Current challenges when using numbers in patient decision aids: Advanced Concepts

Running head: Applying numeric information in patient decision aids

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Abstract:

Background: Decision aid developers have to convey complex task-specific numeric information in a way that minimises bias and promotes understanding of the options available within a particular decision. While our companion paper summarises fundamental issues, this paper focusses on more complex, task-specific aspects of presenting numeric information in patient decision aids.

Methods: As part of the International Patient Decision Aids Standards (IPDAS) third evidence update, we gathered an expert panel of nine international experts who revised and expanded the topics covered in the 2013 review working in groups of 2-3 to update the evidence, based on their expertise and targeted searches of the literature. The full panel then reviewed and provided additional revisions, reaching consensus on the final version.

Results: Five out of the 10 topics addressed more complex task-specific issues. We found strong evidence for using independent event rates and/or incremental absolute risk differences for the effect size of test and screening outcomes. Simple visual formats can help to reduce common judgment biases and enhance comprehension but can be misleading if not well-designed. Graph literacy can moderate the effectiveness of visual formats and hence should be considered in tool design. There is less evidence supporting the inclusion of personalised and interactive risk estimates.

Discussion: More complex numeric information such as the size of the benefits and harms for decision options, can be better understood by using incremental absolute risk differences alongside well-designed visual formats that consider the graph literacy of the intended audience. More research is needed into when and how to use personalised and/or interactive risk estimates since their complexity and accessibility may impact on their feasibility in clinical practice.

Introduction:

A large body of evidence now exists demonstrating that patient decision aids are an effective way to increase informed choice across a range of health decisions. (1) Good quality decision aids provide balanced information about the available options, the benefits and harms of each option, and how likely they are to occur. (2) By quantifying the outcomes of different options using best practice methods, patients will have a more accurate perception and understanding of the size of those benefits and harms. (1, 3) This is obviously a fundamental component of good quality health decisions.

However, unless the science of risk communication is appropriately applied, decision aids can introduce bias, manipulate, and persuade patients to choose one option over another. Since a core premise of patient decision aids is to enable patients to make an informed decision that aligns with their preferences and values, such biases should be minimised wherever possible. (4)

As part of the updating of the background evidence for the International Patient Decision Aids Standards (IPDAS), we undertook a broad review of the evidence related to approaches for conveying numeric information for maximal understanding. Because the literature on presenting probability information is both broad and rapidly growing, we divided our findings into two papers. The first, our companion paper in this special issue, focusses on fundamental principles.

However, even if decision aid developers understand and incorporate fundamental principles in data communication, they often grapple with how best to implement task-specific risk communication within their tools. As health decisions become more complex, technology becomes more advanced, and our ability to estimate risks becomes more sophisticated, we face a trade-off between the desire to develop a 'state-of-the-art' tool and the need for feasibility and equitable accessibility in 'real world' clinical settings. While acknowledging the relevance of fundamental concepts in communicating using numbers that we summarized in our companion paper, we focus here on the evidence-base for applying these principles in varied risk communication contexts and discuss a number of emerging areas for further research.

Methods:

This paper is the second half of the evidence update for International Patient Decision Aid Standards (IPDAS) chapter on 'Communicating Probabilities'. The original standards were developed in 2005 and updated in 2013. (2, 5) Our current chapter update followed the same approach as previously with an invitation to previous authors initiated in early 2019 and new co-authors invited to cover all aspects of the chapter. The authors are experts from North America, Europe and Australia who convened over several teleconferences, one meeting at the International Shared Decision-Making Conference in July 2019 and via email. Several opportunities were also provided for the chapter leads (LT and BZ-F) to liaise with other chapter lead authors about overlap and gaps between the standards.

As before, the team reviewed the previous chapter sections and decided whether to remove, merge or add any further issues. Ten topics were agreed as covering the key aspects of communicating numeric information in patient decision aids. Five of these were considered to be fundamental principles and are detailed in our first paper. The remainder apply numeric information in more complex contexts and are outlined in this second paper. Authors worked in groups of 2 or 3 on sections of the chapter that most closely reflected their areas of expertise and developed a series of narrative reviews. We have continued to provide this update as a non-systematic expert review of the literature on these 10 topics, drawing on the depth and breadth of the authors' expertise. Following the development of the expert-written section updates, all co-authors further contributed to the update which includes more than 230 references.

