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Review Article

Common methods of measuring ‘informed choice’ in screening participation: Challenges and future directions

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ABSTRACT

There is general agreement among public health practitioners, academics, and policymakers that people offered health screening tests should be able to make informed choices about whether to accept. Robust measures are necessary in order to gauge the extent to which informed choice is achieved in practice and whether efforts to improve it have succeeded. This review aims to add to the literature on how to improve methods of measuring informed choice. We discuss and critique commonly-used approaches and outline possible alternative methods that might address the issues identified. We explore the challenges of defining what information should be provided about screening and hence understood by service users, appraise the use of ‘thresholds’ to define e.g. positive attitudes towards screening, and describe problems inherent in conceptualising ‘informed choice’ as a single dichotomous outcome that either does or does not occur. Suggestions for future research include providing greater detail on why particular aspects of screening information were considered important, analysing knowledge and attitude measures at an ordinal or continuous level (avoiding problematic decisions about dichotomising data in order to set thresholds), and reconceptualising informed choice as a multifactorial set of outcomes, rather than a unitary one.

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1. Introduction

There is broad consensus in the United Kingdom (UK) that when people are invited to participate in health screening, they should make an ‘informed choice’ (Department of Health, 2011; National Screening Committee, 2013; General Medical Council, 2008). Individuals differ in how they appraise the balance of potential harms and benefits of screening, and hence whether they consider it worthwhile. This has

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Abbreviations: UK, United Kingdom; NHS, National Health Service; GMC, General Medical Council; IPDAS, International Patient Decision Aid Standards.

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led to a perceived ethical duty to encourage people to decide for themselves. For example, the National Health Service (NHS) in England informs people that "*deciding whether or not to have a screening test is a personal choice and one which only you can make*" (NHS Choices, 2015). To varying degrees this perspective is shared internationally (Andermann et al., 2008). The longstanding paternalistic view that screening communications should prioritise high levels of uptake has thus been superseded by a view that uptake can only be maximised within the constraints of informed choice. However, despite this consensus, there is a notable lack of agreement, consistency, and clarity about how informed choice should be defined and measured in practice (House of Commons Science and Technology Committee, 2015; Fox, 2006). The inevitable consequence is that efforts to improve it have made little progress (Biesecker et al., 2013).

Conceptual and methodological challenges are not necessarily apparent as authors usually have limited space to define informed choice and its underlying concepts. Descriptions are typically brief, e.g. "*an informed decision is one where all the available information about the health alternatives is weighed up and used to inform the final decision; the resulting choice should be consistent with the individual's values*" (Bekker et al., 1993). Similarly, "*an effective decision is one that is based on relevant knowledge, consistent with the decision-maker's values and behaviourally implemented*" (O'Connor and O'Brien-Pallas, 1989). Arguably, this gives the impression that informed choice is an uncomplicated interaction between i) a decision maker's knowledge about the proposed intervention; ii) their evaluation of the intervention with respect to their core values; and iii) their decision on whether or not to be screened (Marteau et al., 2001).

There are several ways in which informed choice is operationalised (see Biesecker et al., 2013 for examples) but this 'trinity' is often an instrumental aspect: researchers aim to measure screening invitees' knowledge using multiple-choice items or true/false statements (e.g. "*screening is for women without symptoms;*" Hersch et al., 2015). Values are measured in terms of participants' attitudes towards screening (e.g. "*some people find the test a bit unpleasant but it is simple to do and is designed to be done in the privacy of your own home. How does this make you feel about screening?*: *Against screening*|*Unsure*|*For screening*;" Smith et al., 2010). Screening behaviour can sometimes be determined by clinical records and screening intentions are often used as a proxy when it is not possible to measure behaviour directly (although this has well-recognised limitations; Sheeran, 2002). Thresholds are selected for each of these dimensions to categorise participants: knowledge may be labelled 'good', 'adequate', or 'satisfactory' vs. 'poor', 'inadequate', or 'unsatisfactory' and attitudes may be 'positive' vs. 'negative'. Similarly, screening participation may be described in terms of having had or not had (or intending vs. not intending to have) the test. Participants are considered to have made an informed choice if they are categorised as having 'adequate' knowledge and behave in a way that is consistent with their values (e.g. if they have positive attitudes and undergo screening). Conversely, they are categorised as having made an uninformed choice if they are rated as having 'inadequate' knowledge or behave in a way that is inconsistent with their values. It should be acknowledged that informed choice overlaps with several related concepts (discussed below) such as broader umbrella terms like 'informed decision-making' (Sheridan et al., 2004; Briss et al., 2004) and more specific concepts within this (e.g. decisional conflict (O'Connor, 1995) and shared decision-making; Briss et al., 2004). However, the literature on informed choice contains numerous examples of the previously described approach to operationalise informed choice (e.g. Biesecker et al., 2013; Marteau et al., 2001; Hersch et al., 2015; Smith et al., 2010).

