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# Information provision to facilitate vascular surgery shared decision making in the face of uncertainty

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## **Shared decision-making and the need for accurate outcome prediction**

Recent guidelines recommend that surgeons facilitate shared decision-making and highlight that implementing and improving shared decision-making are research needs.<sup>1-3</sup> Shared decision-making is a collaborative decision between a patient and clinician that aims to achieve customised healthcare aligned with the patient's values. This process is underpinned by information as to what is likely to happen after each intervention considered and exploration of the patient's values and goals.

Information would ideally comprise accurate individualised outcome predictions. Examples include predicting the risk of amputation after revascularisation, death after abdominal aortic aneurysm repair, or stroke after carotid endarterectomy. In its crudest form, predicting outcomes relies on clinicians combining their experiential knowledge with data from relevant evidence to the patient in front of them. Clinicians' accuracy in predicting outcomes after surgical intervention using their 'gestalt' (intuition) alone depends on the outcome being predicted and the intervention considered, but is often imprecise, and sometimes woefully poor.<sup>4</sup> This imprecision can be due to availability heuristic (events which provoke negative emotion in our memories are more readily recalled), self-serving bias, and confirmation bias.<sup>5,6</sup> Statistical prediction models, devoid of these biases, would therefore appear to be an attractive solution. However, prediction models also have their limitations; a model's quality is impacted by biases in its development, arising from poor study design, sample size, and quality and completeness of data.<sup>7</sup>

## **The ideal prediction model**

Defining an ideal prediction model is critical since implementing inaccurate models into clinical practice could lead to patient harm. Prediction models should be accessible, easy to use, and rely on information that's readily available. Metrics such as discrimination, calibration, and classification are used to evaluate models and quantify uncertainty. If our goal is to differentiate patients into low/medium/high risk groups, a model with excellent discrimination (a measure of the tool's ability to differentiate between cases of high and low probability of the outcome) will be acceptable even if it has poorer calibration (accuracy of the predicted probability of an outcome). Conversely, if our goal is to provide patients with an accurate estimation of the percentage probability of an outcome, good calibration is required.

Striving to continually improve prediction models has led to utilising recent advances in artificial intelligence. When compared to traditional statistical models, most artificial intelligence models performed better.<sup>8</sup> Models with impressive results include those predicting mortality or major adverse cardiovascular events after abdominal aortic aneurysm repair and carotid endarterectomy,<sup>9-12</sup> and major adverse limb events after lower limb revascularisation.<sup>13,14</sup> We look forward to their prospective evaluation in other populations.

## **Problems with current models**

Unfortunately, most published prediction models have not been thoroughly externally validated. Comparison as to how well a clinician can make the prediction using gestalt alone is seldom researched but absolutely relevant;<sup>4</sup> a model has limited value if clinicians perform better using

gestalt alone. Studies evaluating a model's implementation and impact are rare; if models are hard to implement into practice or have little impact on shared decision-making/clinical outcomes their utility is minimal.<sup>15</sup> Prediction models are too simplistic on their own because decisions are complex and models on their own do not account for the patient's values and goals. After exploring these with the patient, we should ideally predict the outcomes that are most important to them. Furthermore, we should share this information with a degree of precision which makes most sense to them (e.g. absolute percentage risk, or a categorisation of risk; low/medium/high).

### **The certainty of uncertainty**

There are no perfect predictions within medicine, owing to unavoidable uncertainty when applying population-based information to an individual patient. Uncertainty in shared decision-making takes several forms: probability, ambiguity, and complexity.<sup>16</sup> Uncertainty in probability is the result of having imperfect predictions. Ambiguity refers to when results for different tools provide different results. Complexity arises from having numerous relevant outcomes, the relative importance of each varying case-by-case.

Addressing the complexity individualised decision-making is taught in medical school. We know that during our consultations we should explore our patients' ideas, concerns, and expectations to determine their values and goals. Doing so increases patient satisfaction with consultations and increases the likelihood of achieving shared decision-making.<sup>17</sup>

Clinicians are intimately aware of uncertainty arising from probability and ambiguity, as William Osler noted: "medicine is a science of uncertainty and an art of probability". Surgeons have learnt how to deal with this and are partially removed from the potential outcomes of the treatment they offer. Our patients are not afforded these luxuries. Patients may not be aware of the innate uncertainty in medicine and sharing this knowledge insensitively can increase anxiety. Patient satisfaction is inversely correlated with clinician expression of uncertainty, especially so when clinical reasoning is not explained alongside this disclosure. Communicating uncertainty can challenge the doctor-patient relationship where 'doctor knows best' that some patients hold true, which can negatively impact patient-perceived competence, confidence, and trust.<sup>18</sup> A natural response to a patient experiencing emotional distress before an important decision is to reassure with statements of certainty. However, shared decision-making demands transparency and disclosure of uncertainty.

