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REPCAN

RESEARCH ARTICLE

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REPCAN: Guideline for REporting Population-based CANcer Registry Data

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Abstract

Background: The objective of this study was to develop a guideline on how to report result of a population-based cancer registry. **Methods:** The guideline's development involved a core working committee and a scientific committee comprising experts from diverse domains. The process comprised three steps: 1) a comprehensive review of existing tools and guidelines and the development of the initial draft of the guideline based on a review of literature, 2) refinement items through several rounds of focus group discussion among the core group, and development initial draft, and 3) Evaluation of the initial draft by scientific committee members. Items in the guideline were organized to accommodate reports of population-based cancer registries as a scientific manuscript. **Results:** The core committee developed 47 items distributed in the major heading of a scientific manuscript presented as a checklist. The evaluation of the scientific committee led to a consensus on the majority of the items included in the checklist. Among 10 committee members, 7 provided unreserved approval, validating each item's necessity, applicability, and comprehensibility in the checklist. Feedback from the remaining 3 members was carefully analyzed and integrated to enhance the guideline's robustness. Incorporating feedback, a first final draft was presented in a meeting of scientific and core working committee members. Collaborative discussion ensured clarity of expression for each items and a final checklist was developed. **Conclusion:** The guideline abbreviated as REPCAN offers a standardized framework for reporting population-based cancer registry, fostering transparency, comparability, and comprehensive data presentation. The guideline encourages flexibility while promoting comprehensive and robust reporting practices.

Keywords: Guideline- medical writing- cancer registry-population-based cancer registry- information distribution

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Introduction

Cancer, a global health challenge of immense significance, continues to exert a substantial impact on individuals, families, and societies worldwide. The intricate interplay of genetic, environmental, and lifestyle factors has led to a diverse landscape of this group diseases presenting challenges in prevention, treatment, and research. As the second leading cause of death globally, cancer's multifaceted nature calls for rigorous efforts to comprehend its prevalence, incidence, and outcomes across diverse populations (Hulvat, 2020; Katzke et al., 2015; Weiss, 2021).

In response to this imperative, population-based cancer registries (PBCRs) have emerged as pivotal tools for capturing and analyzing comprehensive cancer data. These registries systematically collect, collate, and disseminate data about cancer occurrences within specific geographic

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regions or populations. Unlike hospital-based registries that only cover specific facilities, PBCRs encompass a broader spectrum, encompassing entire populations and providing a more accurate representation of cancer trends and burdens (Katalinic et al., 2023; Piñeros et al., 2021).

The reporting of results from studies employing similar methodologies can exhibit a striking degree of diversity, resulting in challenges to the comparability and standardization of findings. This variability can arise from differences in data presentation, statistical analyses, outcome measurements, and terminology, leading to difficulties in synthesizing and comparing study outcomes across the literature (Liao and Quintana, 2021; Tratwal et al., 2020; Vintzileos et al., 2014). The lack of consistent reporting hinders the establishment of a coherent body of evidence, thereby limiting the robustness of conclusions and impeding the formulation of actionable recommendations. Moreover, variations in definitions of key variables, exposure categories, and outcome measurements contribute to the complexity of drawing meaningful comparisons. To address these challenges and enhance the comparability and standardization of reporting, the implementation of a comprehensive guideline implemented as a checklist in reporting result of cancer registry is essential. Such a checklist would serve as a standardized framework, guiding researchers in the consistent reporting of study design, methods, results, and conclusions. By promoting adherence to a common set of reporting criteria, the checklist aids in mitigating the impact of diversity in reporting practices, ultimately facilitating more accurate comparisons, pooling in systematic reviews, and meta-analyses (Braga et al., 2016; Cardinali et al., 2023; Hanmer et al., 2020; Jiang et al., 2020; Prodinger et al., 2016; Ruger and Reiff, 2016). Furthermore, the checklist ensures that definitions are transparent and aligned, fostering a shared understanding of crucial terms and concepts across studies. This comprehensive approach not only improves the quality of reporting but also contributes to cumulative knowledge within the field by promoting a more consistent and rigorous methodology across studies (de Klein et al., 2020; Manamley et al., 2016; Ranganathan and Aggarwal, 2020; Vandermause et al., 2014).

