Performance indicators for participation in organized mammography screening

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ABSTRACT

Background A population’s acceptance of a screening programme is reflected by its participation. Participation can be measured by cross-section, in an individual screening round, or by cumulative examination rate, which covers participation in numerous rounds at a pre-specified frequency. To establish an informed overview of programme performance, the relationship between these measures was analysed.

Methods The Central Population Register (CPR) of Denmark was used to define the total population. The data sources were mammography screening programmes in Copenhagen (1991–2008) and Funen (1993–2008) and participation and coverage rates were calculated according to European guidelines. Long-term adherence was defined as the cumulative examination rate.

Results The participation rates were 71% in Copenhagen and 91% in Funen. The cumulative examination rates across all invitation rounds were between 21 and 24% lower than the average participation rates.

Conclusions If the cumulative examination rate across all, or the majority of, invitation rounds is substantially lower than the average participation rate it may suggest that standard cross-sectional performance indicators overestimate the level of protection provided to the women targeted by the programme. Consequently, it may prove valuable to include cumulative examination rate as a performance indicator of mammography screening.

Keywords cancer, health services, screening

Introduction

The purpose of mammography screening programmes is to reduce breast cancer mortality, by detecting breast cancers before they become symptomatic and thus increasing the chances of survival with early treatment. The European Council recommends population-based mammography screening for women aged between 50 and 69 years.¹

For a screening programme to be effective it requires acceptance by the target population. As stated by the European Commission: ‘Success is judged, not only by the outcome of the programme and its impact on public health, but also by the organization, implementation, execution and acceptability of the programme’.¹ On this basis, the European Commission developed ‘The European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis’¹ (hereafter referred to as ‘the European guidelines’), which recommend the continuous monitoring and evaluation of programme performance.

The targeted population’s acceptance of a programme is reflected by its participation, where the European guidelines distinguish between the participation rate and the programme coverage. According to these guidelines,¹ the participation rate is defined as the proportion of invited women who participate. Participation rates >70% are considered acceptable, while >75% is considered desirable. The European guidelines¹ have two definitions of coverage, by examination and by invitation. Coverage by invitation is

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defined as the proportion of the total population invited, while coverage by examination is defined as the proportion of total population that participated. The European guidelines do not specify reference levels for coverage nor have performance indicators for long-term adherence to a programme.

In order to form an accurate picture of programme performance within a targeted population, it is necessary to investigate the relationship between the indicators. For example, if not all women in the total population are invited to a screening the participation rate can greatly exceed coverage by examination. Furthermore, yearly or biennial cross-sectional measures of participation rate and coverage by examination may not adequately reflect a long-term acceptance.

In Denmark, mammography screening started in the municipality of Copenhagen and the county of Funen, in 1991 and 1993, respectively. Both programmes offer biennial screening to women aged between 50 and 69 years and are population based, organized by personal invitation.

Furthermore, Denmark maintains population and health registers, which can be linked by unique personal identification numbers, making it an ideal setting for investigating the relationship between the European recommended cross-sectional performance indicators, participation rate and coverage, and long-term adherence.

The availability of individual screening data allowed for the production of all routinely used indicators of participation, supplemented by an estimate of the long-term acceptance among targeted women, with the aim of producing a more comprehensive assessment of programme performance.

**Methods**

**Definitions**

For definitions of concepts, see Table 1.

**Data sources**

This study was based on data from the first eight invitation rounds of population-based, organized mammography screening programmes in the Copenhagen municipality (1 April 1991 to 14 April 2008) and the first seven invitation rounds of the Funen programme (1 November 1993 to 18 February 2008). In Copenhagen all eligible women aged between 50 and 69 years, at the start of an invitation round, were invited to a screening, unless they had declined further invitation in a previous round. Exceptionally, mammography screening was offered to women aged between 48 and 69 years in the eighth invitation round, while no non-responders from round 7 were re-invited to round 8. The invitation sequence was generated according to participants’ date of birth. In Funen all eligible women aged between 50 and 69 years, at the time of the invitation, were invited to a screening, unless they had declined, or failed to respond to, an invitation, and the sequence of invitations was planned according to the general practitioners with whom the women were registered. Full descriptions of the programmes have previously been published.