This narrative review draws on key studies in order to critique this method and suggest possible alternatives. Research on informed choice in screening is becoming more commonplace internationally and receiving greater attention from policymakers, particularly in the UK (House of Commons Science and Technology Committee, 2015). It is therefore crucial that methodologies are appropriate. We focus on three major issues. First, we discuss the challenge of defining what information is important for people when they are offered screening. Second, we consider the limitations inherent in setting thresholds for 'adequate' knowledge and 'positive' attitudes or intentions. Finally, we comment on the standard tripartite operationalisation of informed choice, described above. To our knowledge, we are the first to draw explicit, specific attention to these issues collectively and explore them in detail. We hope that this will contribute to discussions on how to ascertain whether informed choice is being achieved in screening. Our discussion is oriented around this context but our comments may also be applicable to other scenarios. For example, the same conceptualisation of informed choice is sometimes applied in areas such as shared decision-making and informed consent (e.g. Berger-Höger et al., 2015). Although these will not be the primary focus of this review and we will not address this literature directly, there are also no 'gold-standard' methods of measurement related to these concepts (Right Care Shared Decision Making Programme, 2012; Gillies et al., 2015).

2. Review

2.1. Defining important screening information and knowledge

The information that invitees might consider about screening participation includes exceptionally complex and multifaceted risks, benefits, and practical issues, comprising both conceptual and numerical components that are unfamiliar to most people. Statistics such as positive predictive value and the differences between survival vs. mortality are so challenging that an appreciable proportion of medical professionals misunderstand them (Wegwarth and Gigerenzer, 2013; Whiting et al., 2015). The potentially relevant information is even more complex in a screening setting that does not aim to identify a single disease but a range of diseases or risk factors, each with a unique set of risks and benefits resulting from detection (e.g. genomic screening; Elias and Annas, 1994). Consequently, an early step in the design of any study on informed choice is to make a judgement on which elements constitute pertinent information to those offered screening, in order to decide which aspects of their knowledge to assess. Generally, researchers aim to complete this step by attempting to follow recommendations of published guidelines or the stated preferences for information among (potential) screening service users. However, both approaches have important limitations.

There are several sets of applicable guidelines; one of the most prominent in the UK is published by the General Medical Council (GMC), which states that screening invitees should be provided with the information that they "*want or need about… the potential benefits, risks and burdens, and the likelihood of success, for each option*" (General Medical Council, 2008). These recommendations are broad in order to apply to a wide range of medical decision-making contexts, meaning that they lack specific suggestions on what invitees should be informed of when deciding whether to have a screening test. However, it is notable that the recommendation that communicators "*should not make assumptions about the information a patient might want or need*" is not compatible with many organised screening programmes, in which the entire eligible population typically makes screening decisions after being provided with identical information materials, without speaking to health professionals. These guidelines have similarities to another set published by the International Patient Decision Aid Standards (IPDAS) Collaboration for improving 'decision quality' (Elwyn et al., 2006). These also include standards relating to what information should be conveyed to people being asked to make a healthcare decision, although in some respects these are more detailed (e.g. "*use event rates specifying the population and time period*"). Previous studies of informed choice have been guided by both sets of recommendations (e.g. Marteau et al., 2001; Smith et al., 2010; Smith et al., 2009; Michie et al., 2002; Kellar et al., 2008).

We consider it debateable whether there is a clear reason to favour any particular set of guidelines. Ostensibly, they offer the benefit of