

# Engaging patients and the public in Choosing Wisely

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## WHY PATIENT AND PUBLIC ENGAGEMENT IS IMPORTANT FOR TACKLING OVERUSE

Choosing Wisely campaigns aim to engage physicians and the public in tackling the problem of overuse in medicine.<sup>1</sup> Choosing Wisely has been adopted by medical and other clinician societies worldwide, having now spread to approximately 20 countries. While physicians have demonstrated a high degree of interest, engaging patients and building wider public awareness is far more challenging. The belief that more testing and more treatment lead to better outcomes is widespread, and physicians rarely discuss the risks and harms of overuse with patients.<sup>2–4</sup> Indeed, there is a marked tendency among both patients and physicians to overestimate the benefits of medical interventions and underestimate harms.<sup>5</sup> Further, physicians' perceptions of the unacceptability to patients of applying Choosing Wisely recommendations appear to be a major barrier towards implementation.<sup>6</sup> There is concern that the impact of the campaigns will be blunted if patients and the broader public are not receptive to the message of Choosing Wisely. Evidence demonstrates that up to 30% of all medical care adds no value to patients, and in fact can lead to harm.<sup>7</sup> Yet, overuse persists as both clinicians and patients are victims of the 'therapeutic illusion.'<sup>8</sup> Choosing Wisely campaigns attempt to tackle this problem through establishing specialty-specific lists of recommendations of 'Things Clinicians and Patients Should Question.'<sup>9</sup> A central goal of Choosing Wisely campaigns is to change patient and public knowledge and attitudes, in addition to physician practice, in order to influence the culture of medicine that has driven overuse.<sup>1</sup>

Patient and public expectations are often cited by physicians as a major cause

of overuse, although the extent to whether this is true is unclear.<sup>9</sup> The concepts of overdiagnosis, overtreatment and overuse can be confusing for laypeople, yet the consequences are serious to individuals through harm, and to society through diversion of resources.<sup>10</sup> Increasing public understanding of these issues should therefore be a priority, but communication about overuse is challenging. A significant risk is that Choosing Wisely campaigns will be perceived as rationing exercises by media or patient organisations.<sup>11</sup> Campaign mechanisms and strategies can be difficult to explain to a lay audience, particularly in the context of pressure to contain or cut healthcare expenditures.<sup>12</sup>

The forces that drive overuse have been well described, are many and complex, and are embedded within the medical profession as well as the broader media, social and cultural environment.<sup>13</sup> People's attitudes—clinicians as well as patients and public—are influenced by factors such as personal experiences and that of family and friends, education, training and employment, media reports, commercial and interest groups, and political affiliations. Meanwhile, commercial and political pressures to promote or undergo unproven screening tests, such as whole body scans or gene sequencing for healthy people, or cognitive impairment tests for 'pre-dementia' are growing, fuelling concerns about unmanageable demand.<sup>14</sup>

The public are key stakeholders, both as users of the healthcare system and as citizens/taxpayers through the political process. If they perceive that services they believe are needed, or might be needed in the future are being withheld or removed for political or financial reasons, they will resist change. Choosing Wisely campaigns represent a concerted effort to change the

terms of the public debate and to educate the public about the individual and social harms of overuse.

Participants at a recent meeting of the Choosing Wisely International Roundtable, a forum for campaign leaders to share ideas and develop common approaches, agreed on the need to develop a systematic strategy for addressing this challenging aspect of the campaign and measuring its impact.<sup>15</sup> Here we propose a framework for patient and public engagement in Choosing Wisely campaigns and suggest approaches to local measurement and evaluation. The framework can also be used to drive forward a research agenda to better understand the role and impact of patient and public engagement in addressing overuse.

The framework is focused on Choosing Wisely campaigns, and is relevant to decision makers and campaign participants. These include national medical specialty societies and clinician associations whose members are practising clinicians.

The framework contains the following four elements: (A) *Partner*: establishing partnerships with patient or consumer organisations, (B) *Engage*: involving patient representatives in planning and steering campaigns, (C) *Inform*: providing public information about the issues and monitoring its impact, and (D) *Empower*: supporting shared decision making at the clinical level.

## PARTNER

The rapid uptake and spread of Choosing Wisely campaigns are often attributed to the fact that the initiative is physician led and professionally owned.<sup>16</sup> No attempts have therefore been made to cede leadership of local campaigns to laypeople, but there is potential advantage in working with patient organisations and identifying specific roles for their members.

In an effort to build trust among patients and the public, from the outset Choosing Wisely campaigns have partnered with national patient organisations or other consumer groups to support public and patient communication about the campaign. Patients can play a key role in identifying, developing and evaluating information materials for use in clinical consultations and materials for public information campaigns,<sup>17</sup> but there are other potentially useful roles for laypeople that could further strengthen the campaign. These might include playing a more active part in planning and steering groups, determining priorities, implementing and managing change, and evaluating impact.

