CLINICAL DATA

CASE IDENTIFIER SPREADSHEETS

Data source	Data type	Internal controls	Storage	Data preparation	Analysis	Outputs	Destruction
Data Controller: Healthcare provider organisations Data Processor:Healthcare providers	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 Data Processor:Healthcare providers	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 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 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 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 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 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 Data Processor: NCEPOD
All healthcare providers via Local Contacts /Clinicians	**Case identifier spreadsheets sent password protected to NCEPOD NHS.net address** *identifiable* *NATIONAL DATA OPT OUT APPLIES HERE TO HOSPITALS - BEFORE DATA ARE SENT TO NCEPOD*	**Spreadsheets checked for completeness** *identifiable*	**Complete spreadsheets are entered into a database** *identifiable*	**Each patient case is allocated a unique 'NCEPOD number' linked to organisation providing data** *pseudonymised*		**Report - NCEPOD website** *anonymous*	**All data anonymised or shredded three months after reportpublication**
		Incomplete spreadsheets are returned to the local reporter password protected *identifiable*		**Data sampled for patients included in clinical questionnaire completion and case note return and if other healthcare providers have been involved who need contacting** *identifiable* *NATIONAL DATA OPT OUT APPLIES HERE TO NCEPOD IF DATA ARE SHARED BY NCEPOD WITH A HOSPITAL/GP DIFFERENT TO THE ORIGINAL DATA SOURCE*		**Summary sheets/infographic/QI tools - NCEPOD website** *anonymous*	
						Secondary analysis for editorials or peer reviewed journals for enhanced dissemination *anonymous*	

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** *pseudonymised*	**Checked for completeness and if other healthcare providers have been involved** *pseudonymised*	**Electronic data held on a protected standalone server. Paper questionnaires are entered into a database and the hard copy destroyed** *pseudonymised*		**'NCEPOD number' only is used as a case identifier** *pseudonymised*		
	Blank or partially completed ones are notified to the local reporter using the NCEPOD number only so that they can ask the clinician to take another look *pseudonymised*		**Check with the additional healthcare providers if the patient is known them, if so add their details to the database with a unique NCEPOD number and send out q and request case notes** *identifiable*				

CASE NOTES

All healthcare providers via local contacts /clinicians	**Case notes** *identifiable* *NATIONAL DATA OPT OUT APPLIES HERE TO HOSPITALS - BEFORE DATA ARE SENT TO NCEPOD*	**Case notes checked for completeness** *identifiable*	**Locked cupboards** *identifiable*	**Anonymised** *anonymous*	**Peer reviewed in NCEPOD office or using secure remote access** *anonymous*		
	Incomplete sets of case notes are kept safe and local contacts asked to return the outstanding items *identifiable*						

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 in NCEPOD or via hard copy** *non-sensitive data*	**Checked for completeness** *non-sensitive data*	**Database** *non-sensitive data*	**Stored on the standalone server** *non-sensitive data*	**A 'SITE ID' only is used as an identifier** *non-sensitive data*		
		Blank or partially completed ones are notified to the local reporter *non-sensitive data*					

LINKED SURVEYS/INTERVIEWS

Data source - all UK	Data type	Internal controls	Storage	Data preparation	Analysis	Outputs	Destruction
Data Controller:PARTICIPANT 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 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 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 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 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 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 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 Data Processor: NCEPOD
Clinicians	**Online clinician survey about a particular procedure** *Clinician data are anonymous, or their name provided with their consent* *Patient data are pseudonymised using partial NHS number/Hospital number for linkage purposes only*	**Surveys checked for completeness** *Clinician data are anonymous, or their name provided with their consent* *Patient data are pseudonymised using partial NHS number/Hospital number for linkage purposes only*	**Complete surveys are exported and stored in Excel on a protected stand alone server** *Clinician data are anonymous, or their name provided with their consent* *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'** *pseudonymised*	**Unique number only is used as a case identifier - both for the linked and unlinked data** *anonymous*	**Report and summaries - NCEPOD website** *anonymous*	**All data destroyed/ aggregated three months after report release**
		Incomplete surveys are deleted from the table *anonymous*					

UNLINKED SURVEYS/INTERVIEWS

Data source -all UK	Data type	Internal controls	Storage	Data preparation	Analysis	Outputs	Destruction
Data Controller:PARTICIPANT 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 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 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 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 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 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 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 Data Processor: NCEPOD
Clinicians	**Online clinician survey** *anonymous or names given with consent for follow-up*	**Surveys checked for completeness** *anonymous or names given with consent for follow-up*	**Complete surveys are exported and stored in Excel on a protected stand alone server** *anonymous or names given with consent for follow-up*	**Each respondent is allocated a unique 'NCEPOD number'** *pseudonymised*	**Unique number only is used as a case identifier** *anonymous*	**Report and summaries - NCEPOD website** *anonymous*	**All data destroyed/ aggregated three months after report release**
		Incomplete surveys are deleted from the table *anonymous*					
Clinicians/ Commissioners	**Clinician/ commissioner interviews** *anonymous or names given with consent for follow-up*	**Interviews checked for completeness** *anonymous or names given with consent for follow-up*	**Recordings and transcribed interview data are held on a protected standalone server** *anonymous or names given with consent for follow-up*	**Each respondent is allocated a unique 'NCEPOD number'** *pseudonymised*	**'NCEPOD number' only is used as a case identifier** *anonymous*		
Patients/parents/carers	**Parent/carer & patient focus groups/interviews** *identifiable but names given with consent for follow-up*	**Responses checked for completeness** *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** *identifiable but names given with consent for follow-up*	**Each respondent is allocated a unique identifier** *pseudonymised*	**NCEPOD number only is used as case identifier** *pseudonymised*		
Patients/parents/carers	**Parent/carer online survey** *anonymous or names given with consent for follow-up*	**Surveys checked for completeness** *anonymous or names given with consent for follow-up*	**Completed surveys are exported from survey monkey and stored in Excel on a protected stand alone server** *anonymous or names given with consent for follow-up*	**Each respondent is allocated a unique identifier** *anonymous or names given with consent for follow-up*	**NCEPOD number only is used as case identifier** *anonymous or names given with consent for follow-up*		
		Incomplete surveys are deleted from the table *anonymous*					

Responsible owner: Marisa Mason |Date completed: 11/06/25 version 7 Date of next review 31/03/26