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Title: Decision support tools for low dose computed tomography (LDCT) lung cancer screening: a scoping review of information content, format, and presentation methods

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ABSTRACT

Several countries mandate informed or shared decision-making for low-dose computed tomography (LDCT) lung cancer screening, but there is limited knowledge about the type of information and presentation techniques used to support decision-making in practice. This review aimed to characterise the content, format, mode, and presentation methods of decision support tools (DSTs) for LDCT lung cancer screening. DSTs reported within peer-reviewed articles (January 2000 to April 2021) were identified systematically from Pubmed, PsycInfo, EMBASE, and CINAHL Plus. Inclusion criteria revolved around the development or evaluation of a resource or tool intended to support individual or shared decision-making for LDCT lung cancer screening. The data-charting and extraction framework was based on the International Patient Decision Aids Standards instrument and Template for Intervention Description and Reporting. Extracted data were organised within two categories: 1) study characteristics and context, format, and mode of DST use; and 2) DST content and presentation methods. This review identified 22 DSTs in paper, video, or electronic formats across 26 articles. Most DSTs (n=13) focused on knowledge exchange, while seven used interactive techniques to support values clarification (e.g., Likert scales) and nine DSTs guided deliberation (e.g., suggested discussion topics). The DSTs addressed similar topics, but the detail, quantification of probability, and presentation methods varied considerably. None described all the potential screening harms and results. The heterogeneity in DST design may affect the quality of decision-making, particularly for participants with lower literacy and numeracy. Evidence-based consensus guidelines for DST content and presentation methods should be developed collaboratively with screening-eligible adults.

Keywords: Lung cancer screening; Decision support tools; Informed decision making; Shared decision-making; Health inequality

Abbreviations: LDCT = Low-dose computed tomography; DST = Decision support tool; SDM = shared decision-making; IPDASi = International Patient Decision Aids Standards instrument; TIDIER = Template for Intervention Description and Reporting

INTRODUCTION

Lung cancer remains the leading cause of cancer mortality globally, with incidence highest within socioeconomically deprived communities[1]. Consequently, several countries have introduced screening programmes for asymptomatic, early-stage lung cancer using low-dose computed tomography (LDCT). Eligibility is based on risk (primarily age and smoking history) as increased risk increases the likelihood of benefit. In the National Lung Screening Trial (NLST)[4], LDCT screening reduced lung cancer mortality among high-risk adults by 20% and 24% (men only) in the Nederlands–Leuvens Longkanker Screenings Onderzoek (NELSON) trial[5].

However, there are potential risks to be considered by eligible screening candidates, including radiation exposure, overdiagnosis and the potential harms of further tests[6,7]. Individuals should therefore be supported in making an informed decision about participating in the context of their values and preferences; a shared decision-making (SDM) process which is required for US government insurers to reimburse screening[8]. However, this is difficult to achieve. Risks are inherently challenging to communicate due to the uncertainty they pose for the individual[9]. Primary health care providers may lack specific knowledge of LDCT screening, preventing them from endorsing screening or being able to offer advice[10]. People with lower numeracy are particularly likely to be deterred by and distrust ambiguous information, to overestimate probabilities, and to rely on heuristics (e.g., emotions) when making decisions rather than numerical estimates[11]. Perceived information burden can also cause some aspects of information to be missed or ignored and may discourage individuals with lower health literacy from participating in LDCT screening leading to uninformed non-participation[13]. This is particularly important within lung cancer screening because screening-eligible candidates are overrepresented within socioeconomically deprived communities where literacy[14] and numeracy[15] are lower. On the other hand, there is early evidence from the US of individuals being referred for screening in the community without any information about, or discussion of, the trade-offs[16]. This is particularly problematic when many tend to overestimate benefit from screening interventions, potentially leading to uninformed participation[17].

The presentation techniques and format of information are therefore critical to ensuring decision support tools (DSTs) are equitable, accessible, engaging, and comprehensible[18]. For example, highlighting numerical risk information using simple visual displays such as icon arrays can support those with lower numeracy by drawing and sustaining attention to numerical information, helping the recipient interpret the absolute figures (thereby reducing the cognitive burden) and minimising biases in comprehension due to framing effects and denominator neglect[19] Similarly, using time-framed natural frequencies with a consistent denominator for multiple outcomes (smaller the better) can aid interpretation of the absolute increment in probability relative to alternative outcomes and avoid over- or under- estimation of probabilities. Both methods of communicating risk were recently recommended as best practice when probabilities are known[20]. However, this depends on the size of the probability and the numeracy and graph literacy of the target audience[19]. Furthermore, the evidence base for presenting probabilities that are unknown is still evolving, with mixed findings concerning the use of verbal techniques such as evaluative labels[20]. Several studies have designed DSTs to be used by potential lung cancer screening participants and clinicians. Fukunaga and colleagues'[21] systematic review of DSTs used in the shared decision-making context found they were highly acceptable, improved knowledge and reduced decisional conflict[21]. Whilst this review investigated the impact of shared decision-making DSTs on knowledge, little is known about the design, information content and presentation techniques used by DSTs in individual as well as shared decision-making contexts. Heterogeneity in design choice is important to understand because this may positively or negatively affect their comprehension and equity. For the first time, this scoping review aimed to identify the content, format, mode, and presentation characteristics of DSTs for LDCT lung cancer screening.