## ENGAGE

The work of developing and implementing Choosing Wisely lists of recommendations has been largely left to professionals up to now. As a result, many recommendations do not address what is important to patients. For example, recommendations about technical issues related to blood transfusion may be of lesser interest to patients than those concerned with their expectations or requests, such as imaging for low-back pain. To

address the second type of recommendation, specialty groups involved in Choosing Wisely campaigns are now being encouraged to involve patient representatives in list development.

Documented examples of how patients have been involved in list development are limited, but can be informative. For example, one patient with lived experience participated in the steering committee for the Choosing Wisely Canada Psychiatry list.<sup>18</sup> The American Academy of Paediatrics Section on Perinatal Paediatrics included parents along with clinicians in a survey of potential Choosing Wisely list items.<sup>19</sup> And the Canadian Rheumatology Association had three members of the Canadian Arthritis Alliance patient group participate in the list development committee.<sup>20</sup> As yet, no attempt has been made to evaluate the impact of engaging patients in list development to determine whether it leads to selection of items that have broader relevance.

## INFORM

Messaging is important. Choosing Wisely campaigns to date have employed a variety of social marketing techniques to engage with patients and the public. Research in the USA has suggested that campaign messages about waste, and blaming overuse on providers do not resonate with patients and the public and can enhance concerns about rationing. Focusing on harms arising from overuse and emphasising the importance of effective clinician–patient communication appears to have a greater impact.<sup>21</sup> More research is needed to understand the complex relationship between knowledge, attitudes and behaviour in this area. Health promotion messages can sometimes lead to unanticipated results, as seen in the example of attempts to reduce parental misperceptions about vaccine risks that had counterproductive results on uptake among certain subgroups.<sup>22</sup>

Well-planned, researched and executed public awareness campaigns require expert assistance from experienced communications professionals, which can be effective but costly.<sup>21</sup> In many countries, such as the USA, Canada, England and Australia, Choosing Wisely campaigns have received widespread and supportive media coverage.<sup>15</sup> More targeted audiences have been reached through partnering with consumer organisations, such as *Altroconsumo* in Italy and *Consumer Reports* in the USA.<sup>15 23</sup> However, the level of resources required to mount effective public awareness campaigns is beyond the reach of less well-funded campaigns.

## EMPOWER

Choosing Wisely recommendations do not usually suggest that specific interventions should never be used, but rather underline the need for careful application of the evidence, acknowledging trade-offs between benefits and harms. This involves value judgements as

well as evidence, so determining individual patients' values and preferences is an important component of avoiding overuse. The promotion of better conversations between patients and physicians to facilitate informed decisions is a core aim of Choosing Wisely.<sup>15</sup> This reflects the shift in medicine from paternalism—making decisions for patients—to a partnership approach incorporating shared decision making.<sup>24</sup>

Choosing Wisely campaigns have focused on the clinical encounter specifically as an opportunity to address treatment expectations and reduce demand for unnecessary care. Well-designed strategies focused on increasing patient understanding and engagement can be effective in reducing overuse.<sup>25</sup> For example, shared decision making, supported by patient decision aids, increases patients' knowledge of the benefits and harms of options, and reduces the likelihood that they will undergo low-value interventions such as antibiotics for upper respiratory infections that are likely viral or prostate cancer screening.<sup>26 27</sup> Encouraging patients or caregivers to ask questions of clinicians can also lead to more appropriate use,<sup>28</sup> so Choosing Wisely campaigns in several countries have published brief sets of generic questions that patients can ask about whether tests, treatments or procedures are necessary.

A common critique of Choosing Wisely campaigns is that many recommendations are 'low hanging fruit' related to well-known topics such as antimicrobial overuse, which have many drivers beyond improved conversations or shared decision making. Fee-for-service payments can exert a powerful influence on unnecessary testing and treatment, perhaps requiring more robust strategies than simply promoting better conversations.<sup>29</sup>

Persuading physicians to modify their practice styles, to provide balanced information about benefits and harms and engage patients in decision making has proven difficult.<sup>29–31</sup> Shared decision making, supported by patient decision aids, could lead to fewer unwanted tests and procedures and less unnecessary care,<sup>25</sup> but a sophisticated, multifaceted strategy is required for successful implementation and spread.<sup>32</sup>

## THE FRAMEWORK

Choosing Wisely campaigns use a wide range of strategies and approaches. While list development has a set of principles which are well articulated and consistent across campaigns worldwide, approaches to patient and public engagement in the campaigns are less clearly defined and their impact has not been measured nor evaluated.<sup>1</sup>

The extent, depth and range of public engagement efforts in healthcare is often described as a spectrum or even a hierarchy, but uncertainty remains about when, where, why and how to engage public and patients and how to evaluate the impact of these efforts.<sup>13 33 34</sup> We undertook a selective narrative literature review of

existing frameworks,<sup>33 35 36</sup> and based on this and the authors' involvement in Choosing Wisely campaigns, offer this framework to help plan, measure and evaluate patient and public engagement in Choosing Wisely (table 1).

