



Clinical and Disease Registries Course: Design, Data Quality and Outcomes Reporting



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Introduction:

Clinical and disease registries design, data quality and outcomes reporting is a 5-day course for registry, health information, surveillance and clinical audit staff in public health agencies, hospitals and research centres, ending with a Registry Establishment and Data Quality Plan for a case organisation. Many registries start without an agreed purpose, minimum data set or case definition, so records arrive incomplete, duplicated or late and outcome reports lose clinician trust. Nominees already collect, code or report patient-level data, and work through case studies on registry extracts and audit samples. CoreConcept Training Center delivers this clinical and disease registries course.

Course Objectives:

- Define a registry's purpose, scope, governance and custodians, and choose between population-based, hospital-based, product and procedure registry designs
- Specify a minimum data set with a data dictionary, permissible values and coding standards such as ICD, ICD-O, SNOMED CT and LOINC
- Design case ascertainment from pathology, admission, death certificate and pharmacy notifications with validated inclusion and exclusion rules
- Link registry records to other datasets with deterministic and probabilistic methods under pseudonymisation and data access controls
- Audit registry data for comparability, completeness, validity and timeliness and resolve duplicate and unverified cases
- Produce survival, incidence and benchmarking reports and assemble a Registry Establishment and Data Quality Plan for a case organisation

Target Audience:

- Registry managers and coordinators responsible for running a disease, procedure or product registry
 - Health information and clinical coding leads who supply diagnosis, procedure and pathology data to registries
 - Public health surveillance managers who maintain cancer and notifiable condition registration systems
 - Hospital quality and clinical audit unit heads who use registry data to compare clinical outcomes
 - Research centre data managers who oversee cohort and clinical study registries
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Course Outline:

Day 1: Registry Purpose, Types and Current-State Assessment

- Registry Purpose Statement and Primary Research or Quality Questions
- Population-Based Versus Hospital-Based Registry Scope Decisions
- Product, Procedure and Rare Condition Registry Design Variants
- Registry Governance Board, Steering Roles and Data Custodianship
- Registry Readiness Assessment of Existing Sources and Gaps

Day 2: Minimum Data Sets, Coding Standards and Registry Data Architecture

- Minimum Data Set Selection with Core and Optional Items
- Data Dictionary with Definitions, Permissible Values and Formats
- ICD and ICD-O Topography and Morphology Coding Rules
- SNOMED CT and LOINC Terms for Clinical Findings and Tests
- Registry Database Schema, Electronic Case Report Forms and Edits

Day 3: Case Ascertainment, Abstraction and Record Linkage

- Case Definition Inclusion and Exclusion Rules with Validation
- Multiple Source Notification from Pathology, Admissions and Pharmacy
- Abstractor Manual and Inter-Rater Reliability Checks
- Deterministic and Fellegi-Sunter Probabilistic Record Linkage Methods
- Vital Status Follow-Up and Loss to Follow-Up Tracking

Day 4: Data Quality Audits, Privacy Controls and Outcomes Reporting

- Comparability, Completeness, Validity and Timeliness Audit Indicators
- Re-Abstraction Audit Sampling and Death Certificate Only Proportion
- Pseudonymisation, Bloom Filter Linkage and Data Access Agreements
- Survival Curves, Incidence Rates and Risk-Adjusted Outcome Measures
- Benchmarking Reports with Funnel Plots and Outlier Alert Rules

Day 5: Case Study: Registry Establishment and Data Quality Plan

- Case Organisation Registry Purpose and Scope Statement Review
 - Case Minimum Data Set and Coding Map Drafting
 - Case Ascertainment Source Map and Linkage Design
 - Case Data Quality Audit Schedule and Outcomes Report Template
 - Registry Establishment and Data Quality Plan Completion
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Skills You Will Gain:

- Registry Scope Definition
- Minimum Data Set Design
- Clinical Terminology Mapping
- Case Ascertainment Design
- Registry Abstraction Auditing
- Probabilistic Record Linkage
- Registry Privacy Safeguards
- Registry Outcomes Reporting

Why Attend This Course:

- Deliver a Registry Establishment and Data Quality Plan to the registry steering board, medical director or research committee
- Decide which notification sources, data items and case definitions a registry should rely on before collection starts
- Avoid duplicated cases, unreliable coding and privacy breaches that undermine published registry outcomes
- Share data dictionary templates, audit checklists and linkage procedures with abstractors, coders and analysts

Conclusion:

Back at work, the participant hands the Registry Establishment and Data Quality Plan to the registry steering board, medical director or research committee. They use it to approve the minimum data set, notification sources, linkage method and access rules before collection begins or before an existing registry is restructured. After the first audit cycle, the registry team should compare completeness, validity and timeliness results with the plan's targets, review unresolved duplicate and unlinked records, and update the data dictionary and abstractor manual.

Frequently Asked Questions FAQ:

What should participants know before a clinical and disease registries course?

Participants should already collect, code, abstract or report patient-level health data. Familiarity with diagnosis coding and spreadsheets helps. Bringing an anonymised data dictionary or extract from their own registry or data source lets them apply the audit and linkage exercises directly.

How does a clinical and disease registries course differ from a population health management or hospital analytics course?

This course builds and maintains the registry itself: purpose, data set, case finding, coding, quality audits, linkage and outcomes reports. Population health courses use registries to stratify risk and target care, and hospital analytics courses build KPI dashboards; both appear only briefly here.

Why do clinical and disease registries need case ascertainment from multiple sources?

No single source captures every case. Pathology misses clinically diagnosed cases, admissions miss outpatient care and death certificates arrive late, so registries combine notifications and link them to remove duplicates, raising completeness and making incidence and outcome figures trustworthy.

What do participants take back from a clinical and disease registries course?

Participants take back a Registry Establishment and Data Quality Plan for a case organisation, with a purpose statement, minimum data set and coding map, ascertainment and linkage design, audit schedule and outcomes report template they can adapt to their own registry.