METHODS

A scoping review was undertaken using the stages defined by Arksey and O'Malley (2005)[22] to map how information about LDCT lung cancer screening is presented within resources designed to support individual or shared decision-making; referred to herein as 'decision support tools' (DSTs). Scoping review methodologies provide a way of mapping broad fields of research with diverse study designs[23], rather than aggregating or synthesising outcomes. We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR).

Eligibility criteria
Peer-reviewed papers were included if:

- Published between 1st January 2000 and 15th April 2021.
- Written in English.
- Reported the development, testing or evaluation of a resource intended to support individual or shared decision-making for LDCT lung cancer screening.

Papers were excluded if they:

- Did not concern lung cancer screening using LDCT.
- Included an information resource designed for a purpose other than decision-making (e.g., uptake, awareness).
- Were review articles or conference abstracts.

Information sources and data extraction
Articles were retrieved from Pubmed, PsycInfo, EMBASE, and CINAHL Plus. The search strategy was devised (SB and SQ) using the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research Type) framework. The search strategy was refined iteratively (SB) by running the search terms in the databases to establish the contributions of individual terms and to ensure key papers were included. Details of the final search strategy are in Supplementary Table 1.

Duplicate results were removed automatically and manually. Eligibility screening was conducted independently by two researchers (CK and SB). Article titles and abstracts were screened first, followed by full-text reviews. Disagreements were resolved by a third researcher (MJ), who also assessed all full text articles. Reference lists from eligible articles and review papers were manually searched. Authors of included studies were contacted to request access to the DSTs.

A data-charting and extraction framework was formulated (MJ and SQ) and presented for consideration by all authors (Supplementary Tables 2A, 2B and 2C). MJ independently extracted and charted the data with input from SQ.

The extracted data comprised two categories:

1. **Contextual information:** Derived from the Template for Intervention Description and Reporting (TIDIER) framework[24] and included study characteristics, target population characteristics, and DST characteristics (including format and mode).

2. **DST content and methods of information presentation:** Informed by the International Patient Decision Aids Standards instrument (IPDASi)[25], the TIDIER framework[24] and a systematic review of communicative aspects of decision aids[26].

RESULTS

The search yielded 2557 articles, of which 1982 remained after removing duplicates (Figure 1). Following full-text review of 176 articles,29 initially met the eligibility criteria in addition to two identified from reference searches. However, three were excluded because it was not possible to access the DSTs described. This resulted in 26 eligible articles, including 22 distinct DSTs.

Contextual information

Studies were mostly conducted in the USA (n=24) and published in 2019 (n=9; Table 1). Their designs were heterogeneous with randomised controlled trials (n=6) most frequently used. Most (n=22) studies used samples representative of characteristics that confer likely eligibility for LDCT screening, including age (range 55-75/80 years; mean 63.1 years) and current or former smoking status. Predominantly, participants were male, current smokers and of a white ethnic background. Only one study[27] targeted individuals from low-income and racially diverse populations.

Most (n=17) DSTs were designed to be used by the individual considering LDCT screening, while the remaining five DSTs were designed either for individuals considering screening or healthcare professionals offering screening (Table 2). Of these, 13 were intended to support shared decision-making, four to support individual decision-making, and five were intended for shared and individual decision-making.

The DSTs were predominantly paper-based (n=10), although six used video, and five were web-based interactive tools. The timing of DSTs varied by study design. The majority (n=20) were used before and/or during a health consultation.

Supplementary Table 3 presents detailed information on individual DSTs, including name, purpose and citing studies.

DST content and methods of information presentation

Supplementary Table 4 summarises the components included within each individual DST, which are now described in turn.

