# Questioning context: a set of interdisciplinary questions for investigating contextual factors affecting health decision making

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# **Abstract**

**Objective** To combine insights from multiple disciplines into a set of questions that can be used to investigate contextual factors affecting health decision making.

**Background** Decision-making processes and outcomes may be shaped by a range of non-medical or 'contextual' factors particular to an individual including social, economic, political, geographical and institutional conditions. Research concerning contextual factors occurs across many disciplines and theoretical domains, but few conceptual tools have attempted to integrate and translate this wideranging research for health decision-making purposes.

**Methods** To formulate this tool we employed an iterative, collaborative process of scenario development and question generation. Five hypothetical health decision-making scenarios (preventative, screening, curative, supportive and palliative) were developed and used to generate a set of exploratory questions that aim to highlight potential contextual factors across a range of health decisions.

Findings We present an exploratory tool consisting of questions organized into four thematic domains - Bodies, Technologies, Place and Work (BTPW) – articulating wide-ranging contextual factors relevant to health decision making. The BTPW tool encompasses health-related scholarship and research from a range of disciplines pertinent to health decision making, and identifies concrete points of intersection between its four thematic domains. Examples of the practical application of the questions are also provided.

**Conclusions** These exploratory questions provide an interdisciplinary toolkit for identifying the complex contextual factors affecting decision making. The set of questions comprised by the BTPW tool may be applied wholly or partially in the context of clinical practice, policy development and health-related research.

# Introduction

People make health decisions daily: for example, whether or not to seek health-care services, whether or not to take prescribed medicines, what to eat and what not to eat. A person may have varied options from which to choose based on his or her external environment, personal preferences,<sup>2</sup> perceived availability of 'choice'<sup>3</sup> or access.4 Health decisions are often influenced by factors other than strictly biomedical criteria.5-7 Thus, decision-making processes and outcomes may be shaped by a range of nonmedical or 'contextual' factors particular to an individual<sup>8</sup> including social, economic, political, geographical and institutional conditions.

Contemporary Western health care has promoted patient-centred care models such as shared decision making. 9-14 Incorporating individual values into health decision making has received renewed focus, particularly in preference-sensitive decisions in which the optimal course of action may vary between individuals. 15-17 Ideally, when values are taken into account, principles such as personal autonomy and patient involvement may be incorporated meaningfully into health services and research.<sup>7,18,19</sup>

However, research suggests that patient participation in decision making remains limited.<sup>20</sup> This may be due to issues<sup>21–25</sup> including brevity of clinical encounters,26 inattention to cultural factors,<sup>27</sup> lack of agreement about existing and/or reasonable options,28 individuals' preferences that physicians make decisions about their health care<sup>29,30</sup> or institutional constraints.31,32 Contextual factors challenge health behaviour models that assume rational patterns of shared decision making.

The importance of non-medical factors to general health is well established.<sup>33</sup> In this paper, we explore interdisciplinary perspectives on nonmedical factors that can influence how and why people make different health decisions. Other studies describe dimensions of patient involvement and values in health-care practice and decision making, 33-39 or examine how variables such as an individual's estimation of the likelihood of an event can be subject to biases, 40 manipulated by framing effects<sup>3,41</sup> or misunderstood due to poor health literacy or numeracy.<sup>42</sup> These approaches have explored aspects of decision making that fall outside typical medical spheres; however, they may represent a narrow range of disciplinary perspectives. Less attention has been directed towards articulating the complex range of contextual factors that might influence how individuals make such different – or seemingly irrational – health decisions. More to the point, such factors are more likely to be considered when the intellectual resources of multiple disciplines and interdisciplinary discussion are readily mobilized for use in research, clinical practice and policy development.

Our interdisciplinary group sought to integrate theoretical and practical perspectives from a range of traditional and nontraditional domains of health research into a set of exploratory questions accessible to researchers and practitioners in many fields. Our ultimate goal was to produce a tool that will facilitate systematic consideration of factors that might influence particular health decisions. To guide our work, we adopted four conceptual themes – Bodies, Technologies, Place and Work (BTPW) - developed by the Health Care, Technologies and Place Strategic Training Program at the University of Toronto: 43,44 an established pedagogical framework for facilitating interdisciplinary perspectives on health research, practice and policy. As applied to this project, the Bodies theme aims to identify the impact of historical and contemporary discourses about the body in health decision-making practices; Technology investigates philosophical, physical and computational shifts in health introduced by new technologies; Place explores how decisions are shaped by physical and social contexts; Work investigates how contemporary shifts in the nature of health-care work affect health decision making.