In 1996 The Consolidated Standards of Reporting Trials (CONSORT) statement was developed (Moher et al., 2001). Similar initiatives have followed for other research methodologies and fields. Examples of this include meta-analyses of randomized trials (Moher et al., 2000), diagnostic studies (Bossuyt et al., 2003), observational studies (STROBE) ("The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: Guidelines for Reporting Observational Studies," 2007), PRISMA (Enhancing Systematic Review Reporting) (Moher et al., 2009), or AIMRDA (Development of a Critical Appraisal Tool for the Peer-Review of Studies Assessing the Anticancer Activity of Natural Products) (Ahmad et al., 2022). These initiatives have been supported by many medical journals, which have aided in enhancing the quality of manuscripts reporting studies based on different methodologies.

Access to valid and high-quality cancer data is the key indicator in cancer control programs all over the world. A population-based cancer registration (PBCR) is the standard method for producing epidemiologic data on cancer patients at community levels (Forman D, 2014; Piñeros et al., 2017). Complete and adequate reporting of PBCR data plays a crucial role in offering credible and dependable information to researchers and health policymakers, who are the primary individuals interested in understanding the burden of cancer, the actions needed, evaluating the actions and plan future control policies. The routine and baseline way of proposing population-based cancer registry data is by using cancer incidence reports. These reports hold data on all reportable cancers and represent the main deliverable of a cancer registry. PBCR reports may also cover different aspects including designing, implementation, and maintenance as well as different types of data including patients' information, tumor characteristics, and indices of data quality (Bray et al., 2014).

While population-based cancer registries (PBCRs) serve as invaluable repositories of cancer-related information, their potential impact is maximized when the data they contain are accurately, comprehensively, and consistently reported. The need for a standardized Guideline for Reporting Population-based Cancer Registry Data becomes evident as these registries amass vast quantities of information from diverse sources and jurisdictions. Such guidelines are crucial for several reasons: 1- Ensuring Data Quality and Consistency (Barchuk et al., 2021; Bashar et al., 2021; Behera and Patro, 2018; Bhatia et al., 2021), 2- Facilitating Transparent Methodology (Bustin and Nolan, 2016; Lawson et al., 2020; Wichman et al., 2020), 3- Supporting Evidence-Based Decision-Making (El Mikati et al., 2023; Ruger and Reiff, 2016; Whitty, 2015), 4- Enhancing Research Collaboration and Meta-Analyses (Vaccarino et al., 2018; Zhang et al., 2020), 5- Addressing Emerging Challenges (Krzyszczyk et al., 2018).

As the number of registries has been growing in in many countries all over the world (Moore et al., 2014), the reporting of the registries growing as well with unrepresented variations in reporting quality and structure of these report. In the light of such variations in reporting and considering the specificities pertaining to the cancer registry, there is a need to develop a consensus-based guideline for an objective quality improvement these report as well as a tool for assessment of the quality of report of cancer registry.

The aim of this study was to develop a guideline as a quality improvement guideline for authors and an assessment tool for reviewers and critical appraisal of reports of cancer registry result.

Materials and Methods

The road map to develop this tool (as a quality assessment instrument for reviewers and a quality improvement guideline for authors) includes three steps. A core working committee consisting of epidemiologists and cancer registry experts developed an initial draft of the guideline based on a comprehensive review

of literature and existing guidelines and a scientific committee consisting of editors, and cancer registry experts commented, evaluated, and improved the initial draft. The whole process of development consists of three steps (detailed below).

Step one

A core working committee of four experts developed the first draft of the guideline and went through the following steps:

a. Comprehensive literature reviews of available relevant quality assessment tools, cancer registry's reports.

b. Developing a list of items that needs to be included in a quality population-based cancer registry report.

c. Holding several rounds of fucus group discussions and online meetings to discuss the importance of each item in the list.

d. Developing the first draft of the guideline and implementing the guideline as a checklist of items based on the general structure of a scientific manuscript.