Risk-based eligibility criteria: Most (n=20) DSTs described the eligibility criteria for screening using written text alone or accompanied by verbal narration. All DSTs stated the eligibility criteria for screening as age (55-75/80 years), smoking status (current or former smoker quit<15 years), and smoking history (>30 pack years). Seven DSTs referred to national guidelines (e.g., U.S. Preventive Services Task Force[28]) as the basis of these criteria; five explained that eligibility was based on individual risk of lung cancer or chance of benefit whilst the remaining provided no justification. Some of the web-based DSTs also included interactive tools such as a smoking pack year calculator (n=5) or a lung cancer risk calculator (n=3). These were electronic questionnaires that produced an individualised summary of personal risk estimates (e.g., % risk score) and/or binary eligibility status.

Benefits and harms of LDCT lung cancer screening: All DSTs described some form of benefit from screening (Figure 2) with a mean average of 2.3 types of benefit (range: 1-4) presented in total by each DST. Those most frequently included were early diagnosis (n=16) and a reduced risk of dying from lung cancer (n=15). The benefit of early diagnosis was commonly described with no probability or quantification of its size or likelihood (n=9). However, seven DSTs quantified this benefit, using either verbal value labels (n=2, e.g., "higher chance"), percentages (n=2) or natural frequencies (n=3). The context of these probabilities were presented in either absolute terms (n=3) or relative (n=4) to not attending screening. One DST also used a quotation from an individual who had participated in lung cancer screening, describing how this had been life-saving[29,30].

Each DST also described at least one harm of screening, with a mean average of 4.5 types of harm (range: 1-6) mentioned in total across all DSTs. Seven different harms were defined across the different DSTS but no DST included all of these, with the frequency of inclusion varying markedly by the type of harm (see Figure 2). For example, radiation exposure (n=18), false-positive results (n=21), and harms from follow up procedures (n=18) were most frequently presented, whereas fewer mentioned false-negative results (n=5), or the possibility of dying from lung cancer, even though lung cancer was detected through screening (n=6).

Harms were also presented differently across the DSTs. While risk of radiation was usually quantified, either using verbal value labels (n=10; e.g., "small doses") or numbers (n=7), nine DSTs provided no information with which to quantify the frequency of overdiagnosis. Those that did (n=9), did so in absolute terms using numbers (n=8), verbal value labels (n=1: e.g., "sometimes"), or a combination. In contrast, the probability of radiation risk was more commonly presented in relative terms (n=13) when compared with other sources of radiation exposure (e.g., standard CT scans, X-rays, or natural radiation from the environment).

False-positive results were mainly quantified numerically using natural frequencies (n=10) and the context of this probability was always presented in absolute terms. However, six of the DSTs only used verbal descriptions, with no quantification of their probability. Five DSTs mentioned the chance of experiencing a false-negative result, with two giving no quantification of their likelihood. Few (n=5) described the possibility of death when lung cancer is detected through screening which was presented as natural frequencies. Six DSTs compared the incidence of lung cancer death in both screened and non-screened groups.

Most (n=18) DSTs described the risk of experiencing physical harm during follow-up or diagnostic procedures for abnormal screening results, while two-thirds (n=12) cautioned of potential psychological distress. The absolute risk of physical harm was predominantly quantified using natural

frequencies (n=8), although six gave no information to quantify the likelihood. Nearly all those describing the possibility of psychological distress (termed as "stress" "worry" or "anxiety") did so without quantifying its likelihood, intensity, or duration.

While all DSTs used written or narrated text as a minimum to present the harms and benefits, a small proportion also included visual illustrations, bar charts, icon arrays, grids or tables to aid comprehension or attentional engagement (Figure 3). For example, five DSTs used an illustration(e.g. CT scan of the lungs), icon array or table to illustrate their written descriptions of early diagnosis, while others used an illustration or animation of a balancing scale to illustrate the overall benefits and harms (n=5). Others used icon arrays to explain the relative rates of the different harms and benefits within a screened population using a common denominator. Most presented the probability of outcomes in the screening population in isolation in an absolute context, although five DSTs included a separate icon array to show outcomes within a 'non-screened' population for comparison. To demonstrate the level of radiation exposure from LDCT scans, four DSTs used bar charts with written text to compare different sources of radiation while five also used an animation of a CT scanner (alongside written text or verbal narrations).

Lung cancer information: Around a third (n=9) of the DSTs briefly described the causes of lung cancer, with the majority (n=14) citing tobacco smoking as the main cause. Others (n=5) included additional risk factors such as age, asbestos exposure, chronic obstructive pulmonary disease, and family history. National incidence and prevalence were cited in 14 DSTs, but fewer (n=5) mentioned the survival rate. Those that did largely presented this information in absolute terms and numerically, using natural frequencies or percentages. A quarter (n=6) of DSTs gave information about lung cancer symptoms, most commonly "chronic cough", "loss of weight", "coughing blood" with a modal average of five symptoms described. There was also an emphasis that early-stage lung cancer may not cause any symptoms.