Results:

The science in some aspects of this field has remained relatively unchanged since the previous update (effect sizes for treatment options, interactive and web-based formats) so we have provided a brief overview and a statement about the strength and quality of the evidence. Other aspects have seen considerable advancement since the previous update (visual formats, graph literacy, personalised risk estimates) and we have provided more detail along with an indication of the strength and quality of the evidence. Where emerging issues for future research and/or future systematic reviews were identified, these were highlighted and expanded further in the Discussion section.

The key recommendations where stronger evidence exists, are summarised in Table 1 below.

(Insert Table 1)

How should the effect sizes of treatment and screening options be presented?

Patient decision aids usually require communication of the benefits and harms of options within a particular health decision. For example, this might be the amount by which the chance of dying from breast cancer is reduced if you have treatment 'x' or the amount by which your chance of a side effect is increased by taking drug 'y' (this can also be described as the 'effect size' or the 'magnitude of effect').

Where possible in decision aids, effect sizes should be presented as either independent event rates (using simple frequencies or percentage formats) and/or as an incremental (or absolute) risk increase or decrease from a 'baseline' risk frequency. (3, 6, 7) A hypothetical example would be that 5 out of 100 (5%) people in a particular population group are likely to die from disease 'X' over the next year *without* receiving treatment 'A'. This could be described as the 'baseline frequency' or 'control event rate'. By contrast, if these 100 people *receive* treatment 'A' their chance of dying from disease 'X' over the next year becomes 4 out of 100 (4%). This second frequency is the event rate *with* the intervention or treatment. To illustrate how to present the size of the benefit of treatment 'A' the absolute (incremental) risk reduction would be to say that 1 less person out of 100 will die of disease 'X' over the next year if treatment 'A' is received. (NB: The relative risk reduction with treatment 'A' in this example is 20%). It has been consistently recommended that relative risk presentations alone should be avoided as they tend to magnify risk perceptions and decrease understanding in both patients and clinicians. (7-13) Similarly, number needed to treat (NNT) and number needed to harm (NNH) formats should also be avoided in patient decision aids as they lead to overestimates of treatment effects and are poorly understood. (14) There is no advantage to providing baseline risk alongside relative risks and this practice should continue to be avoided. (15, 16) These recommendations are based on two systematic reviews and five additional RCTs. (3, 6, 8, 11-13)

The framing of outcomes in terms of losses or gains also affects people's choices. (17) Framing outcomes in terms of potential gains (e.g., the chances of survival) often generates risk-averse choices, whereas framing outcomes in terms of potential losses (e.g., the chances of death) often generates risk-seeking choices. This guidance is based on a systematic review and two RCTs. (18-20)

The principle of using absolute rates also applies for reporting the benefits and harms of testing and screening. Screening decision aids should include estimates of 1) disease and disease-specific mortality with and without screening; 2) false positives; and 3) false negatives. The presentation formats in screening decision aids should reflect the type of information being conveyed. For example, the baseline risk of getting breast cancer should have the reference group clearly defined over time and will probably be best understood as a simple frequency since it will be a relatively rare event. As a percentage, it will be less than one and may be less well understood due to the use of decimal points.

Despite consistent evidence about best formats, many clinical guidelines continue to use treatment effect formats incorrectly and inconsistently. In fact, a review of US cancer screening and prevention guidelines (21) found that many guidelines presented benefit information in relative risk terms, and harm information in absolute risk terms. This imbalance has the potential to overemphasise testing and treatment benefits relative to their harms. Care needs to be taken to present information in a neutral manner in the development of patient decision aids.