### **Ways of approaching uncertainty**

Research concerning prediction models has historically tended to hone in on a very limited number of outcomes – we could reduce the uncertainty arising from complexity by developing and evaluating models that consider other outcomes that are relevant to patients (ideally guided by the development of core outcome sets).

To help patients deal with uncertainty arising from predictions we must earn their trust and confidence. Sharing clinical reasoning alongside the explanation of uncertainty and exploring the patient's health-related values are methods by which the clinician can inspire confidence.<sup>19</sup> The aim is to make the disclosure of uncertainty a demonstration that the decision is patient-focussed and a shared one, rather than making the patient feel isolated in decision-making.<sup>19</sup> It is easy to overlook patients' concerns regarding uncertainty, but specifically acknowledging and empathising with these concerns will nurture trust.

Awareness of the framing effect (two logically equivalent statements, one portrayed positively and the other negatively) when communicating risk/benefit can help in communicating uncertainty.<sup>20</sup> Perceived risk and decisions in healthcare are influenced by this framing effect.<sup>21,22</sup> Framing risk information in a positive manner (e.g. a 1 in 6 chance of preventing a stroke with carotid endarterectomy, rather than a 5 in 6 chance of carotid endarterectomy being unnecessary) results in more patients opting for surgery.<sup>23</sup> Importantly, patients are not all equally susceptible to the framing effect, most likely because of varying health literacy and numeracy.<sup>24,25</sup> Other relevant factors are presentation format and complexity of the risk concept being discussed: 15.6% absolute risk reduction versus 1 stroke prevented for every 6 patients undergoing carotid endarterectomy for example. Methods of reducing the framing effect include assessing communication preferences and literacy so that the language and concepts can be tailored to the patient, avoiding verbal information in isolation, and utilise other formats to illustrate uncertainty such as visual representations.<sup>26–28</sup>

### **Improving shared decision-making**

Barriers to improving shared decision making include the limitations of outcome prediction and risk communication described above, a lack of emphasis on individual patient's values and goals on an individual and systemic/research level, a need for shared decision-making education (patients and clinicians), and systemic barriers to implementing measures such as pre-conceived impressions of shared decision-making amongst clinicians and resources.<sup>29</sup>

Firstly, we should aim place greater emphasis on evaluating and considering patients' views and values during consultations. Decision aids, if implemented prior to face-to-face consultations, can serve this purpose and may help overcome a commonly cited barrier to shared decision-making – 'time resource'.<sup>30–32</sup> The OVIDIUS study is a good example of how decision aids could impact shared decision-making in vascular surgery. Decision aids that could be accessed before consultations improved shared decision-making for patients with abdominal aortic aneurysms, intermittent claudication, or varicose veins and increased patients choosing non-surgical options.<sup>33</sup> The study showed that focused training improved shared decision-making, but this did result in longer consultation times. This study suggests that pre-consultation education and exploration of patients' goals by utilising a decision aid, longer consultation times, and shared decision-making training for surgeons could improve our ability to navigate uncertainty with patients and provide better shared decision-making. Clinician time is one of the most important resources needed to deliver some of these interventions.

However, further improvements are possible. Information should ideally be shared in different formats depending on patient preference or health literacy/numeracy, and evidence suggests that we are currently lacking in our exploration of patients' information sharing preferences.<sup>34</sup> The exploration of the individuals' values and goals are an essential pillar of shared decision-making. Identifying these early in the consultation should be prioritised, which will then allow certain elements of information deemed critical to the patient could be selectively expanded, and proven prediction models could be implemented within this information. An example of a comprehensive intervention that addresses these challenges is an online shared decision-making tool for older women diagnosed with breast cancer,<sup>35</sup> comprising a validated prediction model, a decision aid, and an information booklet which provides tailored shared decision-making. We should aspire to achieve this within vascular surgery.

To design and implement effective shared decision-making interventions, we need a coordinated collaborative effort. Recently, we undertook a mixed method study (PERCEIVE) aiming to evaluate the accuracy of clinicians, and outcome prediction models, in predicting outcomes following major lower limb amputation, and qualitatively evaluate shared decision-making for patients where major lower limb amputation was being considered.<sup>36,37</sup> We demonstrated that healthcare professionals' estimation of outcomes often outperformed relevant published prediction models, but for some outcomes our predictions come with considerable uncertainty, and a few select prediction models could have a role in complementing shared decision-making.<sup>38,39</sup> A workshop including patients and healthcare professionals identified the selective use of prediction models implemented within decision aids as a potential intervention that could improve shared decision-making. This was the groundwork needed to begin designing interventional studies.

This is a complex topic, and the evidence within vascular surgery is presently at an early stage. A greater appreciation for the sources of uncertainty and the impact on patients, especially in vascular surgery where there is a risk of profound consequences, will stand us in good stead for being better surgeons.

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