Smoking cessation information: Smoking cessation was promoted by 18 DSTs, which broadly stated the benefits (e.g., "the best way to improve health") and reduced risks (e.g., "lowering the chances of dying from a variety of diseases"). These were primarily presented using written text or verbal narration with no information given about the magnitude of benefit or risk reduction. Eleven DSTs signposted individuals to support, and five gave detailed information on how to access support and medication.

LDCT lung cancer screening procedure and results: The majority (n=16) of DSTs described the experience of a LDCT scan in varying detail, with most of the video DSTs showing a person undergoing a scan, and three of the written DSTs using illustrations of the scanner to demonstrate the process. Information about the scanning process included practical details such as the time taken (n=8), the procedure of laying on a table and raising arms (n=5), an emphasis that there is no special preparation and reassurance about the scan being painless, needle free, and the scanner being an open ring rather than an enclosed tunnel (n=5). One DST also used a personal story of an individual's experience of the screening process.[31]

Many (n=16) of the DSTs described at least one type of LDCT screening result (range: 1-5), but the frequency of inclusion varied by type of result, with only four DSTs describing all five possible results (Figure 4). Incidental findings (n=12) and urgent/suspicious for cancer findings (n=11) were most

frequently mentioned, with negative results described least frequently (n=7). DSTs primarily explained what these results meant, but some also quantified their probability, typically using natural frequencies in the context of absolute risk within written or narrated text alone or in combination with icon arrays to illustrate their relative rates within the screening population (Figure 5). Some described the post-screening process, including recommendations to repeat the scan every year for those with negative screens, and further appointments, follow-up, and possible biopsy for those with abnormal results. Four DSTs gave information about the possible treatment options for lung cancer.

Values clarification, guidance in deliberation and decision prompts: Over half (n=14) of the DSTs prompted individuals to consider their values in relation to screening. This was usually suggested as something individuals should do (e.g., "think about what's important to you") rather than offering any guidance on how to do so. Seven DSTs included brief, structured and interactive values clarification exercises (e.g., Likert scales for ranking or rating values). Some asked individuals to list their reasons for and against attending, and others provided specific questions to guide thinking through the decision.

Fourteen of the DSTs provided prompts and reminders to consult healthcare professionals, including cut-outs to facilitate shared decision making. Of these, nine offered a list of topics and points for discussions or questions. Three included spaces for noting down questions in advance of their consultation.

Reading level or other strategies to help understanding: Only two studies designed DSTs specifically for those with lower literacy (5th and 8th grade reading level) and two DSTs were available in languages other than English.

DISCUSSION

This is the first scoping review to characterise current practices in the information content, format, and presentation methods of DSTs for LDCT lung cancer screening via in-depth review of individual DSTs. The scoping review identified and accessed 22 DSTs derived from 26 primarily US-based studies. Most were intended for use by individuals considering LDCT lung cancer screening to promote shared decision-making with their healthcare professional and primarily served to convey information. However, some also included values clarification exercises designed to prompt individuals to consider their personal values and preferences.

While the type of content was broadly similar, the detail varied considerably. Based on the totality of risks and screening results described across the different DSTs, no single DST was comprehensive in describing all these potential harms or types of result from LDCT screening. On the one hand, this could lead to prospective screening candidates being ill-informed; particularly if the DST is used as the only available avenue for information. On the other, briefer DSTs implemented in combination with other resources and discussion with a healthcare professional may provide a process of decision-making that supports comprehension while mitigating any potential to feel overwhelmed by too much information in a single episode. The methods of presenting information were also heterogeneous, both between different DSTs and within the same DSTs depending on the topic of information, with some employing best practice techniques for supporting comprehension and others giving no indication of frequency or quantity, either verbally or numerically.

This variation in the information content and presentation techniques of the DSTs is important to highlight because these design choices may positively or negatively affect the extent to which individuals engage with and comprehend the information[20]. Most DSTs covered similar topics of information, including eligibility criteria, the screening procedure, smoking cessation, lung cancer, and the benefits and harms of screening. They also dedicated relatively more space to the harms of screening than the benefits, consistent with other cancer screening decision aids,[26] hence the same ratio of space in presentation within the results section of this review. Indeed, there was a particular focus on the harms of radiation, false-positive results, and harms of follow up across DSTs. However, the detail of information content varied substantially, as did the way in which information was quantified, making some information less accessible to individuals with lower literacy and numeracy. No DST described every possible harm, with psychological consequences and false-negative results among those least frequently mentioned.

