCAPOP data. HQIP and Digital Health and Care Wales are joint controllers for the Welsh NCAPOP data<br>Data Processor: NCEPOD |
| Clinicians   | Online clinician survey<br><br>anonymous or names given with consent for follow-up   | Surveys checked for completeness<br><br>anonymous or names given with consent for follow-up<br><br>Incomplete surveys are deleted from the table  | Complete surveys are exported and stored in Excel on a protected stand alone server<br><br>anonymous or names given with consent for follow-up  | Each respondent is allocated a unique 'NCEPOD number'   | Unique number only is used as a case identifier   |
|  |  | anonymous   |   | pseudonymised   | anonymous   |
| Clinicians/ Commissioners  | Clinician/ commissioner interviews<br><br>anonymous or names given with consent for follow-up  | Interviews checked for completeness<br><br>anonymous or names given with consent for follow-up  | Recordings and transcribed interview data are held on a protected standalone server<br><br>anonymous or names given with consent for follow-up  | Each respondent is allocated a unique 'NCEPOD number'   | 'NCEPOD number' only is used as a case identifier   |
|  |  |   |   | pseudonymised   | anonymous   |
| Patients/parents/carers  | Parent/carer & patient focus groups/interviews<br><br>identifiable but names given with consent for follow-up  | Responses checked for completeness<br><br>identifiable but names given with consent for follow-up   | Focus group data is transcribed and held on a protected standalone server. Recordings are held on a protected stand alone server<br><br>identifiable but names given with consent for follow-up   | Each respondent is allocated a unique identifier  | NCEPOD number only is used as case identifier   |
|  |  |   |   | pseudonymised   | pseudonymised   |
|  | Parent/carer online survey<br><br>anonymous or names given with consent for follow-up  | Surveys checked for completeness<br><br>anonymous or names given with consent for follow-up<br><br>Incomplete surveys are deleted from the table  | Completed surveys are exported from survey monkey and stored in Excel on a protected stand alone server<br><br>anonymous or names given with consent for follow-up  | Each respondent is allocated a unique identifier<br><br>anonymous or names given with consent for follow-up   | NCEPOD number only is used as case identifier<br><br>anonymous or names given with consent for follow-up  |
|  |  | anonymous   |   |   |   |