



Review

# Sorting out measures and definitions of screening participation to improve comparability: The example of colorectal cancer



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**Abstract** Participation is a key indicator of the potential effectiveness of any population-based intervention. Defining, measuring and reporting participation in cancer screening programmes has become more heterogeneous as the number and diversity of interventions have increased, and the purposes of this benchmarking parameter have broadened. This study, centred on colorectal cancer, addresses current issues that affect the increasingly complex task of comparing screening participation across settings. Reports from programmes with a defined target population and active invitation scheme, published between 2005 and 2012, were reviewed. Differences in defining and measuring participation were identified and quantified, and participation indicators were grouped by aims of measure and temporal dimensions. We found that consistent terminology, clear and complete reporting of participation definition and systematic documentation of coverage by invitation were lacking. Further, adherence to definitions proposed in the 2010 European Guidelines for Quality Assurance in Colorectal Cancer Screening was suboptimal. Ineligible individuals represented 1% to 15% of invitations, and variable criteria for ineligibility yielded differences in participation estimates that could obscure the interpretation of colorectal cancer screening participation internationally. Excluding ineligible individuals from the reference population enhances comparability of participation measures. Standardised measures of cumulative participation to compare screening protocols with different intervals and inclusion of time since invitation in definitions are urgently needed to improve international comparability of colorectal cancer screening participation. Recommendations to improve comparability of participation indicators in cancer screening interventions are made. © 2013 Elsevier Ltd. All rights reserved.

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## 1. Introduction

Participation is a key indicator of the potential effectiveness of any screening intervention since it reflects the degree to which a population is exposed to the intervention. For cancer screening programmes, minimal thresholds of participation are recommended to ensure the intended benefits of the intervention can be achieved [1–3].

Monitoring participation is paramount to screening programmes and other groups, including cancer control agencies and public health authorities, as a benchmarking parameter for comparing screening performance across jurisdictions. Over the past decades, more countries have implemented cancer screening programmes in increasingly diverse settings. For instance, the prevalence of opportunistic screening (screening performed outside the setting of an organised programme) varies considerably across countries and influences participation since recent opportunistic testing usually renders an individual ineligible for the screening programme [3]. The growing number of programmes and factors affecting the analysis and interpretation of participation rates heighten the need to be more precise and comprehensive in approaches taken to monitor screening participation [4,5].

The International Cancer Screening Network (ICSN) is a consortium encompassing 33 countries with population-based cancer screening programmes, sponsored by the U.S. National Cancer Institute for the purpose of fostering international efforts to evaluate the quality and effectiveness of screening programmes [6,7]. Recent ICSN projects have determined how performance parameters could most suitably be compared for breast cancer [8–10]. With the lessons learned from well-established breast and cervix screening programmes and the emerging need to monitor performance of more recently established colorectal cancer (CRC) screening programmes, it is an opportune time to consider a common set of indicators that can be used to provide an accurate picture of participation rates in CRC screening internationally.

The objectives of this paper are to examine literature to (1) highlight the issues related to measuring, reporting and comparing CRC screening participation across programmes and countries, (2) identify definitions of participation that have been used and (3) assess the impact of varying definitions on estimates of participation. Although the focus is on colorectal, most of the issues addressed are relevant to other population-based cancer screening programmes.

## 2. Materials and methods

To identify definitions and reports of CRC screening participation, a multistep search strategy was adopted. A search of articles was first conducted on Medline

(National Library of Medicine, Bethesda, United States of America (USA)) using the PubMed query interface, and included Medical Subject Headings (MeSH) corresponding to ‘colon cancer’, ‘colorectal cancer’ or ‘bowel cancer’ and ‘screening participation’, ‘screening uptake’, ‘screening compliance’ or ‘screening adherence’. The search, restricted to publications in English (at least the abstract) between 1st January 2005 and 30th June 2012, identified 1497 potentially relevant papers. The retrieved articles were reviewed independently by two investigators (J.L.B. and M.G.) and their references were manually checked. We also searched the Web for monitoring and evaluation reports and guidelines addressing eligibility criteria and definition of participation in order to include important unpublished material (J.L.B.).

This study focused on screening interventions with a defined target population (i.e. designated age groups and geographic catchment areas) and a systematic invitation scheme, because a precise assessment of participation rate is otherwise problematic. For example, cross-sectional studies of CRC screening use cannot assess medical eligibility, are often based on self-report of attendance and render difficult the distinction between screening and diagnostic tests; screening recruitment through GP visits does not allow accurate estimation of the population fraction exposed to the intervention [11–14]; and interventions targeting selected sub-populations such as health plan members [15,16], volunteers [17], veterans [18] or reporting on two-stage recruitment strategy, where non-compliers or screen-negative individuals are subsequently offered an alternative screening test [19–21], limit international comparability.

Where several publications were available for a country or a programme, the most recent or complete one, with respect to participation indicators, was used. For countries with national screening programme delivered at a regional level, nationwide reports were given greater weight than region- or centre-based reports (i.e. Italy, Spain and United Kingdom (UK)), but additional information from complementary sources was included. National participation estimates were computed from unpooled regional data when necessary [22]. Pilot and trial studies were reported separately as their particular settings generally favour higher participation rates.

The definitions of coverage and participation proposed in the first edition of the European Guidelines (EG) for Quality Assurance in CRC Screening were used [3]. The coverage rate by invitation (C: % *screen-eligible subjects that are invited in the target population during a given time frame*) reflects a programme’s ability to invite its target population. Although the participation rate (P: % *invited people during a time frame that were screened/tested during this time frame*) is independent of the coverage rate, both indicators should be assessed concomitantly since they contribute to

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