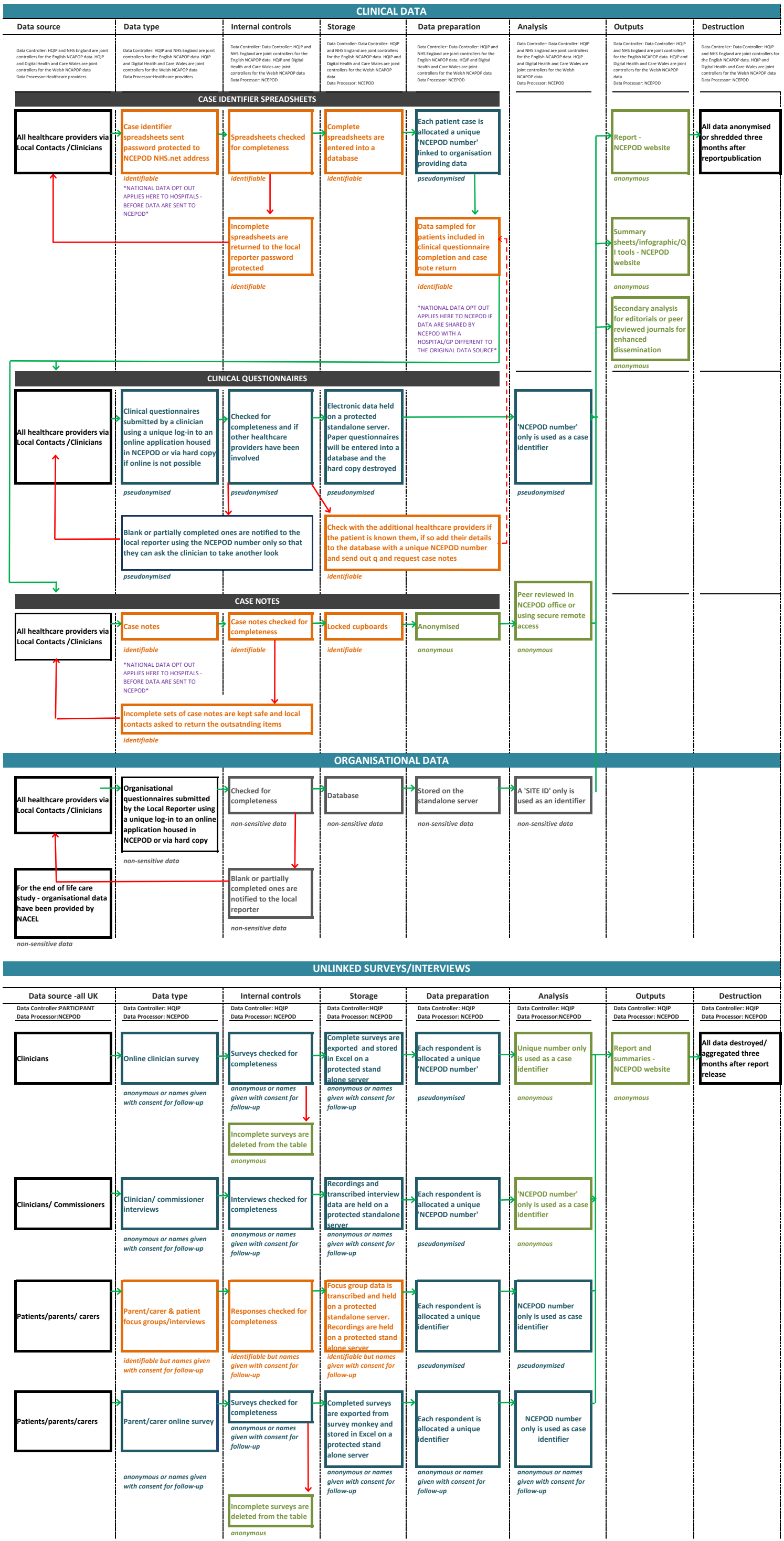
CLINICAL DATA
Data source
Data type
Internal controls
Storage
Data preparation
Analysis
Outputs
Destruction
Data Controller: HQIP and NHS England are joint controllers for the English NCAPOP data. HQIP and Digital Health and Care Wales are joint controllers for the Welsh NCAPOP data
Data Processor:Healthcare providers
Data Controller: 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
CASE IDENTIFIER SPREADSHEETS
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
Incomplete spreadsheets are returned to the local reporter password protected
identifiable
Complete spreadsheets are entered into a database
identifiable
Each patient case is allocated a unique 'NCEPOD number' linked to organisation providing data
pseudonymised
Data sampled for patients included in clinical questionnaire completion and case note return
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*
Report - NCEPOD website
anonymous
Summary sheets/infographic/QI tools - NCEPOD website
anonymous
Secondary analysis for editorials or peer reviewed journals for enhanced dissemination
anonymous
All data anonymised or shredded three months after reportpublication
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
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
Electronic data held on a protected standalone server. Paper questionnaires will be entered into a database and the hard copy destroyed
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
'NCEPOD number' only is used as a case identifier
pseudonymised
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
Incomplete sets of case notes are kept safe and local contacts asked to return the outsatnding items
identifiable
Locked cupboards
identifiable
Anonymised
anonymous
Peer reviewed in NCEPOD office or using secure remote access
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 in NCEPOD or via hard copy
non-sensitive data
Checked for completeness
non-sensitive data
Blank or partially completed ones are notified to the local reporter
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
For the end of life care study - organisational data have been provided by NACEL
non-sensitive data
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
Data Processor: NCEPOD
Data Controller:HQIP
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
Incomplete surveys are deleted from the table
anonymous
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
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
Incomplete surveys are deleted from the table
anonymous
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