The Danish Central Population Register (CPR) is updated daily and includes demographic information, including migrations and deaths, for all persons ever residing in Denmark, since its inception in 1968. The CPR was used to estimate the total population and eligible target population in both screening areas, and data from the mammography registers were linked to CPR data by a personal identification number, in order to identify not invited women. Women aged <50 or >69 years were excluded from the analysis. In both geographical areas, mammography registers contain personal identification number, date of invitation, date of

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**Table 1 Definitions used for classification and analysis**

<table>
<thead>
<tr>
<th>Concept</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total population</td>
<td>All women in the targeted age group living in the screening area at any time during an invitation round</td>
</tr>
<tr>
<td>Not eligible women</td>
<td>Women, who moved from the municipality or died before invitation, already had breast cancer or (in Funen) had a recent mammogram</td>
</tr>
<tr>
<td>Eligible target population</td>
<td>Total population except not eligible women</td>
</tr>
<tr>
<td>Invitation round</td>
<td>An administrative interval of dates of ~2 years</td>
</tr>
<tr>
<td>Invited women</td>
<td>All women in the eligible target population invited for an invitation round</td>
</tr>
<tr>
<td>Participation rate</td>
<td>Participants/invited women</td>
</tr>
<tr>
<td>Coverage by invitation</td>
<td>Invited women/eligible target population</td>
</tr>
<tr>
<td>Coverage by examination</td>
<td>Participants/eligible target population</td>
</tr>
<tr>
<td>Cumulative examination rate</td>
<td>Number of participants in a given invitation round, who also participated in all previous rounds/number of eligible women in a given invitation round, who were also eligible in all previous invitation rounds[e.g. cumulative examination rate in invitation round 3, Copenhagen: Number of participants in round 3, who also participated in rounds 1 and 2 (n = 15,941) divided by eligible target population in round 3, who were also eligible in rounds 1 and 2 (n = 28,342)]</td>
</tr>
</tbody>
</table>
screening and outcome of screening, for each invitation round. In Funen, the system for registration of invitations allowed only one record per woman, resulting in records being overwritten with each subsequent invitation round. Consequently some estimation had to be made in order to reconstruct previously invited populations, and all women in the total population were considered ‘invited’, unless they were not eligible, had previously failed to respond or had denied invitation.

Analysis
Coverage by invitation and examination, participation rate and cumulative examination rate, as listed in the definitions, were all analysed. SAS 9.2 was used for statistical analysis (SAS Institute, Cary, NC, USA).

Results
The eligible target population of the Copenhagen programme decreased from 43 055, in round 1, to 41 891, in round 7, mainly due to a decline in the total population. In the Funen programme, the eligible target population increased from 48 314 in round 1 to 61 225 in round 7. The percentage of women not eligible for screening in the total populations varied between 2.0 and 6.0% (Table 2, Fig. 1).

The average coverage by invitation, i.e. the number of invited women divided by the eligible target population for all rounds, was 89.4% in Copenhagen and 91.0% in Funen. In both regions coverage by invitation decreased over the study period. In Copenhagen, it was fairly stable around 92.0% in rounds 3–5, but in the final three rounds a marked decline was observed and coverage by invitation decreased to 81.6% in round 8. This was partly induced by a notable increase in not invited women in the rounds 6 (11.8%) and 7 (10.0%), as a result of technical errors. Furthermore, 11.9% of the eligible target population were not invited to round 8, because of a change in the invitation procedure, which excluded women who had not responded in round 7, i.e. had neither participated nor cancelled the invitation, from future invitations. Finally, the percentage of women who declined further invitation in previous rounds increased in the study period. In Funen, the decrease in coverage by invitation over time was due to an increase in the proportion of women who were not invited because they had either denied, or not responded to, a previous invitation (Table 2).

In Copenhagen, coverage by examination, i.e. the number of participants divided by the eligible target population,
In Copenhagen, the participation rate, i.e. the number of participants divided by the number of invited women, decreased from 70.5% in round 1, to 66.8% in round 5, after which a considerable increase was found in rounds 6–8. In Funen, the participation rate increased fairly steadily until round 5 before falling slightly (Table 2). Compared with the average coverage by examination, the average participation rate was \( \sim 9\% \) higher for both Copenhagen (70.7–62.0%) and Funen (91.3–81.9%). In both areas, the average coverage by invitation decreased with age, while the difference
between the average coverage by examination and the average participation rate increased with age (Table 3).