An emerging issue for screening decision aids is the inclusion of estimates of 'overdiagnosis'. Overdiagnosis can be caused by over-detection or over-definition (22) and some countries now recommend that it be included in cancer screening information for the general public. (23) However, this concept is not well understood and can influence screening decisions. (23, 24) Misperceptions about cancer risk and patient preferences may also play a role in responses to information about overdiagnosis and subsequent cancer screening decisions. (25) Early trials that have included information about overdiagnosis in cancer screening decision aids have shown an improvement in understanding of this concept. (26, 27)

One trial of a mammography decision aid evaluated the effect of including over-detection estimates as simple frequencies with icon-arrays on screening decisions. (27) The estimate for over-detection provided in the decision aid was 19 per 1000 women over 20 years, and the decision aid included wording to explain the difference between 'over-detection' and 'false positives'. There was an improvement in understanding of over-detection when estimates were included in the decision aid. (28) Optimal presentation formats for overdiagnosis estimates and their effects on decision outcomes in screening decision aids are an emerging area for the field and should be flagged for future research.

How and when should visual formats be used?

Presenting event rates with visual formats such as icon arrays (e.g., where stick figures of different colours represent those affected vs. not affected by a disease; see Figure 1), bar charts, or flow diagrams is generally recommended to support interpretation for numerical data. (29-32) This general recommendation is based on strong and often high-quality evidence, a lot of which we will summarize subsequently. This recommendation has also been put forward in recent systematic review (30). As caveats, it should be noted that the effect sizes in these studies are typically small to moderate, and that the evidence is less clear-cut for more specific recommendations (such as which graph to use exactly for which purpose and for whom). Future systematic reviews on this topic could aim to quantify the strength of existing evidence and identify precisely which specific questions need more research.

Visual formats can help reduce biases such as denominator neglect, (33, 34) framing effects, (35, 36) and the undue influence of anecdotes (37) and they can aid the comprehension of more complicated concepts such as incremental risk. (6) Graphs can also improve accuracy in Bayesian reasoning tasks, such as inferring the positive predictive value of a test. (38-44) Even for experts (here: surgeons), transparent visual aids can help to reduce judgment biases in interpreting the scientific medical literature, which still frequently represents risk information in a misleading fashion. (45) People also often prefer graphs over numbers (46) and rate them as more attractive, likeable or helpful. (40, 47-49)

The beneficial effects of visual displays can be partly attributed to their cognitive and motivational advantages, that is, to being easier to process in some cases and attracting more attention. As compared to numerical risk information, graphs can require less cognitive effort to understand. (50) Graphs can also reduce the required processing time relative to tables, particularly for more complex data. (51) They can reveal data patterns that may otherwise go undetected, and evoke automatic mathematical operations (e.g., subtraction in comparing the heights of two bars). (52, 53) Additionally, graphs can attract more attention than numerical risk information, (50) particularly among the less numerate. (54) Hence, they may increase the time that people invest in assessing the information compared to mere numbers. (55)

Graphs have sometimes been shown to be suited best to convey the essential aspects of the information (i.e., "gross-level information") (56, 57) bottom line meaning, or gist (58) whereas numerical representations can be better suited to convey more precise aspects of the information (i.e., detailed-level information or verbatim). (56, 59, 60) The value of visual displays thus can depend on the risk communication goal; a potential weakness of visual displays is that people may focus more on the pattern of data than the precise values, if that is the main objective. For instance, patients presented with a bar graph may make gist-based judgments by comparing the heights of bars, and only pay attention to specific numerical details if reminded. (58) This can lead to misinterpretations of displays such as risk ladders that include logarithmic scales, as these may be neglected in some cases. (61) To illustrate, a recent RCT showed that graphs using a log scale to depict the evolution of Covid-19 deaths were associated with less accurate understanding and predictions than graphs using a linear scale. (62)

The effectiveness of specific visual displays depends crucially on how they are designed. Developers of patient decision aids should be aware that graphical display features that promote risk understanding may have other effects like reducing risk perceptions or intentions for behaviour change, depending on the context. The most important general principle to improve understanding is that visual displays should be transparent, which means that they promote unbiased risk understanding and evaluation. (63, 64) Transparency requires that all elements of the display are well defined and that part-to-whole relationships in the data are visually available and comparable to accurately and clearly represent the essential risk information. This can be

accomplished by using displays that depict both the number of people affected by a risk (the 'foreground') and the number of people at risk (the 'background'), such as icon arrays or stacked bar charts. Such displays can reduce overestimations of risk, (65, 66) particularly among less numerate individuals. (55) In contrast, 'foreground-only' displays (e.g., simple bar graphs representing only those affected) can decrease understanding of absolute risk magnitudes relative to 'foreground-background' displays (36, 67) and to purely numerical information. (68) At the same time, foreground-only displays tend to increase perceived risk and risk aversion (e.g., willingness to take a drug to prevent disease or to pay for an improved product). (67, 69, 70) A recent RCT, however, found that this tendency becomes weaker as the size of the probability conveyed increases. (71)

