

# Walking the tightrope: communicating overdiagnosis in modern healthcare

Communication that empowers the public, patients, clinicians, and policy makers to think differently about overdiagnosis will help support a more sustainable healthcare future for all, argue **Kirsten McCaffery and colleagues**



**Overdiagnosis and overtreatment have serious implications for individuals, healthcare systems, and society,<sup>1 2</sup> and effective strategies are urgently needed to help the public, clinicians, and policy makers address this problem. Communication about overdiagnosis has been highlighted as essential for moving forward but presents several challenges, such as the potential to confuse the public, undermine trust, and adversely affect people who already have a diagnosis. Various communication based strategies offer real promise; we describe what is known and what we need to know to communicate effectively and safely about overdiagnosis and overtreatment.**

## Box 1 | Overdiagnosis and its consequences<sup>12</sup>

Overdiagnosis occurs when a diagnosis is “correct” according to current professional standards but when the diagnosis or associated treatment has a low probability of benefiting the person diagnosed.<sup>2</sup> It is caused by a range of factors such as:

- Use of increasingly sensitive tests that identify abnormalities that are indolent, non-progressive, or regressive (overdetection)
- Expanded definitions of disease—for example, attention-deficit/hyperactivity disorder and dementia—and lowering of disease thresholds, such as osteoporosis (overdefinition)
- Creation of pseudodiseases (also called disease mongering), such as low testosterone and restless leg syndrome
- Clinicians’ fear of missing a diagnosis or litigation
- Public enthusiasm for screening or testing and desire for reassurance
- Financial incentives

## Potential consequences of overdiagnosis

- Psychological and behavioural effects of disease labelling
- Physical harms and side effects of unnecessary tests or treatment
- Quality of life affected by unnecessary treatment
- Hassles of unnecessary tests and treatments
- Increased financial costs to individuals
- Wasted resources and opportunity costs to the health system
- Overmedicalisation of society

## WHAT YOU NEED TO KNOW

- Overdiagnosis provides no benefits to patients and is a challenge to the sustainability of modern healthcare systems
- Communication based strategies could help reduce overdiagnosis and its negative impact on individuals and health systems
- Mass media education, shared decision making, terminology changes for disease states, and deliberative methods (juries) all have potential as effective communication strategies

### What are the key messages to be communicated?

Understanding of overdiagnosis among the *general* public and health professionals is limited, so it is essential to communicate what it means for individuals, the health system, and society (box 1). For societies with free public healthcare, the financial strain and opportunity cost are usually at system level—resources wasted on unnecessary tests and treatments are unavailable for people in greater need. But in private healthcare systems, overdiagnosis can be a huge personal financial burden, even for those with insurance.

Communication is further complicated because it is usually impossible to know whether an individual has been overdiagnosed or benefited from the diagnosis—overdiagnosis can

only be observed at the aggregate level. Recent efforts to communicate the concept and likelihood of overdiagnosis in breast screening have had some success, albeit with much room for improvement. When given a patient decision aid including an infographic and icon array (see figure on [thebmj.com](http://thebmj.com)), 29% of women understood both the concept and quantitative outcomes of breast screening (including deaths avoided, false positive results, and overdiagnosis); 59% of women understood the conceptual information alone.<sup>3</sup>

### Communication based strategies to mitigate overdiagnosis

Several communication based strategies have been directed at individual, community, or policy levels (box 2).

#### Strategies for individuals

*Shared decision making* is a consultation process where a clinician and patient jointly make a health decision. It changes the way decisions are framed by identifying that there is a decision to be made (not an obligatory test or default treatment), and explaining the range of options available and their benefits and harms. It also involves deciding with patients “what is most important to them” in terms of their values, preferences, and

circumstances.<sup>4</sup> Importantly, the option of doing nothing or active surveillance can be discussed as a deliberate or positive action<sup>5</sup> to counter people’s bias for tests and treatment, especially in cancer.<sup>6</sup>

