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## **The problem with uptake as a quality metric for population-based screening programmes**

### ***Introduction***

Quality measurement that focuses on important processes and outcomes within healthcare is typically seen as an essential feature of well-functioning healthcare systems.<sup>1</sup> While outcome measures are concerned with assessing the impact of healthcare interventions (e.g. the number of adverse drug events, or the average length of stay for inpatients), process measures focus instead on assessing whether elements or steps within healthcare systems are happening as planned (e.g. the number of patients seen in a clinic, or the proportion of patients receiving a particular intervention). The relationship between processes and outcomes is acknowledged to be complex.<sup>2</sup>

Many population-based screening programmes, both in the UK and internationally, have as a key performance indicator (KPI) some sort of measure that assesses how many of the population eligible for that screening intervention participate in it (typically referred to as either 'uptake' or 'coverage'). For example, for the adult (non-pregnancy) screening programmes offered by the NHS in the UK, all five programmes include a KPI of this kind, with acceptable (i.e. minimum) thresholds made explicit.<sup>3</sup>

But is this simple process measure of the uptake of screening programmes a good assessment of healthcare quality? In this viewpoint paper, we highlight some of the shortcomings in using uptake to measure quality in this context and offer some possible ways forward.

### ***The tension between uptake and informed choice***

Many of the shortcomings of uptake as a quality metric that we will discuss have at their root the tension between measuring uptake of screening on the one hand and on the other a commitment to screening participation based on informed choice. Informed choice for screening is not a particularly new idea; back in the late 1990s in the UK, for example, arguments were being made both about the importance of informed choice in this clinical context and the challenges of achieving this.<sup>4 5</sup>

Informed choice is important in this context because the potential harms of population-based screening are increasingly being acknowledged, e.g. psychological harms, the potential for overdiagnosis and overtreatment of anomalies that would not otherwise cause a problem. How to balance these potential harms against the possible benefits that screening might bring at both individual and population levels is recognised to be challenging and efforts to do so may be highly contested. Methods to achieve this at the population level have been emerging since the foundational work of Wilson and Jungner in the late 1960s.<sup>6</sup> There is recognition that evaluation of the balance of potential benefits and harms of screening at the population level should be made when starting screening, and regularly after implementation to ensure net benefit at a population level.<sup>7</sup> To achieve this population level net benefit requires sufficient uptake of screening, and there can be a tension between this and achieving the opportunity for informed choice at the individual level.

A good example of this is the international debate that has taken place over the relative benefits and harms of screening for breast cancer with mammography. Criticisms of this form of screening are longstanding, both in relation to the UK-based programme and other breast screening programmes internationally. Such criticisms have concerned screening's effectiveness, the potential for avoidable harm, and the quality of the information that is provided to women when they are invited to participate. Debate on the benefits and harms of this form of screening was ignited by a Cochrane review in 2011 that suggested the prolongation of one life came at the cost of overdiagnosis and overtreatment for some other participants.<sup>8</sup> Subsequent to this, the UK-based programme was the

subject of an independent review following mounting criticisms of its effectiveness, with the verdict being that screening does reduce breast cancer mortality but with the associated cost of overdiagnosis and overtreatment (meaning that some women will be diagnosed with and treated for a cancer that would never have troubled them in their lifetime).<sup>9</sup> The review placed the figure at about three overdiagnosed cases identified and treated for every one breast cancer death prevented, but with considerable uncertainty in these figures. The review called for information about the possible costs and benefits of screening to be made clearer and more transparent to women when they were invited to attend for screening.

As a result of this recognition that screening may harm individuals as well as help them, it is increasingly explicitly framed as a personal choice based on informed decision-making by individuals when offered the opportunity to participate.<sup>10</sup> Work seeking to develop an internationally agreed set of principles to apply to the development and provision of evidenced-based information for individuals invited for screening has been undertaken.<sup>11</sup> Focusing on screening for breast cancer and fetal anomaly, the review identified a range of interventions seeking to improve informed choice and knowledge, and to decrease decisional conflict (defined as personal uncertainty about which course of action to take when choice among competing options involves risk, regret, or challenge to personal life values). In both cases, the available evidence showed that informed choice and knowledge improved among those who received decision aid interventions, and that this was achieved without raising decisional conflict.

There has long been a concern that the principle of informed choice about participation in screening and uptake as a KPI for screening programmes may be in tension.<sup>12</sup> However, it does not necessarily follow that people who report feeling more informed about screening are then less likely to participate. For example, work from Australia has shown only that being better informed about the possible harms and benefits *might* mean women were less likely to be screened for breast cancer.<sup>13</sup>

### ***Uptake and equity***

Publicly funded screening programmes increasingly have expectations placed upon them in relation to the duty to decrease health inequalities – which may relate to both screening participation and health outcomes. This focus on equity is important, of course – and indeed ensuring that healthcare is equitable is recognised as a key domain of healthcare quality.<sup>14</sup> We recognise that there are some notable patterns in screening participation amongst particular groups.

