# Cabrini Research Data Governance Check-list

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Dimension | Questions | Absent | Emerging | Present | Optimised | |
| Data Purpose | There is a clear statement of the purpose for the data collection |  |  |  | |  |
| The data subjects are clearly defined: age, gender, ethnicity, disease marker |  |  |  | |  |
| Excluded data subjects are clearly defined |  |  |  | |  |
| The audience for reports is clearly defined |  |  |  | |  |
| Data owners and governance structures are defined |  |  |  | |  |
| Comments: | | | | | |
| Data Element Management | The purpose of each data element is documented and required |  |  |  | |  |
| Each data element is clearly defined:   * element name, definition, class (text, value, date etc), units of measure, relationships, source |  |  |  | |  |
| Date of collection is recorded |  |  |  | |  |
| Unique identifiers are used to track and link individual patients and episodes |  |  |  | |  |
| Mandatory data elements are identified |  |  |  | |  |
| Process for changes in data elements is documented |  |  |  | |  |
| Comments: | | | | | |
| Data Capture | Location(s) of data collection is clearly defined |  |  |  | |  |
| Mechanism of data capture and entry is defined: manual, electronic |  |  |  | |  |
| Tools for data capture and entry are developed and documented |  |  |  | |  |
| Identity and qualifications of data collection and entry staff is defined |  |  |  | |  |
| Timing of data collected and entry is defined |  |  |  | |  |
| Training for data collection and entry staff is documented |  |  |  | |  |
| Comments: | | | | | |
| Data Verification | The process to identify data errors/mistakes/omissions is defined |  |  |  | |  |
| The process to correct data errors is defined |  |  |  | |  |
| How will errors be corrected |  |  |  | |  |
| Permissible values and ranges for data elements is defined |  |  |  | |  |
| Referential integrity of data elements is maintained |  |  |  | |  |
| Comments: | | | | | |
| Data Repository Management | The platform/application used to store the data is industry recognised |  |  |  | |  |
| Data is stored securely with security measures in place |  |  |  | |  |
| Users are clearly defined and registered |  |  |  | |  |
| Access is determined by security levels and user class |  |  |  | |  |
| Access is logged and monitored |  |  |  | |  |
| Data is indexed to optimise search and reporting |  |  |  | |  |
| Backups processes are defined and scheduled |  |  |  | |  |
| Processes for the destruction of data are documented |  |  |  | |  |
| Comments: | | | | | |
| Data Analysis | Fields and algorithms used in analysis and reporting are defined |  |  |  | |  |
| Purpose and audience for analysis is documented |  |  |  | |  |
| Qualifications and competencies of analysts is defined |  |  |  | |  |
| Mechanisms to statistically validate analysis is documented |  |  |  | |  |
| Peer review of analysis prior to release is defined |  |  |  | |  |
| Comments: | | | | | |
| Data Reporting | Purpose of reports clearly defined |  |  |  | |  |
| Audience(s) are defined and the nature of their reports documented |  |  |  | |  |
| The process for distribution of reports is defined |  |  |  | |  |
| Structure and visualisation of data in reports is documented |  |  |  | |  |
| Frequency of reporting is determined |  |  |  | |  |
| The level of confidentiality of reports is defined |  |  |  | |  |
| The identity of patients and clinicians is protected |  |  |  | |  |
| Comments: | | | | | |
| Data Sharing | Where data is shared, the mechanisms for sharing are defined |  |  |  | |  |
| Security, confidentiality, encryption of shared data is documented |  |  |  | |  |
| Comments: | | | | | |
| Data Linkages | Where data is linked with other data collections, the process is documented |  |  |  | |  |
| Linkage elements are clearly defined and validated |  |  |  | |  |
| Linkages are periodically verified |  |  |  | |  |
| Security of any data linkages is documented |  |  |  | |  |
| Comments: | | | | | |
| Relationship Management | User, managers and custodians regularly and collaboratively communicate |  |  |  | |  |
| Systems are in place to regularly update data contributors and users |  |  |  | |  |
| Funding of the data collection and reporting is sustainable and documented |  |  |  | |  |
| Comments: | | | | | |

Any concerns or clarifications should be raised with:

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