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Citizens' Perspectives on Disinvestment from Publicly Funded Pathology Tests: A Deliberative Forum

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ABSTRACT

Background: Deliberative forums can be useful tools in policy decision making for balancing citizen voice and community values against dominant interests. **Objective:** To describe the use of a deliberative forum to explore community perspectives on a complex health problem—disinvestment. **Methods:** A deliberative forum of citizens was convened in Adelaide, South Australia, to develop criteria to support disinvestment from public funding of ineffective pathology tests. The case study of potential disinvestment from vitamin B_{12}/folate pathology testing was used to shape the debate. The forum was informed by a systematic review of B_{12}/folate pathology test effectiveness and expert testimony. **Results:** The citizens identified seven criteria: cost of the test, potential impact on individual health/capacity to benefit, potential cost to society, public good, alternatives to testing, severity of the condition, and accuracy of the test. The participants not only saw these criteria as an interdependent network but also questioned "the authority" of policymakers to make these decisions. **Conclusions:** Coherence between the criteria devised by the forum and those described by an expert group was considerable, the major differences being that the citizens did not consider equity issues and the experts neglected the "cost" of social and emotional impact of disinvestment on users and the society.

Keywords: deliberative methods, disinvestment, health policy, pathology testing.

Introduction

Increasing expectations from patients, in combination with highly marketed expensive or high-volume biomedical technologies, place pressure on health systems globally [1]. In this environment, decision making can be found wanting if effectiveness, budget impact, and safety are addressed with inadequate attention to public acceptability and priorities [2,3]. Public participation is increasingly relevant in the development of health policy, including the assessment of new and existing health technologies, services, and programs [4–9].

Within health technology assessment, rigorous science-based knowledge is mostly undisputed and seen as unbiased and objective [10–12] whereas experiential and values evidence provided by patients and lay citizens tends to be seen as subjective and potentially biased. This "demarcationist model" [13] presumes that lay citizens do not contribute relevant knowledge and experts and decision makers do not contribute values to decision making. Contemporary epistemological debates challenge the demarcationist model, arguing that normative assumptions and science knowledge are coconstituted and that experts and nonexperts like reason using both knowledge and normative assumptions [10,12,13]. Public deliberations, in which participants consider the realities of health policy development, can be conceptualized as collective processes of inquiry maximizing mutual learning and accountability within and across expert and nonexpert groups [13].

Deliberative forums provide unique opportunities for "ordinary" citizens to engage in informed deliberation, be exposed to the perspectives and experience of others, and reach consensus on recommendations for action [1,4,8,14–17]. Public deliberations, using disinterested nonexpert contributors, can make explicit nontechnical barriers and facilitators to health care policy [18]. As such, they balance the perspectives of dominant interests with those of less powerful citizen stakeholders [9,13,19].

This article describes the use of a deliberative forum to explore community perspectives on a complex health problem—disinvestment. "Disinvestment" is "the process of (partially or completely) withdrawing health resources from any existing health care practices, procedures, technologies or pharmaceuticals that are deemed to deliver little or no health gain for their cost, and thus are not efficient health resource allocations" [20, p. 2]. More recently, disinvestment has been rebadged as "choosing wisely," "reappraisal," or "reprioritization" in the lifecycle of technologies [21]. Disinvestment evaluates existing health care services to redirect funding away from areas of

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potential inefficiency [9]. As such, disinvestment presents scientific, political, and ethical challenges: in particular, stakeholders may be vested in current practice and such proposals may challenge long-held beliefs and put livelihoods at risk [22]. Some pathology services exhibit characteristics, such as low test accuracy and wide variability in test use, that suggest that they may be candidates for disinvestment (e.g., [23]). In particular, vitamin B_{12} pathology testing has highly variable diagnostic accuracy and inconsistent cutoff values are used across laboratory sites to define deficiency. In addition, there are geographical differences in test use and indications of usage outside guidelines, and combined serum B_{12}/folate testing grew rapidly, with an annual growth rate in excess of 20% between 2000 and 2010 [23]. Pathology testing, as a whole, grew in excess of any other medical activity within the Australian health system [24].