The proposed framework suggests multiple approaches that can be used simultaneously for different purposes, ranging in intensity—from limited to substantial. Importantly, Choosing Wisely campaigns are structured as partnerships with medical societies, patient associations and other public groups, working together with the shared purpose and commitment to reducing overuse. Campaign efforts are led by many different partners with diverse audiences, stakeholders and objectives, and many of the levels of engagement are intertwined and inter-related. The framework is not a blueprint indicating what all campaigns should do; it is merely intended to demonstrate the breadth of possibilities. Choosing Wisely campaigns worldwide are resourced differently, operating in diverse media and consumer contexts and while some have funding and capacity for broader mass media campaigns and communications, others do not.

A shared challenge of Choosing Wisely campaigns is to demonstrate impact through measurement.<sup>37</sup> The framework offers suggestions for measuring progress towards the challenging aim of building patient and public awareness. For example, targeted surveys can provide useful feedback on the impact and reach of public media campaigns. They can also provide information on the extent to which people understand the issues and are knowledgeable about overuse. For example, a study of primary care patients found that after exposure to educational materials about Choosing Wisely, their readiness to discuss unnecessary care increased.<sup>38</sup> Further research would be needed to explore connections between this type of attitudinal change and utilisation rates, bearing in mind the possibility that these may not be causally linked. A number of standardised tools are available that may help monitor progress and impact, but their use in different settings would need to be validated. The framework can be applied practically by Choosing Wisely campaign stakeholders, and in addition is intended to deepen research on these practices by suggesting opportunities for measurement and evaluation.

## CONCLUSIONS

Choosing Wisely campaigns aim to change the medical culture and reduce overuse. The model of a grassroots, physician-led campaign, alongside a commitment to building partnerships with patient and consumer organisations, has established traction. However, the success of campaigns depends on the strength of these partnerships to influence patient and public receptiveness to Choosing Wisely, and related health behaviour changes. Measuring and evaluating impact remains a challenging issue for Choosing Wisely, including

**Table 1** Framework for patient and public engagement in Choosing Wisely

Nature of engagement	Description	Possible measures
Partner: Direct involvement in campaign at national level	Establish partnerships with patient/consumer organisations to develop and implement campaign strategy, materials and initiatives	<p>Number of formal partnerships established</p> <p>Assess effectiveness of partnerships using partnership analysis tool, for example, <a href="https://www.vichealth.vic.gov.au/media-and-resources/publications/the-partnerships-analysis-tool">https://www.vichealth.vic.gov.au/media-and-resources/publications/the-partnerships-analysis-tool</a></p> <p>Evaluate reach and impact of campaign:</p> <ul style="list-style-type: none"> <li>▶ number of patient/consumer organisations that have partnered</li> <li>▶ attitudes/opinions of partner groups members on Choosing Wisely</li> </ul> <p>Per cent or number of recommendations with corresponding user-friendly content (eg, web pages, pamphlets, decision aids)</p> <p>Evaluate readability, comprehensibility and acceptability of campaign materials using standardised checklists</p> <p>Monitor distribution and reach of campaign materials and website</p>
Engage: Direct involvement in campaign at specialty level	Work directly with patient and public representatives to incorporate their perspectives and opinions into the campaign's initiatives and recommendations	<p>Per cent or number of societies who engaged patient/public in:</p> <ul style="list-style-type: none"> <li>▶ steering group</li> <li>▶ topic selection and recommendation development</li> <li>▶ developing and testing information materials</li> <li>▶ monitoring impact</li> </ul>
Inform: Building public awareness	Public information about overuse, including benefits, harms and uncertainties of tests, treatments and other procedures via print and broadcast media and social media	<p>Public opinion surveys to gauge awareness of overuse (eg, before, during and after media campaigns to judge their reach and impact)</p> <p>Public-reported measures of level/ usefulness of information provided</p> <p>Tools and checklists to measure the quality of patient information, for example, Health of the Net, <a href="https://www.hon.ch/">https://www.hon.ch/</a>, and the International Patient Decision Aids Standards Collaboration, <a href="http://www.ipdas.ohri.ca/">http://www.ipdas.ohri.ca/</a></p>
Empower: Promoting better conversations at the individual level	Patients engage in shared decision making with providers to make informed choices about their treatment plans	<p>Patient-reported measures of decision quality, including:</p> <ul style="list-style-type: none"> <li>▶ knowledge (extent to which patients are informed)</li> <li>▶ concordance (match between patients' goals and treatment received)</li> <li>▶ involvement (extent to which patients are involved in decisions about their care)</li> </ul> <p>For example, The Decision Quality Measures Tool, <a href="http://www.massgeneral.org/decisionsciences/research/DQ_Instrument_List.aspx">http://www.massgeneral.org/decisionsciences/research/DQ_Instrument_List.aspx</a></p>

its impact on patients and public.<sup>39</sup> In addition to monitoring utilisation rates of treatments and procedures deemed unnecessary, it will be very important to identify the extent to which patients and public are informed, involved and supported in healthcare choices. We hope our proposed framework will prove useful in this endeavour.

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