Step two

After developing the first draft, we formed a "scientific committee" including at least 10 cancer registry experts from different countries, various journals, and international societies. The scientific committee members assessed each item's necessity, applicability, and comprehensibility through a comprehensive online questioner. The three measures were defined as following:

Item Necessity

This assessment gauged the extent of necessity for a particular item in the quality assessment of cancer registry report. The assigned rating, ranging from 1 to 10, discerns the item's significance, with 10 indicating utmost essentiality and 1 implying negligible necessity. An assigned score of 7 signifies the suggestion for inclusion, while a score below 3 denotes insignificance. Aggregated scores for individual items culminate in final determinations.

Item Applicability

This assessment evaluates the item's relevance within the context of cancer registry reports. Ratings, from 1 to 10, gauged the item's applicability across studies, with 10 denoting universal applicability and 1 implying rare relevance (less than 10% of studies). An assigned score of 7 signifies the suggestion for inclusion, while a score below 3 denotes insignificance. Aggregated scores for individual items culminate in final determinations

Item Comprehensibility

This metric measured the clarity and simplicity of an item's wording, gauging its ease of comprehension for both authors (those who develop the report) and reviewers (those who evaluate a cancer registry report). The rating spectrum, from 1 (worst) to 10 (best), delineates the extent to which an item's wording fosters clarity, aiding effective communication between stakeholders.

Step Three

After collecting the scientific committee comments on the draft, the core working committee applied the comments of the scientific committee and a first final draft was generated by core working committee members through workshop and finalized the final and full text of the draft. To better organize the items, it was decided that the guideline be structured based on the main heading of a scientific manuscript (Title, Abstract, Introduction, Materials and methods, Result, Discussion, and Acknowledgment) and each coded with character and a number (T for title, A for abstract, I for introduction, M for method, R for result, D for discussion, Ak for acknowledgment)..

Results

Upon submission of the initial draft of the REPCAN guideline to the scientific committee, a comprehensive evaluation was conducted to ensure the effectiveness and appropriateness of the proposed checklist items. Out of the 10 esteemed members comprising the scientific committee, 7 experts provided their approval without any comments, signifying a consensus on the checklist's contents. This majority endorsement reinforced the robustness of the guideline's development process and its alignment with the goals of enhancing reporting quality in population-based cancer registry studies.

The items included in the guideline

The guideline or implemented checklist consists of 47 items related to the article's title and abstract (title, structured abstract), the introduction (background / rationale objectives), methods (study design, study population, and registration area, data collection and definitions, quality control, statistical analysis, ethics code), results (frequencies, rates, geographical distributions, indices of data quality), discussion sections (key results, interpretation of results, data limitations) and the acknowledgment section (Table 1).

The Importance of Each Item that Was Included in Each Manuscript Section of REPCAN guideline

Table 1 presents the guideline statement, which outlines a comprehensive checklist of items to be addressed in manuscripts reporting results from cancer registries. This checklist has been meticulously designed to ensure the thorough and coherent reporting of population-based cancer registry data. Each item within the checklist corresponds to specific sections of the manuscript, contributing to a well-structured and informative presentation of the study's findings.

Title and Abstract

The checklist commenced with the Title and Abstract section. The title of the manuscript (Item T1) is required to provide essential details about the cancer registry, including its name, type, time period, and relevant country/region. Moreover, it emphasizes the importance of including specific information, such as child/adult cancer or selected sites, when relevant. The Structured