(Insert Figure 1)

Another important principle to support understanding is to ensure that spatial features (e.g., heights of bars) convey the same meaning as conventional features such as titles, axes labels, legends, and numerical values on scales. Violations of this principle occur, for example, when scales are inverted or truncated (e.g., where the *y*-axis scale doesn't start at 0) , which can lead to systematic misinterpretations, particularly among less graph literate individuals. (72) Such graphs can be misleading, and hence this principle should always be followed if the goal is to improve risk understanding. It should be noted though that in some cases truncation of the *y*-axis may be needed to depict meaningful differences which may be unnoticeable using a zero baseline (e.g., mean differences in quantitative laboratory test results, where there is no meaningful zero). There might also be instances where space constraints prevent from showing the full range of values in scales. In all cases designers should consider the range and magnitude of effect sizes they wish to communicate and take steps to avoid misinterpretations, such as including clear marks to indicate axes breaks.

Enhancing accuracy in estimates can also generally be aided by displaying the most crucial elements, hence omitting redundant information. (73, 74). In some cases, however, redundant elements (e.g., numerical labels above bars) may be useful to draw people's attention to information that otherwise may be neglected (e.g., axes scales). (69) Indeed, there is some

evidence that complementing visual displays with numerical and textual information that describes what is seen may also improve performance and reduce the association between numeracy and accuracy. (75, 76)

When informing about different risks, visual displays such as icon arrays should ideally use equal denominators to facilitate comprehension. Whereas displays using different denominators can reduce denominator neglect among more graph-literate individuals, they are less effective among people with low graph literacy. This tendency has been documented in RCTs involving student samples (33, 73) as well as surgeons and patients (72).

For icon arrays, accuracy can be enhanced by using icons that are arranged as groups in a block instead of scattered randomly throughout the array - the latter of which is useful to convey the concept that events (e.g., who is afflicted by disease) occur at random (77) and can increase subjective uncertainty about risk, if that is the communication goal. (78) Studies have also examined whether the specific type of icon used matters, yielding mixed findings. Whereas some studies found that more concrete, high-iconicity arrays (e.g., person-like icons) improve outcomes such as risk recall, (79, 80) others found no effects of icon type. (48, 81)

The relative effectiveness of different displays also depends on the type of graph used and the task at hand. For instance, some studies found that bar graphs and icon arrays with grouped icons are perceived more accurately and easily by patients than pie charts or icon arrays with ungrouped icons. (56, 75) Pie charts, however, may not necessarily hinder understanding of the gist or bottom line meaning (e.g., which treatment is better). (59, 82) Recent work also found better risk understanding for icon arrays and bar charts, relative to other graph types (e.g., line graphs). (76) A unique aspect of icon arrays is that they show frequency information and at the same time convey numbers in a graphical way. This may in some cases result in both better verbatim and gist understanding, as compared to text or tables. (49) However, several studies suggest that bar graphs can often be equally beneficial to improve accuracy of risk understanding and reduce overestimations. (36, 55, 76) Additionally, two reviews have highlighted that line graphs are generally better suited for conveying trends over time, whereas bar graphs are often better suited for comparisons across groups. (52, 53). As noted earlier though, evidence for

specific recommendations concerning which graph to use exactly for which purpose is not always clear-cut.

There is also some evidence that the magnitude of probabilities may affect the relative effectiveness of different graph types. For instance, icon arrays have been shown to lead to better accuracy of understanding than bar graphs when probabilities are not too small (e.g., 1% or larger) (83) and numerators are not too large (e.g., less than 100/1000). (84) Studies also suggest that graphs may have a limited influence on people's perceptions of very rare risks (e.g., .2%) (85) or relatively large risks (>20%), (55) but more research is needed examining this issue.