In this paper, we introduce the four themes and describe how they were used to translate theoretical knowledge into a set of practical questions that can be applied to health decisionmaking scenarios. We also present the set of questions – which we refer to as the BTPW tool – as a resource for health professionals, researchers, and policy-makers who wish to consider the impact of contextual factors on health decision making. The BTPW tool is a comprehensive, theoretically diverse set of questions that directs attention to a broad range of issues which may be influential but not immediately apparent to single – or limited – disciplinary methodological approaches. Researchers and practitioners may use the questions as a complete set or - more likely - draw upon them selectively. The questions are exploratory,

serving to identify salient issues rather than to provide definitive solutions in the context of clinical practice, policy development and healthrelated research.

# **Methods**

This project was collaboratively conceived during the authors' participation in the Health Care, Technology, and Place Strategic Training Program at The University of Toronto, Canada. Project objectives were facilitated by biweekly meetings between September 2007 and April 2008, and via a wiki, an online collaborative editing tool. Authors represented a range of disciplinary backgrounds (public health sciences, social work, human factors engineering, nursing, English literature, computer science, geography, pharmaceutical sciences, architecture and bioethics) with prior research interests in health. Preliminary discussions identified appropriate topics for collaborative interdisciplinary investigation: the role of non-medical factors in individual decision making and translating interdisciplinary insights about such factors into a useful exploratory tool for health-related services and research.

We reviewed literature identified through personal libraries, expert recommendation and structured searches of MEDLINE with search term combinations: 'conceptual framework', 'framework', 'medical decisions', 'health decisions', 'decision making', 'context(ual)', 'nonmedical' and 'factors'. Two authors (A.C., H.W.) reviewed all literature for inclusion or exclusion. There was no disagreement requiring resolution. Health decision-making frameworks emphasizing non-medical factors were included (see Table S1, Supporting Information).

To ground our work in plausible, preferencesensitive decision-making scenarios, we used an iterative cycle of question and hypothetical scenario development (Fig. 1). First, we drafted a general list of contextual health decisionmaking factors not well represented in existing frameworks. We then developed five scenarios representing different types of preference-sensitive health decisions (preventative, screening,

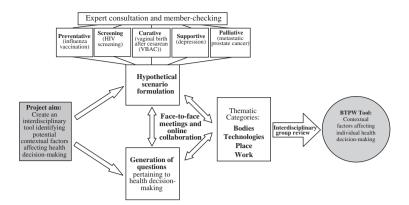


Figure 1 Illustration of Bodies, Technologies, Place and Work tool development using an iterative, multi-step process of question generation and hypothetical scenario development.

Table 1 Abbreviated descriptions of hypothetical scenarios

Type of decision	Individual	Decision
1. Preventative	Healthy 45-year-old teacher who also cares for ageing parents	Whether or not to receive a recommended influenza vaccination in workplace programme following exposure to media suggesting vaccinations are harmful
2. Screening	Aboriginal sex worker who was recently targeted and raped	Whether or not to seek out HIV screening at local crisis centre
3. Curative (single treatment)	Woman classified as obese who had her first child by caesarean and is pregnant again	Whether to plan a repeat caesarean, a vaginal birth after caesarean (VBAC) in hospital or a VBAC at home
4. Supportive care (ongoing treatment)	University student with family history of depression and negative views of treatment	Whether or not to seek treatment for depressive episodes
5. Palliative (end of life)	Man with end-stage prostate cancer and history of preferring traditional Chinese medicine (TCM) over allopathic care	Whether to follow personal preference for TCM or physician recommendation and caregiver son's preference for allopathic pain relief

curative treatment, supportive treatment and palliative care; see Table 1 for abbreviated versions and Supporting Information for full versions). Scenarios were reviewed with appropriate experts, including clinicians, researchers, patient groups and individuals, to ensure face validity. 45 Working with these hypothetical scenarios helped ensure that tool questions were practically informed by, and applicable to, multiple decision-making scenarios.

Each hypothetical scenario was used to generate a list of questions identifying potential contextual factors pertinent to health decision making; this list was developed within each BTPW theme to address health decisions conceived more broadly. Small working groups were assigned to focus on each theme and each hypothetical scenario (Fig. S1). Three authors (A.C., H.W. and S.W.) also ensured translation of ideas between all themes and scenarios. Throughout the development cycle, we conducted large group reviews to refine questions for applicability across scenarios, theme comprehensiveness, representativeness of diverse interdisciplinary perspectives, discreteness from other questions and clarity. Disagreements were resolved by consensus. We integrated brief prompts into most questions to illustrate applicability and clarify potentially unfamiliar language (see Table 2 for abbreviated version with prompts omitted; see Supporting Information for full list). Finally, questions were organized into subthemes or 'constructs' within each BTPW theme.