*Patient decision aids* support shared decision making. High quality evidence from 115 trials shows that they improve patients’ knowledge and understanding of options and their risks and benefits, and increase consistency between patients’ values and choices.<sup>9</sup> Decision aids have successfully informed women about overdiagnosis in breast screening,<sup>3</sup> reduced men’s desire for prostate specific antigen (PSA) testing<sup>10</sup> or surgical management for prostate cancer, and reduced preferences for potentially unnecessary elective surgery.<sup>9</sup>

#### Strategies for communities

Mass media and direct to consumer campaigns can influence large numbers of people simultaneously and promote sustained beneficial changes in behaviour.<sup>16</sup> For example, a mass media campaign about back pain, driven partly by concerns about unnecessary back imaging, changed both community and general practitioner beliefs about management, resulting in reduced imaging, work insurance claims, and healthcare usage.<sup>17</sup> Other important initiatives include the Choosing Wisely campaign, now operating in nine countries ([www.choosingwisely.org](http://www.choosingwisely.org)), and the United Kingdom’s “do not do” list.

#### Policy directed strategies

*Deliberative democratic methods* (such as community juries) support policy decisions by gathering informed public responses about disputed issues. Because overdiagnosis is scientifically and politically contested, this topic is ideal for deliberative democratic methods. Community juries have considered PSA testing in Australia<sup>19 20</sup> and mammographic screening in New Zealand, where participants changed their recommendation at least partly because of potential harms from overdiagnosis.<sup>21</sup>



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*Changing terminology:* Behaviours can be influenced by medical terminology, and changing the names for medical conditions may help reduce the effect of overdiagnosis. Independent experts convened by the US National Cancer Institute<sup>25</sup> and National Institute of Health have proposed dropping the word “cancer” entirely for ductal carcinoma in situ (non-invasive cancer), arguing for it to be reserved for lesions likely to progress if untreated.<sup>25 26</sup> Similar arguments exist for thyroid and prostate cancer,<sup>27</sup> but effects of disease labels extend beyond cancer. Parents were more likely to accept medication when “gastro-oesophageal reflux disease” (compared with no label) was used to describe excessive irritability in infants, even when told the drugs would not control the symptoms.<sup>28</sup>

#### Potential challenges to effective communication

*Low levels of awareness:* Awareness of overdiagnosis is low, particularly for cancer screening, with few people understanding overdiagnosis of cancer is even possible.<sup>29 30</sup> In one study, 18% of Australian men and only 10% of women said they had been told about overdiagnosis in screening for prostate and breast cancer, respectively.<sup>31</sup>

*Cognitive biases and counterintuitive messages:* Longstanding, prominent public health messages have emphasised the benefits and ignored the harms of early diagnosis for many diseases.<sup>36 37</sup> This makes the concept of overdiagnosis unfamiliar, counterintuitive, and difficult to understand. There is widespread faith in the importance of early detection,<sup>38 39</sup> and people may choose cancer screening because it is the apparent default decision, even if their informed preferences would be different.<sup>40-42</sup> Furthermore, when people are predisposed towards an intervention, they may perceive benefits to be high and risks low, even when explicitly told otherwise.<sup>43</sup> Suggesting a reduction in tests that are popular with the public can provoke emotionally

#### Box 2 | Examples of effective communication strategies for overdiagnosis or overtreatment

##### Community back pain campaign (three year campaign 1997-99)<sup>17</sup>

- Significant improvements in community (n=4730) beliefs about back pain over three years in Victoria (where campaign was run) versus New South Wales (no campaign)
- General practitioners (n=2556) knowledge improved—for example, time when patients can return to work, not prescribing complete bed rest. In a patient scenario, GPs in Victoria were 2.51 times less likely to order tests for acute low back pain and 0.40 times as likely to order lumbosacral radiographs. Over the duration of the campaign insurance claims for back pain reduced by 15%

