



## Development of a tool for comprehensive evaluation of population-based cancer registries



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### ABSTRACT

**Objective:** Several methods have been suggested for evaluation of population-based cancer registries (PBCR) worldwide. However, most of these methods evaluate the data and outputs of the cancer registries. This study aimed to develop a comprehensive tool and protocol for evaluation of inputs, processes and outputs of a PBCR. **Methods:** The standards of the North American Association of Central Cancer Registries (NAACCR) were used to draft a comprehensive checklist. In addition, the national guidelines of PBCR were used to develop a questionnaire for evaluation of knowledge and practice of the PBCR personnel. Furthermore, a protocol for evaluation of the completeness and validity of the PBCR data was developed according to the International Agency for Research on Cancer (IARC) and the NAACCR guidelines. A 0–4 Likert based score and expert opinions (10 experts) were used to assess validity of the eight questionnaires/checklists. A modified Delphi method was applied to validate the checklists and questionnaires. Questions with a score higher than 3 remained in the final tools.

**Results:** The final package consists of 546 questions including 108 (19.8%) for evaluation of guidelines, 54 (9.9%) for analysis and reports, 87 (15.9%) for governance and infrastructure, 155 (28.4%) for information technology, 21 (3.8%) for personnel knowledge and 121 (22.2%) for their practice. Additionally, data quality indicators were also considered for evaluation of PBCRs.

**Conclusion:** This comprehensive tool can be used to show the gaps and limitations of the PBCR programs and provide informative clues for their improvement.

### 1. Introduction

According to Globocan, in 2012, 14.1 million new cancer cases and also 8.2 million cancer-related deaths occurred. Out of these statistics, 57% of new cancer cases (8 million) and 65% of cancer-related deaths occurred in less developed countries [1]. In addition, the incidence rate of cancers is rapidly increasing in low and middle-income countries (LMCs) [2–4].

The population-based cancer registry (PBCR) is a key component of any cancer control program [5]. PBCR programs continuously collect, manage, analyze and report valid and reliable data of cancer incidence and mortality in a predefined population from multiple sources [3,5–7].

The information obtained from PBCRs is important for planning and evaluating any cancer control and cancer surveillance program, as well as measuring a variety of indicators such as incidence, mortality and survival rates in a population [8–10].

Establishment of PBCRs is increasing worldwide, especially in developed countries; however, several low and middle-income countries have not established high quality PBCRs yet. In some countries, particularly in Asia and Africa, PBCRs cover a small percentage of the population [3]. The quality of cancer registration is crucial to ensure that a PBCR works properly and produces high quality and reliable results [11–13]. It is clearly useful to evaluate the methods and processes of a PBCR, to identify the gaps in its functions in producing accurate data