The deliberative forum reported in this article aimed to incorporate community values in the development of criteria to support potential disinvestment from public funding of ineffective pathology tests. A case study of vitamin B_{12}/folate pathology testing was used to shape the debate.

Methods

The research is part of the Assessing Services and Technology Use To Enhance Health (ASTUTE Health) study, which, using health technology assessment methods and deliberative democracy, developed, trialled, and evaluated a model to integrate normative and scientific evidence for disinvestment from health services with questionable safety, effectiveness, and/or cost-effectiveness profiles [9]. The ASTUTE Health study also conducted deliberative forums with primary care physicians, pathologists [25], and federal government policy advisors. Findings from the ASTUTE Health study were fed back to policy advisors.

Deliberative Process

The forum was held over a weekend in Adelaide, July 2011, during which a general medical practitioner, an epidemiologist, a health economist, and a pathologist presented information and responded to participants' questions. The evidence provision reflected an evidence-based approach in keeping with the format for the forums with clinicians and policy advisors [9,25]. An independent facilitator was engaged but withdrew because of ill health. A research team member, with qualitative research expertise, undertook the facilitation task. A court reporter provided immediate verbatim-identified transcription of forum proceedings. The forum participants were asked the following questions: 1) What things should be considered when making decisions about how much we should publicly subsidize B_{12}/folate pathology tests? 2) Who should be involved in deciding which pathology tests are publicly subsidized? The forum schedule is provided online.

Recruitment of Community Forum Participants

Using stratified random sampling, jurors were recruited by an independent recruitment company from a database drawn from a statewide survey [26]. Sixteen participants were recruited to fulfill sex, age, and household income criteria, but five withdrew before the forum. One female participant did not return on the second day, leaving 10 participants. An honorarium of $200 was provided.

Theoretical Perspective and Approach to Analysis

Our analysis drew on realist approaches to discourse analysis, particularly the thematic analysis described by Braun and Clarke [27]. Transcripts were coded independently by two authors (P.C. and J.S.), with ongoing discussions throughout the analytic process.

Findings

The makeup of the forum mostly fulfilled the recruitment criteria: half were men, age ranged from 20 to 66 years (median 41.5 years; Australian median age is 36.9 years), and four participants had a weekly household income of less than $800 (median Australian household income).

The citizens identified seven criteria: four primary and three secondary (Table 1). In doing so, they drew not only on the evidence provided in the forum but also on their experience and understanding of medical care provision and community values.

Cost of Test

Participants agreed that the cost of the test was a central point to consider for potential disinvestment, although discussion focused on high item test cost or high overall budgetary impact rather than high cost by volume per se.

> **P8:** I don't think anyone else is saying cost in and of itself would be one factor in isolation that we use, you would weigh it up. [sentence omitted] With a finite amount of resources the cost of every individual test surely is significant, surely has some bearing on your decision making about whether you are going to fund or not.

Participants traded cost against potential outcomes, including accuracy of the test or, as the following extract demonstrates, the severity of the illness:

> **P11:** Cost versus potential outcome. If you are spending a thousand dollars testing for something, which could have dire consequences for somebody, yes; maybe it's worth it. If you are spending $10 on a test for a nosebleed or something, who cares?

Potential Impact

Potential for benefit

Participants linked disease severity, potential life-years gained, and overall capacity to benefit. High potential for benefit was constructed as worthy of funding, with the value of quality-of-life improvements frequently given equal footing with extension of life.

> **P5:** I put down quality of life. So is having the test and subsequently having the treatment, did that prolong their life? Is it going to make their life better?

Participants focused on capacity to benefit for specific subgroups, including vulnerable groups.

In doing so, they drew on their understanding from interventions for seasonal influenza vaccination. Participants rated access by high-risk patient subgroups highly because these subgroups would benefit most from testing, thereby improving test accuracy or "hit rate." Equity arguments per se were not used to justify these choices.

> **P2:** Depending on the disease, depending on who is more prevalent to actually get that type of disease … Obviously you are going to want to have a hit rate that is going to be higher than just the broad community. For example, the flu, they say they give it to the young, the elderly because they are the ones that are going to be more affected by that particular type of thing.… You have to look at the big picture of who would get the best benefit out of having the test.