Table 2 The Bodies, Technologies, Place and Work set of exploratory questions (abbreviated version; see Supporting Information for full version)

#### **Bodies**

#### Autonomy

To what extent is the individual able to make this decision independently of others?

What are the facilitators and constraints to independent decision making?

How might the idea of intercorporeality (i.e. the relationships that exist between bodies) suggest or introduce perceived challenges to one's autonomy?

#### Concepts of self

How might a person's idea of 'self' be affirmed or challenged by the process and effects of this health decision? Who, besides the individual, might influence these concerns?

How might bodily 'enhancements'-surgical, assistive, technological, and so on- shape one's sense of self? To what effect?

#### Knowledge and information flow

How might an individual's embodied experience (of the past, present, and /or projected future) play a role in this

#### 'Natural' bodies

What factors pertaining to the body are valued as 'natural' or 'unnatural' in this decision? By whom? How might such definitions affect both the process and potential outcomes of this health decision?

What is the effect of conflicting perceptions of the natural in this decision? Is it possible to recognize and/or work with such differences within the context this health decision?

#### Risk attitudes

How is 'risk' defined or understood by each individual involved in this decision?

What are the barriers and facilitators to defining or understanding risk in this decision?

In what way(s) can an individual be thought to 'embody' risk? With regard to impact on decision making, what are the potential effects of perceiving an individual in terms of embodied risk?

How do various stakeholders' understanding of risk potentially affect an individual's self-perception? How might it affect the perception of that individual by others?

#### Scope of decision

How many 'bodies' are involved in this situation? (consider not only physical bodies, but bodies of knowledge (e.g. culturally-influenced models of medicine or health) or embodied social roles (e.g. father, breadwinner, community leader, etc.)

#### Social organization

Do differences in culturally-inflected perceptions of the body affect a person's understanding of his/her own body in this situation? How might such perceptions of the body influence decision making?

In what way(s) could culturally-inflected perceptions of the body create difficulty translating symptoms to others with a different understanding of body systems? Is it possible to recognize and for work with such differences within the context of this health decision?

#### Stigma

How might stigma (actual or perceived) influence a person's decision to seek treatment, especially in the case of marginalized populations?

Do perceptions of stigma and its effects differ between various stakeholders in this decision?

In what ways could the (perceived or actual) interaction with a stigmatized body influence the health decisions of others?

In what ways might the stigmatized body be perpetuated by medical interventions, approaches to health research, and/or the presentation of research evidence in this decision?

# Technologies

Availability and accessibility of options

What is the historical background of technologies relevant to this decision?

Are there unequal or competing paradigms of technological intervention in this decision?

To what extent does the popularity of an intervention determine the availability of options in this decision?

In what ways does the acceptability of each technology differ between stakeholders in this decision?

Ethics, legality, professional and social standards

How do the ethical and/or legal consequences of how and where technologies are used affect this decision?

#### Table 2 (Continued)

Knowledge and information flow

Who has access to what information in this decision-making process?

What is the role of information and communication technologies in the decision-making process?

How is information pertaining to this decision shared between individuals and groups?

How do each of the new technologies considered in this decision, if any, affect the landscape of contemporary information flow?

'Natural' bodies

In the context of this decision, does a technological or scientific intervention present a challenge to one's existing understanding of his/her body?

Risks, benefits and costs

Do the risks, benefits and costs of each technology apply equally to all individuals, groups and institutions in this decision?

What are the paradoxical and/or unintended effects of the technologies considered in this decision?

Scope of decision

What technologies are potentially involved in this decision?

What is the role of immaterial technologies in this decision? (e.g. cognitive behavioural therapy)

What non-human tools perform the work involved in this decision?

#### Place

#### Autonomy

In the places relevant to this decision, is there an expectation of choice? For whom?

How does place influence who is involved in the decision-making process?

What power relationships are characteristic of the places affecting this decision?

Availability and accessibility of options

How might material aspects of place affect the decision?

What are the facilitators and barriers to accessing particular options or awareness of those options?

How accessible (physically, economically, socially, culturally, etc.) are the places involved in this decision?

Ethics, legality, professional and social standards

How might the process or effects of an individual's health decision be influenced by the legal status of health-related practices, choices, illnesses, etc.?