A recent study also tested novel visual formats such as a 'spinners' where people must evaluate the probability that an arrow would land on a coloured segment. Results provide initial evidence that the spinner format can improve gist understanding across numeracy levels (47). Future research could further investigate the role of this format or related ones to communicate the gist of a risk. Recent work has also examined formats designed to combine the benefits of different graph types such as icon arrays and bar graphs. (86) Although such formats are promising, more research is needed to determine whether they can improve risk understanding over and above more classical formats. The use of multiple icon arrays within a decision aid has had limited evaluation and it is unclear at what point people reach cognitive overload. (87) When evaluating novel or uncommon formats, it should be considered that participants may need to get used to these novel formats, so that researchers may want to include some learning or habituation phase to ensure a fair comparison to more classical formats. (7)

Whereas some research indicates that people may have a slightly better understanding of risk when receiving a format that they prefer (e.g., numbers only vs. numbers and graphical displays), (88) it is important to note that peoples' preferences for different visual displays are not always aligned with their performance. That is, the graph types that people prefer or evaluate more positively may not necessarily lead to better performance for a given task. (56, 84, 89) For instance, pie and clock charts are often preferred, but generally not well understood, whereas mere tables are often not preferred, but well understood in general and even best among older

adults. (90) Hence, it is not advisable to rely solely on patients' preferences when designing visual displays to communicate risks.

What is the role of graph literacy in developing decision aids?

While people vary in their ability to understand and apply mathematical concepts (i.e., numeracy), (91) they also vary in their ability to extract data and meaning from visual formats, whether static or interactive. Graph literacy refers to the ability to understand graphically presented information, (92) and can be assessed using objective (92, 93) and subjective instruments. (94) Objective instruments assess the ability to understand graphs where a correct answer exists, whereas subjective instruments assess respondents' self-perceived ability to process and use graphs. Higher objective graph literacy is associated with higher education, white ethnicity, and being male. (92, 93) Although graph literacy is far less researched than numeracy, the evidence that it predicts the comprehension of graphically displayed information is strong and of high quality, typically with a moderate effect size that could be scrutinized by a systematic review. Less is known about differences in graph literacy across countries.

Graph literacy can moderate the effectiveness of visual formats in improving health risk comprehension (34, 36, 48) and promoting health management tasks (95) and healthy behaviours. (95-97) High graph literacy is also linked with better performance in Bayesian reasoning tasks that involve visual formats, (98) as well as with doctors' and patients' self-reported use of graphs to communicate health risks to others (94) and of health portals containing graphs. (95, 97) As compared to numeracy, less is known about how graph literacy affects information processing and decision making. Existing evidence suggests that higher graph literacy is associated with a stronger tendency to attend to regions of visual formats that have key information for accurate interpretations (e.g., titles, labels, and scales). Instead, less graph literate individuals tend to rely more on salient spatial features (e.g., heights of bars). (72) Although numeracy can also affect how people process visual formats, (61, 99, 100) graph literacy independently predicts understanding and use of such formats. (90, 93, 97, 101-103) Additionally, graph literacy may affect patients' reactions to graphically presented risks. For

instance, in a study involving risk ladders, individuals with low graph literacy viewed the risks as larger, more severe, and expressed more worry. (93)

These research findings imply that visual formats may have limited effectiveness to improve risk comprehension among patients who lack graph literacy, who could in some cases be better off with mere numbers (48). Visual formats that do not follow general principles of effective design can be particularly misleading for less graph literate patients. When designing a decision aid, measuring objective numeracy and subjective numeracy, graph literacy, and possibly other aspects of the health literacy (104, 105) of the prospective users can help in designing presentation formats that are suitable for their combination of skills. For example, visual formats can be particularly helpful for patients with lower numeracy who have high graph literacy. (36, 48) However, it may not always be feasible to measure users' skills and personalise presentation formats accordingly. In such cases, any visual formats in decision aids should be simple and provide clear explanations to convey the meaning of important information and bring patients' attention to it. (31) Simple design features such as explanatory labels may enhance understanding of visual formats even among less graph literate individuals. (106)

How and when should personalised risk estimates be presented?