##### Patient decision aids<sup>9</sup>

- A Cochrane review of 115 randomised controlled trials reported that decision aids reduced number of people choosing major elective surgery in favour of more conservative options (relative risk 0.79) and reduced number of men choosing PSA testing (RR 0.87) in nine studies
- A randomised trial of a decision aid for women approaching 50 years (n=879), which explicitly explained the concept of overdiagnosis and presented quantitative information on its likelihood, found that it increased informed choice by 9% (intervention 24% v control 15%), reduced intentions to screen by 13% (74% v 87%)<sup>3</sup>

##### Changing disease terminology

- A study of 394 women compared the commonly used cancer term for ductal carcinoma in situ (non-invasive cancer) with non-cancer terms (breast lesion, abnormal cells). Results showed 47% preferred surgery when cancer term was used compared with 34% and 31%, respectively<sup>22</sup>

##### Citizen juries

- 27 men randomly allocated to PSA screening community jury (12 men) or control (15 men). The jury concluded that the Australian government should not invest in PSA testing and recommended an education programme for GPs with better quality and consistent information about PSA for doctors and patients. After the jury, men had significantly lower intentions to screen compared with controls<sup>24</sup>

#### Research must also consider potential harms of communicating overdiagnosis, and herein lies the problem

charged, even hostile responses,<sup>44</sup> reflecting cognitive dissonance.<sup>45</sup>

*Uncertainty and trust:* Intolerance of uncertainty and anxiety about missing rare cases underpin much medical excess.<sup>46</sup> Communicating about overdiagnosis requires us to acknowledge the inherent uncertainty in the size and extent of the problem and its consequences. These issues are often hotly contested.<sup>47</sup> Communicating uncertainty adds complexity and may lead to confusion and avoidance of decision making<sup>48</sup> and can undermine trust in the healthcare provider.<sup>49</sup> However, distrust can also arise when patients discover that information about harms has been withheld.

*Vested interests and persuasive communication:* Vested interests may influence how information is presented in the media and the scientific arena. Pharmaceutical and device manufacturers have direct interests in maximising product sales. Industry funded disease awareness campaigns often increase the numbers of people portrayed as patients.<sup>50</sup> Narrowing the boundaries that define disease or raising diagnostic thresholds is a threat to turnover, profit, and professional interests.<sup>51</sup> Similarly patient advocacy groups, often also industry funded, can have interests in portraying their condition as widespread, severe, and treatable to optimise media, professional, and policy attention and to attract resources.<sup>52</sup> Politicians too have seen mileage in supporting screening programmes without offering more nuanced assessments of their benefits and harms, including risks of overdiagnosis.<sup>53</sup>

#### Further research directions

We need studies about what the public, patients, and clinicians currently know, understand, and want to know about overdiagnosis and their attitudes, reactions, and choices when provided with such information. Then we can research effective communication—how to increase understanding among all parties and the effectiveness and acceptability of such strategies. Once effective interventions are identified, we need to understand how to implement them within healthcare systems that currently reward overdiagnosis. However, research must also consider potential harms of communicating overdiagnosis, and herein lies the problem. Possible harms include overburdening and confusing the public, adversely affecting patients already diagnosed and treated, and creating distrust in conventional medicine.<sup>29</sup>

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# yes

Vaccine schedules are evidence based, safe, and highly effective in reducing the global burden of infectious diseases

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Vaccines undergo extensive testing and review before licensing to evaluate their immunogenicity, safety, and effectiveness in preventing disease.<sup>1</sup> For example, prelicensing trials of pneumococcal conjugate and rotavirus vaccines are among the largest randomised controlled trials ever conducted, enrolling tens of thousands of infants.<sup>2-4</sup> In addition to randomised controlled trials, which produce the highest level of evidence and provide the basis for vaccine licensure, vaccine policy also benefits from the additional supportive evidence obtained from thousands of other types of vaccine studies. Such studies generate critical data regarding age specific immunogenicity, dose and dosing intervals, interaction with other vaccines, duration of immunity, and overall vaccine safety to inform schedules.