Table 1. The REPCAN Guideline Checklist Final Draft

Manuscript Section		Item No	Item Description
Title and abstract			
Title		T1	- Indicate the name of the cancer registry, the type of registry, the time period to which the report relates, and the relevant country/region.
			- If a part of the results is reported, such as child/adult cancer or selected sites, this information should be included in the Title.
Abstract	Objective	A1	Present the objective of the report, the registry name(s), the time period to which the report relates, and the population name (e.g., country/country region/ethnic group, etc.)
	Methods	A2	Briefly indicate: whether the data are population-based, institutionally based, or otherwise/time period/the process whereby registration takes place/the major data source(s)/the population source and its ethnic characteristics and other features
	Result	A3	Report the crude and age-standardized rates for all cancers combined and major cancers recorded by the registry, plus at least one index of data quality
	Conclusion	A4	Provide a conclusion on reported results including a qualitative assessment of the report
Introduction			
	Background / Rationale	I1	Consider adding the context of broader cancer control planning in the country/region and specific cancer prevention activities.
		I2	Include references describing the population denominator, the cancer registry, the relevant history of cancer registration, and the data gap filled by the report
		I3	The report, numbers, proportions, incidence, and mortality rates of cancers based on available reporting for the study population or comparable populations
	Objectives	I4	State-specific objectives of the Cancer Registry
Methods			
Study design		M1	- Present key elements of registry design (e.g., type of registry, organization).
			- State how the registry is managed. Is the registry part of a standalone project (give identifiable information), or part of an ongoing registry?
		M2	Indicate the name of the registry and the "target" population to which it refers
Study population and registration area		M3	Indicate population characteristics (e.g., ethnic subgroups) of the registration area and present population pyramid
		M4	Describe geographic and environmental characteristics (e.g., climate, altitude, latitude) of the registration area
Data collection and definitions		M5	Provide sources of population and mortality data
		M6	Describe the reporting procedures (e.g., active or passive reporting) used by the registry
		M7	Indicate data sources (e.g., hospitals, diagnostic laboratories, and death certificates) including those in the private or public sectors
		M8	Include descriptive variables relating to the person with cancer (sex, age, ethnic group), place of residence, and time
		M9	Include descriptive variables relating to cancer (e.g., diagnosis date, the valid basis of diagnosis, topography, morphology, behavior, grade, stage)
		M10	Describe the standard cancer classifications and coding systems used by the registry including ICD-O or other classification versions used
Quality control		M11	Describe methods used to ensure data validity (e.g. comparability, accuracy, and completeness)
		M12	Provide descriptions of indices used to indicate data quality (e.g. comparability, accuracy, and completeness)
Statistical analysis		M14	Name the statistical software used
		M15	Describe the statistical terms and methods
		M16	Describe the calculated statistics and finding reported (e.g. number of cases, age-specific rates, crude rates, and age-standardized rates)
		M17	Describe methods used for the calculation of standardized rates and indicate the standard population with appropriate reference
Ethics code		M18	Describe ethical considerations about registry-based research in your country/region and report the approval awarded by an ethics committee
Results			
Frequencies		R1	Provide a table showing available demographic data (e.g., sex, age groups, place of residence, ethnicity)
		R2	Report frequency distributions of cancers by site, age, sex, and period/year (Preferred groupings would align with Cancer in Five Continent or ICD-OC groupings)
		R3	Make appropriate use of tables, bar graphs, pie charts, and line graphs for the presentation of frequencies

Table 1. Continued

Manuscript Section	Item No	Item Description
Results		
Rates	R4	Report crude annual incidence rates by site, age, and sex
	R5	Report age-standardized rates by site, age, and sex (preferably using a relevant WHO standard population)
	R6	Report cumulative incidence rates by site, age, and sex
	R7	Show a graphical representation of age-specific incidence rates by sex, for commonly diagnosed cancers
	R8	Make appropriate use of tables, bar graphs, pie charts, and line graphs for the presentation of rates
Geographical distributions	R9	Report frequencies and rates by geographic subdivisions of the registration area
Indices of data quality	R10	Include a table of indices of the validity of diagnoses
	R11	Report the percentages of cases with a morphologically verified diagnosis (MV%) and where the data source was a death certificate only (DCO%) (note: where available)
	R12	Report other indices of data quality (e.g., mortality/incidence ratio (note: where available)
Discussion		
Key results	D1	Summarize key results as relating to study objectives
Interpretation of results	D2	Compare observed incidence and mortality results with corresponding results for other areas and populations
Data limitations	D3	Discuss the likely generalizability (external validity) of study results
	D4	Report the shortcomings of the registry and possible implications they may have for the accuracy and completeness of results
Acknowledgment section		
How the registry data are used?	Ak1	Report if the data from the registry is used in research and publication
How the registry report was funded	Ak2	Describe how the report was funded
Is the registry registered in any central registry system?	Ak3	Report if the registry is part of a central registry and whether associated with local or international associations

Abstract segment (Item A2) comprises four sub-items (A2-1 to A2-4) that collectively address the key objectives, methods, results, and conclusions of the study. This inclusion of essential information ensures clarity and accessibility for readers seeking an overview of the study's core elements.