Personalised risk estimates take into account characteristics that are unique to an individual patient. With the growing availability of increasingly precise, "personalised" estimates of individuals' risks of various diseases and health outcomes, based on personal characteristics and clinical data including genomic information, personalised risk communication will likely become increasingly important and common. In theory, personalised risk information is more relevant to an individual and may therefore be better processed and understood.(107)

In recent times, there has been a plethora of risk calculators published online enabling the calculation of more personalised estimates of the risk of disease and other health outcomes. By entering individual variables (e.g. age, gender, smoking status, blood test results, etc) people can find out a more precise estimate of their chance of disease (or disease-related event) over a designated time period. However, a systematic review of online cardiovascular disease risk

calculators found that they varied in accuracy and reliability, with the same clinical data producing different results. (108) It also found that only 18% of these tools provided graphical representations of risks in a manner consistent with risk communication guidelines. Similar results have been found in a systematic review of online diabetes risk calculators. (109) An analysis of personalised cancer risk tools also found that their outputs varied in the use of best practice risk communication formats, leading to poor comprehension, misperception of cancer risks and potentially inappropriate actions. (110) Both experimental and qualitative studies have also shown that clinicians and patients don't necessarily believe or trust personalised risk estimates and may disregard them. (111-113) Thus, efforts to use risk calculators in patient decision aids to produce personalised risk estimates should consider and acknowledge any known limitations in their accuracy and reliability, and use accepted best practices to communicate and explain the meaning of these estimates.(5, 114)

A Cochrane review concluded that personalised risk estimates appear to have variable effects on health decisions and behaviours such as cancer screening. (107) Another large systematic review and meta-analysis indicated that communicating personalised genetic disease risks has little or no effect on health behaviour compared to generalised risk estimates across a spectrum of behaviours, including cancer screening, alcohol consumption, sun protection behaviours, diet, and physical activity. (115) Limited evidence suggests that individual characteristics, such as worry about breast cancer and educational status, may moderate the effects of personalised risk messages. For example, Bodurtha et al. found that a brief, personalised intervention regarding mammography adherence had no overall effect on mammography intentions, actual uptake, clinical breast examination, or self-examination, but increased mammography rates in the intervention group among patients with higher worry. (116)

Personalised decision aids for a number of health decisions such as stroke treatment (117), cardiovascular disease, and diabetes care (118) have used decision analytic techniques and embedded decision aids within electronic medical records. Personalised estimates in decision aids also often use web-based delivery methods. Whilst these tools can be feasible and acceptable to clinicians and patients, their implementation in routine clinical practice remains challenging. Hence, the ability of personalised risk estimates to be used in 'real world' clinical

settings require further research. Furthermore, the effects of personalised risk information have not been well studied, and more research is needed understand its value for clinicians and patients and its influence on risk perceptions and decision making. One systematic review suggests that personalised or "tailored" risk estimates may be discounted or distrusted by patients, and detrimental to decision making. (119)

In summary, personalised risk estimates are an increasingly common form of information, but important questions remain about their accuracy and reliability (both actual and perceived), effects on decisions and decision makers, and optimal clinical use. Ideally, efforts to integrate personalised risk estimates in decision aids should help patients to understand the meaning and potential value of these estimates, as well as the inherent limits in their accuracy and reliability. Decision aid developers and clinicians should also determine whether the potential precision of personalised risk estimates is actually useful for particular decisions.

When and how to use interactive and web-based formats in decision aids?

Decision aids are often delivered through the use of digital technology – including computers, tablets, and mobile devices. A series of environmental scans have found a large number of decision aids available online, some of which are interactive (e.g. showing the effects of different interventions on reducing CVD risk or selecting different outcomes to compare diabetes medications). (109, 120-122) This includes 25 for cardiovascular disease prevention, seven for diabetes medication, 25 for common musculoskeletal conditions and 4 for prenatal testing.