In Copenhagen, of the 43,055 women eligible for the round 1 invitation, only 7,132 (16.6%) were still eligible at round 8, reflecting the mobility of the capital region’s population. Furthermore, of those who remained eligible, a decreasing proportion participated in each subsequently offered round. Half-way through the 20-year biennial programme, only 50.9% of those eligible had participated every time. The considerable decrease from a cumulative examination rate of 46.9%, in round 7, to 33.0% in round 8, was partly due to a change in the invitation procedure, where the eldest groups were not invited in round 8. In Funen, 18,804 out of 48,314 (38.9%) of women remained eligible for the first seven invitation rounds, reflecting a more stable, less mobile population. Among those eligible for the first seven invitation rounds, 70.4% participated every time (Table 4).

### Discussion

#### Main findings of this study

The study clearly illustrated that using only the participation rate can present a significantly misleading picture of programme performance. The participation rate was 71% for Copenhagen and 91% for Funen, while coverage by examination was 62% for Copenhagen and 82% for Funen, thus, in both areas, 9% lower than the participation rate. For the first seven invitation rounds, in Copenhagen 47% of those eligible for all seven rounds participated and in Funen this figure was 70%. The cumulative examination rate across invitation rounds was thus 12–15% lower than the average coverage by examination and 21–24% lower than the average participation rate. Our cumulative examination rate measured the proportion of women adhering to all invitation rounds. If we had allowed for one or two invitation rounds to be missing, the cumulative examination rates would have been higher. Nevertheless, these results suggest that both the participation rate and the coverage by examination may overestimate the long-term acceptance of the screening programme.

Furthermore, the results show that performance measures are easily influenced by administrative and technical changes or errors, which, as they occurred in such a developed nation as Denmark, where comprehensive CPRs are maintained, it can be assumed to be expected in many other countries.

#### What is already known on this topic

It is challenging to compare performance indicators across screening programmes as they are influenced by numerous country-specific factors, which include completeness of population register, local criteria for eligibility, invitation procedure, age range, screening interval, use of opportunistic screening and organization of the health services. Therefore, comparison of performance indicators across programmes should be undertaken with caution, and necessitates further evaluation of whether observed variations are actually attributable to differences in programme performance, or simply to incompatibility of data.³

Coverage by invitation is highly dependent on the definition of eligible target population and invitation procedures. Screening programmes in Finland and the Netherlands are similar to those in Denmark and they reported coverage by invitation at similar levels as discovered by this study.⁴,⁵

<table>
<thead>
<tr>
<th>Cumulative invitation round</th>
<th>Copenhagen</th>
<th></th>
<th>Funen</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Eligible women</td>
<td>Participants</td>
<td>Cumulative examination rate (%)</td>
<td>Eligible women</td>
</tr>
<tr>
<td>1</td>
<td>43,055</td>
<td>30,370</td>
<td>70.5</td>
<td>48,314</td>
</tr>
<tr>
<td>1 + 2</td>
<td>35,486</td>
<td>21,355</td>
<td>60.2</td>
<td>43,498</td>
</tr>
<tr>
<td>1 + 2 + 3</td>
<td>28,342</td>
<td>15,941</td>
<td>56.2</td>
<td>38,189</td>
</tr>
<tr>
<td>1 + 2 + 3 + 4</td>
<td>22,451</td>
<td>12,053</td>
<td>53.7</td>
<td>32,900</td>
</tr>
<tr>
<td>1 + 2 + 3 + 4 + 5</td>
<td>17,803</td>
<td>9,063</td>
<td>50.9</td>
<td>28,081</td>
</tr>
<tr>
<td>1 + 2 + 3 + 4 + 5 + 6</td>
<td>13,632</td>
<td>6,686</td>
<td>49.1</td>
<td>23,601</td>
</tr>
<tr>
<td>1 + 2 + 3 + 4 + 5 + 6 + 7</td>
<td>9,945</td>
<td>4,664</td>
<td>46.9</td>
<td>18,804</td>
</tr>
<tr>
<td>1 + 2 + 3 + 4 + 5 + 6 + 7 + 8</td>
<td>7,132</td>
<td>2,353</td>
<td>33.0*</td>
<td>NA</td>
</tr>
</tbody>
</table>

*The low number is partly due to changed entry criteria.
Coverage by examination has been reported from England, based on statistical data from the Department of Health, who receive aggregated reports from all breast screening units, where an average of 74.3% was found. In the study covering 1996–2005, women aged 50–64 years have been offered mammography screening every third year, resulting in 6 screenings within the programme, in contrast to 10 screenings offered by Denmark. Consequently, even though coverage by examination was higher in England than in Copenhagen, protection of individual women could potentially be lower.