As a result of this focus on equity, much work on screening non-participation has been undertaken with the express objective of identifying ways to increase uptake by encouraging more of those invited to participate. As an example, a recent paper used qualitative interviews to explore why participation in colorectal screening was lower than for breast and cervical cancer screening and to suggest targets for future interventions to increase it.<sup>15</sup> Various techniques seeking to encourage participation in screening have been tried, such as sending people appointments with their invitation in an effort to ‘nudge’ them towards participation.<sup>16</sup>

But how helpful is an uptake KPI in this context? To operationalise uptake as a KPI, a numerical target has to be set, for example 70%. However, different screening units may serve very different populations and be in different positions relative to the target. For example, a unit serving an urban area with high levels of deprivation and population mobility may be significantly under the target and have no realistic chance of achieving it, meaning the KPI does not function as an incentive to increase the accessibility of screening where this may be most needed. Similarly, a unit serving a largely affluent population who are engaged with healthcare may easily achieve the target and have

no incentive to improve access in the parts of their catchment area where uptake is lower. It is, put simply, a blunt instrument. In some screening units who are close to the uptake target there is even the potential for uptake to act as a perverse incentive to focus solely on numbers screened and lose sight of issues related to equity or informed choice.

### ***The limitations of uptake – what it does not tell us***

Our argument is therefore that focusing on uptake as a quality metric in relation to screening programmes is not without its limitations, and it may have unintended and/or unwelcome consequences.

Uptake as a metric does not help us understand how informed or otherwise the decision to participate has been, or indeed if a decision has actively been made. This has led to the argument that participation rates are not a good indicator of ‘appropriate participation.’<sup>17</sup>

Uptake similarly does not help us to understand the reasons behind non-participation, which may be many and varied, and include deliberate non-participation as well as those who may either mean to participate but never quite get round to it or those who would like to participate but for whom accessing or engaging with health services is difficult. In this way, data on screening uptake is not able to distinguish between non-participation as an intentional and deliberate act of commission (an informed decision not to) and that which represents an act of omission.<sup>18 19</sup> Returning to the issue of interventions to try to increase uptake, we may consider non-participation arising through acts of omission as an appropriate target for such interventions, but would presumably be less comfortable with this in relation to deliberate acts of commission, given the emphasis around informed choice.

### ***Moving beyond uptake?***

So, what might ‘better’ look like? One option might be to seek to assess the quality of decision making around screening participation, for example, through seeking to measure informed choice, value congruence, or decisional conflict.<sup>20 21</sup> However, these are not necessarily straightforward to assess and the methods used to do so may be impractically burdensome in practice. There would also be issues in relation to how such data may be used. For example, what would be the implications if it was found that many people who participated in screening did so based on sub-optimal levels of understanding and/or in tension with their values and preferences?

Rather than focusing so heavily on participation itself, another option might be to think about how to ensure that those who wish to take part in screening have adequate ‘opportunity to participate’. Approaching the issue through such an ‘opportunities lens’ may be helpful in ensuring an appropriate balance is struck between seeking to give people every opportunity to participate with respecting that they have thus far not done so. Ensuring ‘opportunity to participate’ by reducing barriers to access as proactively as possible could involve, for example, a strong focus on accessibility and appropriateness of screening locations that meet the needs of the local population and flexibility in terms of available appointment times including outside working hours, with regular feedback sought on the adequacy of these.

Also important within this would be the judicious use of interventions to encourage and support those who wish to participate to do so, but without too much detriment to those who have made the decision not to. A reminder text message may help the former, but could annoy or be felt to undermine the decision made by the latter. The opportunity to decline screening and to have that choice recorded and respected should also be facilitated. So, for example, a screening programme

could set a KPI for presence of an accessible opt out system, alongside text reminders. If someone has opted out, they should not get a text reminder.

### ***Conclusion***

The focus on screening uptake is understandable, but there are some important limitations to this metric that must be considered and additional measures that could be used in combination with it to ensure a more nuanced understanding of screening programme performance. Similarly, efforts to reduce inequities by encouraging participation in screening, particularly by those from groups who are underrepresented, are understandable, but the potential for this to encroach on people's ability to make informed decisions about whether or not to engage and have those respected needs to be balanced. A focus on assessing how adequately screening programmes have offered those invited a meaningful 'opportunity to participate' might be one way forward.

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