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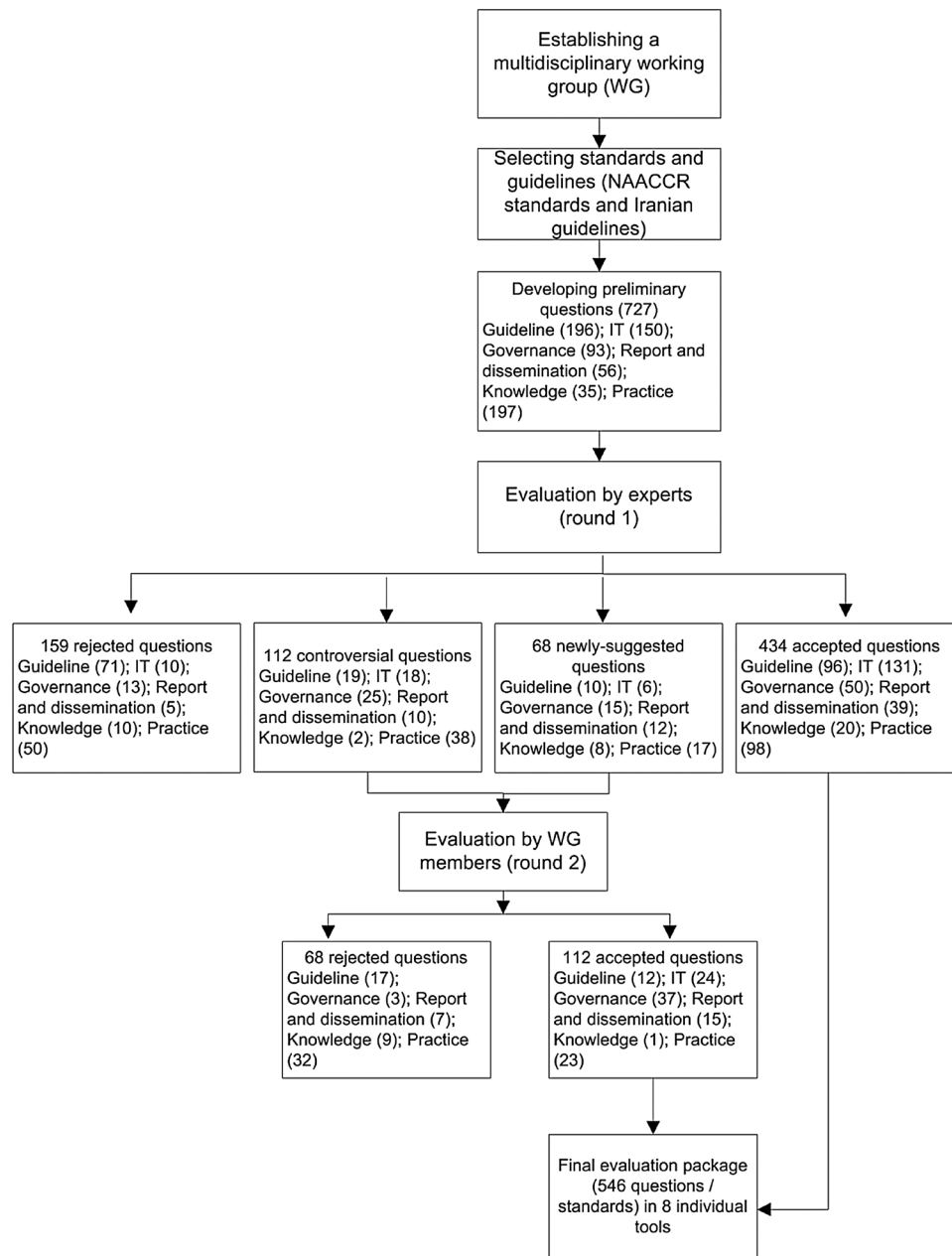


Fig. 1. The evaluation process of possible questions (the number in parenthesis shows the number of questions in each category).

and developing improvement plans. Therefore, comprehensive evaluation of the program considering the inputs, processes and outputs may help in identifying the gaps and improving the program [14–16].

Many researchers have developed numerous criteria or indicators to evaluate PBCR programs. Parkin [14] and Bray [5] emphasized on data quality and suggested four dimensions to evaluate the data quality of a cancer registry program, these include completeness, timeliness, validity and comparability; all are related to the output of the PBCRs. Several groups have evaluated the quality of cancer registry data based on this framework [12,17–23]. In addition, the International Agency for Research on Cancer (IARC), a specialized cancer agency of the World Health Organization, presented a monograph called *Cancer Incidence in Five Continents (CI5)* in which reports from different cancer registries in the world are published. They have an evaluation system focused on data quality. In this system, after receiving data from different cancer registries, the CI5 editors check the data based on the IARC-CHECK programs. Then, they may be accepted for publication [24,25].

Additional criteria and guidelines for assessment of the inputs and

processes of a PBCR have also been considered. In North America, the successful PBCR programs are continuously evaluated based on an accreditation process [26]. In addition, the European Network of Cancer Registries (ENCR) has developed a process called Structured Reviews of Cancer Registries for evaluation of the European cancer registries [27,28]. Navarro et al. [29] also suggested a process for external evaluation of PBCRs in Spain and Latin American countries. They found that the successful PBCRs that published their data in the CI5 achieved high scores in the external evaluation [29]. The results indicate that their external evaluation tool was appropriate and had a high sensitivity and positive predictive value. In other words, results of external evaluation would be good indicator of whether the registry will achieve the objectives and pass the evaluation criteria of IARC monograph group and be published in the CI5.

All these tools are restricted to some aspects of the cancer registry and no comprehensive evaluation program was found. In addition, the available tools should be tailored to the requirements of the PBCR in each country. Therefore, there is a need to develop a comprehensive

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