Coverage by examination has been reported based on questionnaire data from Canada and the USA, with coverage by examination for combined screening and diagnostic mammography of 72 and 66%, respectively. For Australia, data on screening mammography revealed coverage of examination of only 56.9%.8

Participation rates are the most frequently used indicator and have been reported from numerous screening programmes. Finland, Sweden, Norway, England and the Netherlands all have population-based screening and studies from these countries all showed participation rates >70%, a European acceptable level. Participation rates are expected to be higher in previously screened women than in those formerly unscreened. Based on women with subsequent screens, a 92% participation rate was reported in Finland, in line with the participation rate > 91% from round 2 onwards in Funen, where only previous participants were invited.

Participation rates below the European acceptable level of 70% were found, for example, in Luxembourg, Italy and France. In Luxembourg, France and partly in Italy, health-care systems are decentralized, meaning that most physicians are paid on a fee-for-service basis, and patients may attend the physician or hospital of their choice. This involves numerous screening units, where screening is implemented mainly through existing health-care facilities and opportunistic screening is endemic. Consequently, a lower participation rate is expected.

Whilst coverage and participation rates are utilized to measure outcomes of screening activity within a calendar year or invitation round, the purpose of screening activity is to protect targeted women against death from breast cancer. Autier et al. found that tumour size distribution seemed more favourable in subsequent, rather than initial, screenings, suggesting that a programme’s benefit may improve with the detection of early stage tumours at subsequent screens.

What this study adds

The availability of data on individual screening and eligible target populations allowed for the production of all commonly used cross-sectional indicators of participation, and comparison between these indicators with long-term acceptance among targeted women.

Coverage by invitation and examination provides cross-sectional measures of programme performance at a population level, while participation rate measures acceptance by the women invited. Cumulative examination rate or long-term adherence should be included as new performance measures, as both coverage by examination and participation rates tend to overestimate a programme’s actual protection of its targeted woman. These additional measures would include consideration of the cases where not all eligible women were invited and not all invited women participated. The population of eligible women is a dynamic population. However, for simplicity, here we calculated the cumulative examination rate for the closed cohort of women eligible up to and including the studied invitation rounds. It would be a relevant development to define new measures of long-term acceptability that additionally account for ‘part-time’ eligible and ‘sometime’ users. No matter which performance indicators are used, it is important to be critical, and more standardized definitions could facilitate comparisons across programmes. The International Cancer Screening Network is currently supporting a working group to further understand of how countries define screening participation rates.

In conclusion, while participation rates give a cross-sectional picture of the acceptance of invitation, cumulative examination rates, which in this study were 21–24% lower than average participation rates, can be seen as a measure of long-term acceptance of the programme. While the comparison of performance indicators across programmes should be undertaken with great caution, relationships between indicators within programmes are similar, and their combined study could therefore be applied in some circumstances. Where the cumulative examination rate across all, or the majority of, invitation rounds is substantially lower than the average participation rate it may suggest that programme performance tends to overestimate protection of the targeted women. The aim of breast cancer screening is to reduce the breast cancer mortality in the total population. This can only be achieved if individual women are sufficiently protected by their programme. The cumulative rate measures the extent to which eligible women adhere to the programme recommendation of biennial screening. It may, therefore, be valuable to include cumulative examination rate as a standard performance indicator for mammography screening programmes.
Limitations of this study

It was a limitation of this study that the invited population in Funen had to be estimated, which did not allow for distinction between non-responders and uninvited women. Consequently, the number of invited women for Funen could be slightly overestimated, resulting in a slight underestimation of the participation rate. For Copenhagen, the altered invitation procedure between round 7 and round 8 gave an artificially low accumulated examination rate in round 8.

Funding

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References