Similarly, while the types of LDCT screening results were described by 16 of the DSTs, these were typically restricted to incidental, abnormal, and suspicious findings. Few DSTs either raised the possibility of getting a negative result or quantified the likelihood of abnormal findings. Research suggests that participants' understanding of the different LDCT results may be important not only in supporting informed decision-making but also in psychologically preparing individuals to manage the uncertainty associated with indeterminate findings and mitigate over-reassurance following negative screens[32, 33]. The observed heterogeneity in the detail of the information provided may be driven by different perspectives on importance, the availability of research evidence with which DST designers can quantify their frequency, and concern that too much information about harm could discourage engagement. Future research should seek to establish consensus on the type, detail, and timing of information through innovative methods that seek expert and public perspectives, such as deliberative citizen jury approaches[34] or Delphi consensus techniques[35].

Among those DSTs which did quantify information, the use of best practice techniques for supporting comprehension among lower literacy participants varied considerably; particularly those important for presenting and frame frequencies and risk estimates[20]. For example, while all DSTs used written or narrated text as a minimum, this was sometimes accompanied by verbal evaluative terms (e.g., "rarely"), natural frequencies with consistent denominators or visual illustrations (e.g., icon arrays) to facilitate comprehension. Furthermore, absolute (rather than relative) risk was used almost exclusively to quantify the risks, benefits, and different possible results from LDCT lung cancer screening. The two exceptions were the benefits of early diagnosis and the risk from radiation, which were more commonly presented in relative terms, either solely or in combination with absolute risk.

While the primary purpose of the DSTs was to inform individuals and support decision-making, some moved beyond didactic knowledge exchange to engage individuals in deliberation and values clarification. Examples of strategies to encourage deliberation included interpersonal mode of use (e.g., in-person or telephone), demonstration of the screening procedure (e.g., video) or specially designed interactive exercises (e.g., ranking scales). Our review showed the use of these design techniques were in the minority, yet research[36] suggests that standard didactic style cancer screening information may disadvantage individuals of a lower socioeconomic position. The relative appeal and effectiveness of these design techniques by reading age is crucial to understand, because LDCT screening DSTs must be explicitly designed for those with lower literacy. Future studies should test these approaches to improve the equity of DSTs.

A comprehensive search strategy across multiple international databases strengthened this study, and independent reviews by three researchers minimised potential biases. However, the DSTs were identified for inclusion via English language, peer-reviewed, published studies only, excluding DSTs published in other languages and those used in clinical practice outside the research context. Furthermore, we did not critically appraise the studies or individual DSTs in line with scoping review methodology, in order to accommodate the rapid timeline for completing the review and because the focus of the review was the content of the DSTs themselves. Future research will investigate the quality of study designs and DSTs as well as adding further to understanding about the context of information content and presentation, and the evidence behind specific design choices.

Future research could use cognitive testing and experimental designs with high-risk, screening eligible samples to understand how individuals respond to, interpret, and comprehend different types of information and presentation methods, as well as any variation and individual differences. While there is some evidence underpinning best practice presentation techniques for decision aids, this is not yet mature, particularly when probabilities are uncertain[20]. Such research should use purposive sampling methods to ensure a more diverse representation of demographic groups, including different ethnicities and those from lower socioeconomic groups, than those included within the present review. These findings may usefully inform variation in, and tailoring of, the chosen information presentation methods, according to the target population.

DSTs are crucial for informed and shared decision-making for individuals considering LDCT screening as part of a range of resources including practitioner advice. Variety in the inclusion, detail, quantification, and presentation methods of key information could positively or negatively affect engagement, comprehension, and decision-making, particularly for those with lower literacy and numeracy. The type, detail and timing of information included in DSTs should be underpinned by evidence-based consensus guidelines specific to the LDCT lung cancer screening context, and developed collaboratively with screening-eligible adults. The choice of presentation methods, and any variation, should be based on existing and evolving evidence for decision aid design for lower literacy groups and risk communication, for which further research is needed. Doing so could improve and quality assure the effectiveness and equity of decision-making practices.

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TABLE AND FIGURE LEGENDS

Figure 1: PRISMA-ScR flowchart of the search and inclusion process

Figure 2: Methods used to quantify the probability of each benefit and harm of LDCT lung cancer screening

Figure 3: Methods used to present each benefit and harm of LDCT lung cancer screening

Figure 4: Methods used to quantify the probability of each type of LDCT lung cancer screening result

Figure 5: Methods used to present each type of LDCT lung cancer screening result

Table 1: Peer reviewed article characteristics

Table 2: Characteristics of decision support tools