

Adoption of a modified process for the development of minimum clinical dataset to improve data quality

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Outline

- Background and introduction to the domain
- Objectives
- Methodology
- Results and Discussion
- Conclusion
- Recommendations
- References





Introduction to the problem domain: **Overview of the setting**



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Introduction to the problem domain: Information management in CEDC

- Data collection mechanism
 - Collected by Nursing sisters, Medical officers
 - Type: Name based clinical data
 - Frequency: Daily basis, for each client contact
 - Event: Single client multiple events, depending on the case
- Data analysis
 - Type: aggregated data
 - Frequency : Monthly/quarterly basis
 - By medical officers/consultants/administrators/nursing sisters





Introduction to the problem domain: **Data quality issues**

- More than 15,000 records of screened individuals producing a large set of legacy data
- Not explicitly defined the core dataset for cancer screening
- Non-structuring of data elements/variables: open ended textual data more than the structured
- Collecting data which are not essential for practice
- Poorly declared descriptions for data elements in data collection form

Main study focus: Unavailability of a well structured essential clinical data set





Objectives

General Objective:

To improve the quality of data collection by developing a well structured minimum clinical dataset

- Specific objectives:
 - **1**. To identify the feasible processes to improve data quality
 - 2. To develop the structured minimum clinical dataset set by using a scientific process





Key concepts

- Data governance
 - The overall management of the availability, usability, integrity, and security of the data in an enterprise
 - Involves multiple sources of data
- Data quality is not a separate, single activity
- Data quality at the source level
 - More easier and cheaper to fix data issues
 - Multi-faceted concept (Collection, Analysis, Application and Warehousing)
- Quality improvement in data collection
 - Structuring of data
 - Essential/minimum dataset



Framework for developing a Minimum Clinical Dataset

 Framework for developing Minimum Clinical Dataset (MCDS) proposed by Svensson-Ranallo *et al* (2011)





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Methodology: Development of MCDS by following the modified framework (single iteration)





Methodology

- Review of the current data collection tool
 - Qualitative analysis of the data elements
 - Randomly selected client inquiry on the experiences in filling the form
 - Output: Explicit, pruned data elements
- Stakeholder Interview Operational level
 - Clinic staff, NCCP community physicians and the consultant oncologist
 - Output: Set of guiding principles
- Review of the literature related to cancer datasets
 - Open search
 - Key words: "Minimum cancer clinical dataset", "cancer screening dataset", "cancer screening data definitions" and "cancer registry data dictionary"
 - Output: data elements with metadata specifications and structuring





Methodology

Expert review

- Modified Delphi round
- The inclusion criterion: At least 1 year in cancer control programme or the field of oncology or in health informatics within last five years
- Consensus for the data elements derived from the literature review
- Output: Matrix of expert opinion on each data element

Aspect of data quality	Possible selection
Relevancy to the analysis/ purpose	Relevant, Not relevant, No comment
Concordance with literature (has evidence in common literature or other data collection forms at NCCP)	Enough evidence, No enough evidence, No comment
Clarity of the element in relation to the screening process/NCCP policy	Very clear, Clear-but needs revision, Not clear, Not sure
Opinion on the inclusion for the main data entry form	Yes, No, No comment
Structuring	Possible structured values
Other comments	Free text

Table : Data quality aspect of the data elements presented to the experts to comment





Methodology

Harmonizing and stakeholder interview

- A set of essential dataset with appropriate structuring derived
- Interviewed the administrative stakeholders to obtain their opinion on feasibility
- Output- MCDS





Results and discussion

- The existing data collection tool
 - Data elements: 44% free text
 - No proper reference to analysis or patient care (Eg. Individual planned activities, husband's place of birth)
 - Adequate explanations were not provided in the form
 - Some key data elements were not included (Eg. Telephone)
- The existing dataset review was not only limited to document review and the client's view was also obtained





Results and discussion

- Guiding principles
 - Data will be collected, used, and analyzed at the micro-system level for routine care and service monitoring
 - Summary aggregation in defined intervals (Monthly/quarterly)
 - The elements must be supported by the literature
 - Every element should have a defined code, name, description, purpose, type, allowed values, field name, evidence affiliation and a validation rule (where applicable)
 - An iterative process
- Modified Delphi technique
 - 14 out of 19 participants (73%) responded
 - More than 40% were sent subsequent reminders
- 121 data elements with data dictionary and appropriate structuring \rightarrow 103 censored elements \rightarrow 71 elements in MCDS
- New data collection tool
- User participation has had a positive impact for the outcome





Conclusion and recommendations

- Data quality and quality analysis of data for better decisions are central to any new information process improvement
- The process of data quality assurance must commence at the time of problem analysis
- Any Information source should have explicitly declared minimum dataset with adequate level of structuring
- Modified framework for MCDS could be used as a model to develop essential datasets





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Thank you!