The online format allows for the use of interactivity within decision aids. The use of these formats is increasing, despite limited evidence of their effectiveness. A systematic review evaluated this issue and assessed if computer-based decision aids were associated with high quality decision making (improved knowledge and reduced decisional conflict). (119) This review also looked at whether different features of these tools were more effective in achieving high quality decision making. This review of 25 RCTs found that computer-based decision aids were more effective than their comparators (usual care or alternative aid controls). Further, specific features of these tools were assessed for effectiveness and found that tailoring of

decision aids was negatively associated with patient knowledge. The methods of tailoring incorporated in the decision aids included in the review were "superficial" and did not provide risks in context of population risks. The authors suggested that the level of tailoring was not sufficient to be useful by the patients who used them.

A recent RCT of an interactive decision aid designed to increase shared decision making for colorectal cancer screening compared to a similar non-interactive decision aid found that patient decision-making outcomes were not improved in the group that used the interactive decision aid. (123) This group of investigators concluded that the resources required to develop and maintain the interactive component of the decision aid were not justified. A study of five interactive decision aids found that some patients changed their preferences for treatments and that patients became more risk averse or uncertain after use. However, this study did not have a comparison group. (124)

Overall, early evidence is mixed on the use of interactive web-based formats to communicate probability in decision aids. Use of interactivity in computer-based decision aids may improve some aspects of decision making. However, this limited evidence must be weighed against the evidence indicating that tailoring formats may reduce knowledge when compared to evidence-based static formats. (125, 126) Some limited research also assessed whether animation of icon arrays might improve understanding (verbatim and gist), particularly in people with lower numeracy and lower health literacy, but this was not the case. (127) There is very limited evidence about the effect of animated and interactive formats versus static and this component of decision aid design is an emerging field and area deserving future research. (128)

The cost of developing and maintaining interactive decision aids can be significant, and the value of such investments should be better understood. In terms of implementation, interactive online formats for decision aids may be easier to tailor to patient characteristics and quicker to update with emerging evidence. However, they may also be classified as a "medical device" requiring additional regulation and resources to maintain them under emerging guidelines. (129)

Discussion

The topics in this paper address several key issues that commonly arise in the process of applying best practices in the communication of probability information to specific design requirements of patient decision aids. Given that the aim of patient decision aids is to present balanced information about available options, the strategies discussed here all seek to minimise biases and maximise understanding of the benefits and harms. However, the efficacy of these strategies needs to be weighed against the complexity of the decision, the end-users and the clinical context of implementation. Despite the wider uptake of patient decision aids in practice and a greater level of sophistication in many new tools, there are also a number of key areas that require further research.

The science for how to communicate the effect size of a test or treatment (difference in probabilities) consistently calls for the use of absolute risk differences and the avoidance of relative risks and number needed to treat/harm formats. (5) This is relatively straightforward where outcomes are expressed as proportions, but there remains a paucity of evidence about how to communicate standardised mean differences which are often used when reporting continuous outcomes in systematic reviews (e.g., pain, function, blood pressure, etc.). (130)

Decision aid developers may also wish to personalise the risk estimates and effects of options within their tools, but this personalisation has uncertain and inconsistent effects on knowledge, risk perceptions, and informed choice. It is an issue that needs more research. However, despite this lack of evidence for personalising risk, there is a burgeoning availability of online personalised risk calculators for consumers to access. These have variable accuracy and need careful consideration when integrated into patient decision aids. If used, personalised risk estimates should be presented in formats that are consistent with this IPDAS update and guidance. Risk calculators should display their results using simple frequencies or percentages and perhaps visual formats such as icon arrays to convey their results and should be linked to actionable outcomes within decision aids as risk-relevant options. More research is needed to explore how people understand personalised risk information, how it should be communicated, and when, why and for whom personalised risk information is effective in supporting decision making. Finally, it remains an open question whether individuals actually require the added

precision of personalised risk information to make informed medical decisions. (131, 132) The need for more complex web-based formats for patient decision aids with personalised outcome estimates may best be reserved for particular clinical decisions and contexts, and this is an important area for future research.