### What evidence is needed to make the most appropriate schedule?

Data from clinical trials represent only a portion of the evidence considered in determining vaccination schedules.<sup>5</sup> Burden of disease, immunogenicity, and efficacy studies enable countries to select vaccines and schedules appropriate for their populations, as shown by the recent infographic in *The BMJ*.<sup>6</sup> Vaccine schedules are further refined by considerations such as timing and efficiency of access to the target population to optimise uptake. For childhood vaccines, integration with existing local or national well child visit schedules is a critical consideration.

Once vaccines are in general use local surveillance is generally conducted to evaluate their effect on disease burden. Comprehensive surveillance systems are also maintained by the Centers for Disease Control and Prevention in the United States, Eurosurveillance in Europe, and the World Health Organization expanded programme on immunisation (EPI).<sup>7-9</sup>

### Role of expert advisory bodies

In nearly every jurisdiction, decisions regarding vaccine schedules are made

by formal advisory bodies consisting of experienced practitioners, public health officials, vaccinologists, and epidemiologists. Available data are reviewed, burden of disease assessed, and practical considerations for vaccine delivery evaluated to produce an appropriate schedule for each country. So, expert advisory bodies may develop differing recommended schedules, based on local, regional, or national considerations. For example, the second dose of MMR vaccine is routinely given in Germany at 15-23 months of age, while in the US it is administered at 4 to 6 years. Strong trial generated evidence shows that two doses separated by at least 28 days and the first dose administered on or after the first birthday will produce measles immunity in 99% or more of people. The timing of the second dose varies in each country is based on the ability to provide the earliest possible second dose that will minimise the burden of measles. Ongoing surveillance of measles cases ensures that the timing of doses remains appropriate to the epidemiology of disease.

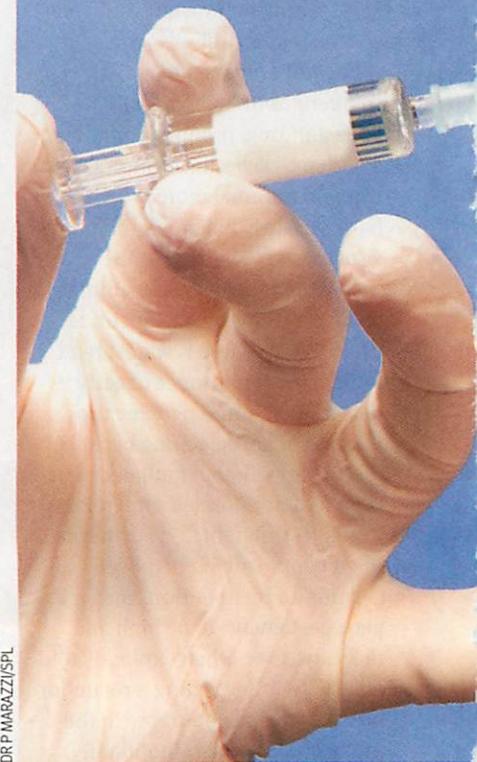
### Monitoring optimises protection

Evidence continues to be gathered and used after implementation. The increase in *Haemophilus influenzae* type b (Hib) cases in the United Kingdom after implementation of a Hib conjugate vaccine schedule at 2, 3, and 4 months prompted an altered schedule that moved the 3 month dose to 12-13 months, with a resultant reduction in the burden of Hib disease.<sup>10</sup> The value of continued surveillance was also highlighted by the introduction of maternal tetanus, diphtheria, and acellular pertussis (Tdap) vaccination to reduce pertussis among infants in the US and many European countries.<sup>11</sup>

In summary, vaccine schedules are evidence based, safe, and highly effective in reducing the global burden of infectious diseases. Evidence to develop and maintain these schedules involves a multifactorial and robust process carried out worldwide. The real world effectiveness is shown by the millions of children spared annually from the morbidity and mortality of vaccine preventable infections.

## Is the timing of recommended childhood vaccines evidence based?

A recent infographic in *The BMJ* highlighted variation in global vaccination schedules. Kathryn Edwards and colleagues argue that schedules are based on good evidence and robust processes but Tom Jefferson and Vittorio Demicheli think we need to know more about threat of disease



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