Introduction: The Background/Rationale section (Item I1) highlights the significance of contextualizing the study within the broader cancer control landscape of the country or region. This establishes a strong foundation for understanding the relevance of the registries establishment objectives. The inclusion of references (Item I2) strengthens the report by linking it to the historical evolution of cancer registration efforts and contextualizing its contribution to filling data gaps. Item I3 emphasizes the importance of providing pertinent numerical data and rates to facilitate a comprehensive understanding of the study population's cancer landscape.

Item I4 mandates the clear articulation of the specific objectives of the Cancer Registry, underlining the necessity of focusing on defined objectives for the successful execution of the registry.

Methods

The Methods section delves into the intricacies of the study design, registration area, data collection, and definitions. Key aspects such as registry management and its organizational structure are addressed in Items M1 and M2, respectively. Items M3 and M4 underscore the importance of the demographic and geographic characteristics of the study population, enhancing the comprehensibility of the report. M5 through M10 delve into data collection methods, reporting procedures, and coding systems, highlighting the meticulous approach required to ensure accurate and reliable data.

Quality control (Items M11 and M12) emphasizes the vigilance necessary to maintain data validity, and the Statistical Analysis section (Items M14 to M17) underscores the transparent and well-defined presentation of statistical methods and findings.

Results

The Results section encompasses comprehensive data presentation. Items R1 to R3 stress the need to present demographic distributions, frequency distributions, and appropriate graphical representations. Rates (Items R4 to R8) demand the detailed reporting of crude and age-standardized rates, cumulative, and age-specific incidence rates, contributing to a comprehensive understanding of the disease burden.

Geographical Distributions

Item R9 highlights the importance of spatial analysis by encouraging the reporting of frequencies and

rates according to geographic subdivisions of the registration area.

Indices of Data Quality

The inclusion of indices of data quality (Items R10 to R12) bolsters the reliability and credibility of the presented data while fostering a transparent environment for understanding the robustness of diagnoses and data sources.

Discussion

The Discussion section encourages thoughtful engagement with the study's results. Items D1 and D2 prompt the summary of key findings and comparative analyses, enabling readers to comprehend the study's implications within a broader context. Items D3 and D4 advocate for a critical examination of the study's limitations and potential implications for result accuracy and completeness.

Acknowledgment Section

The Acknowledgment section (Items Ak1 to Ak3) highlights the broader utility of registry data, its funding sources, and its connection to central registry systems, reinforcing transparency and accountability in the reporting process.

Finally, each item within the guideline/ checklist has been meticulously chosen to contribute to the comprehensive and robust reporting of cancer registry data. This systematic approach ensures that all essential aspects are addressed, fostering transparency, reproducibility, and the generation of meaningful insights from population-based cancer registry studies.

Conclusion

REPCAN, which stands for "guideline for REporting Population-based CANcer registry data", is an international, collaborative initiative of cancer registry personnel, epidemiologists, methodologists, statisticians, researchers, and journal editors involved in the dissemination of population-based cancer registry data. The main aim of the REPCAN is to develop a checklist of items that should be included in PBCR reports as a scientific manuscript. It proposes a standard way for authors to put together reports of population-based cancer registry data. This editorial's purpose is to put forward guidelines to inspire a clearer and more thorough reporting of research outputs for cancer incidence reports.

Although a large number of items have been included in the REPCAN checklist, they should not be considered mandatory items. Cancer registries may select and include relevant items in the report, according to the availability of data and as well as the aim of the report. In other words, the REPCAN should be considered a flexible frame and guide for preparing the cancer registry report.

Author Contribution Statement

All authors contributed equally in this study.

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