Another consideration for decision aid developers is whether to include graphs and visual formats within their tool, and, if so, which formats are most effective at enhancing accuracy of risk understanding. In short, visual displays often have beneficial effects and they can help to support interpretation of numerical data. However, the effectiveness of different graph types and visual formats depends on communication goals, features of the task, and/or the magnitude of the probabilities. When considering whether to use visual displays, decision aid developers should also consider the levels of numeracy and graph literacy of prospective users. It is also important to remember that patient decision aids are, by definition, neutral in their presentation of options.

Regardless of context, however, visual displays that follow the general principles outlined in this paper should help patients to improve their risk understanding and avoid misinterpretations. Visual formats should be transparent and ideally show the part-to-whole relationship. Icon arrays or stacked bar charts allow 'foreground' as well as 'background' estimates to be represented visually. Visual formats should be pilot tested for understanding, and developers should take care to avoid using misleading images (such as graphs with misleading scales) or using different scales within the same patient decision aid. Testing should evaluate whether audience members miss key messages or draw unintended conclusions. (133) Finally, the field is still in dire need of a more systematic theoretical understanding of why, when, and for whom visual displays are effective. (30, 53) This could be achieved by building on recent efforts to develop a unifying framework for understanding decision making with visualizations. (134)

There is also an increasing body of research in numeracy, graph literacy, and related skills of the end-users of decision aids. Several issues are worthy of future research attention. First, there is a need to identify effective ways to communicate probabilities to individuals and support decision-making amongst who lack both basic numeracy and graph literacy skills. Second, research on effective methods to improve both numeracy and graph literacy skills would be of high value to

patient decision aids. Finally, more research is needed to examine the links between objective and subjective skills and how their interplay affects the emotional response, use and interpretation of probabilities in decision aids.

In conclusion, there is a well-established evidence-base confirming the importance of including numeric estimates of outcomes within patient decision aids. (1) When presented in a way that minimises bias, this component of decision aid design significantly improves patients' understanding and accuracy of risk perception. Some aspects of numeric presentation are clearly effective and important and should be considered wherever possible in the development of decision aids. Conversely, there are numeric and visual formats that should be avoided because they introduce bias. As this paper has outlined, there are also decision and context-specific issues that can guide the inclusion of additional features in patient decision aids, and many areas requiring further research.

Table 1: Key Recommendations for decision aid developers

Topic	Recommendations
Presenting the effect sizes of treatment and screening options	• Use either independent event rates (with simple frequencies or percentages) and/or an incremental increase/decrease (absolute) from baseline risk estimates • Try to minimise framing (loss and gain used equally, see visual formats below)
How and when visual formats should be used	• Visual formats for event rates (e.g. icon arrays, bar charts etc) generally improve understanding of numeric estimates and minimise bias from framing and denominator neglect • Ideally convey the 'part-to-whole' relationship by displaying background and foreground estimates (e.g. through icon arrays or stacked bar charts). This promotes transparency and supports understanding of absolute risk magnitudes. • Ensure that spatial features (e.g., heights of bars) convey the same meaning as conventional features (e.g., titles, axes labels, legends, numerical values on scales). This implies avoiding potentially misleading features such as inverted or truncated scales. • Where multiple estimates are conveyed, preferably use the same denominator • Label axes clearly and complement visual formats with information that describes what is seen. • No one visual format is optimal for every situation. Therefore, consider the task at hand and the magnitude of the probabilities when using and selecting visual formats
The role of graph literacy in decision aid development	• Consider that people vary in their ability to extract data and meaning from visual formats • To support understanding among the less graph literate, ensure

	that visual formats are simple and include clear explanations to convey the meaning of important information and bring attention to it. • If possible, conduct pilot testing of visual formats for understanding with the intended audience. However, avoid relying solely on reported preferences for different formats. • If feasible, measure graph literacy of prospective users, as patients who lack graph literacy could in some cases be better off with numbers.
How and when risks should be personalised	• Personalised risk calculators are highly variable in their accuracy and should be carefully evaluated before use in decision aids • When deciding whether to personalise risk estimates within decision aids, consider both the feasibility of use in practice and clinical context
When and how to use interactive web-based formats	• There is limited and mixed evidence on the use of interactive web-based formats for numeric information, and therefore we offer no clear recommendation on their use at this time.

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The authors have no conflicts to declare.

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