Knowledge and information flow

What virtual places might affect this decision-making process?

How might language-use associated with place influence the decision-making process?

Organization of place and work

What physical places might affect this decision-making process?

How might geographical, physical, formal or aesthetic aspects of place affect the decision?

In the context of this health decision, is it possible to recognize and/or modify potential constraints associated with the quality of place?

Perspective of the individual

What is the role of beliefs or values in this decision? What are the effects of such roles, and who is affected by them? What emotions might be associated with the places affecting this decision? What attitudes toward emotion are associated with these places?

How are you placed in relation to these physical, social, and symbolic places? Do you believe that a particular decision is the best one? On what basis? How might your placement affect this decision?

# Risk attitudes

What are the potential effects of differing perceptions of risk between stakeholders in this decision?

What is the meaning and value of a 'safe' place in this situation? How does safety and place pertain to this decision? Risks, benefits and costs

How urgent is the decision? Is there space and time available for considering alternative options?

Scope of decision

Is the decision a singular event or does it occur across changing places and/or times?

Social organization

In the context of this decision, what values are characteristic of relevant place(s)? How might values associated with place encourage or constrain particular decisions?

#### Table 2 (Continued)

Stigma

How might the institutionalized perpetuation of stigma affect individuals directly and /or indirectly involved in this decision? Work

#### Autonomy

Who is able to take action to effect this decision?

In what ways might one's work complicate simple notions of autonomy in this decision?

In what way(s) might the work of caregiving compromise the autonomy, independence, and identity of the cared-for in this decision?

#### Burden, duty of care

How is the work distributed among individuals, groups, and/or institutions in this situation?

How might the decision be influenced by the distribution of work?

To what extent does the responsibility of caregiving work confer decision-making authority in this situation? Would everyone agree?

#### Ethics, legality, professional and social standards

Is the quality of the work involved in the decision formally assessed? By whose standards?

What kinds of qualifications or expertise are required to do the work involved in this decision?

Are there ethical constraints associated with the work involved in this decision? Are these ethical constraints at odds with other factors (work-related or otherwise) associated with this decision?

#### Knowledge and information flow

How might the contemporary flow of information affect the work, workers, and workplace involved in this decision? Meanings and values of work

What purposes or qualities of work are valorized in this situation?

What meaning(s) is /are typically ascribed to the work involved in this decision?

#### Organization of place and work

What coordination is required by each kind of work relevant to this situation? In what ways might issues pertaining to coordination influence the possible forms, processes, or outcomes of work in this decision?

#### Risks, benefits and costs

How are the benefits of the work involved in this decision identified, organized, and distributed? How might the definition of 'benefit' differ between different stakeholders in this decision?

How might one's capacity for livelihood-generating work be affected – negatively and/or positively – by this health decision?

# Scope of decision

What kinds of work are potentially involved in this decision? Consider not only the labour but work involved in the decision-making process itself (e.g. information gathering, financial planning, concealment)

# BTPW tool questions

We now describe the relevant background, definitions and sample applications of the BTPW interdisciplinary themes to health decision making. See Table 2 for an abbreviated catalogue of questions, organized by BTPW themes and subdivided by constructs of related topics (full version available in Supporting Information).

#### **Bodies**

The human body is a fundamental consideration in health decision making. Beyond clinical concerns, attention to the body raises questions of autonomy, self-conceptualization, risk attitudes and stigma. In the first theme of this set of questions, we present the relevance of humanities and social sciences to understanding embodied factors affecting health decision making.

The intrinsically social context of health has been emphasized in late 20th century critical theory, which tends to view the body as a simultaneously corporeal and knowledge-producing entity. In place of traditional Cartesian notions of the body as a bounded, biomechanical machine operating separately from other bodies, philosophical scholarship has argued that bodies are always socially located: '[r]ather than having a body, we are embodied' (46, p. 52). Rather than singular units, bodies are assemblages inseparably linked to and situated

amongst other bodies. 47-49 For instance, can we accurately describe a caregiver of aging parents as making an 'independent' decision against receiving an influenza vaccine? The caregiver's body is inseparable from those of the cared-for. when the cared-for's health outcomes may be adversely affected by the caregiver's 'personal choice' to not receive the vaccine. Multiple bodies in social networks thus challenge simple notions of autonomy and independence. By considering the body as permeable, vulnerable, and in-process<sup>50,51</sup> and emphasizing the role of affect and emotion in establishing the boundaries of bodies, 52-55 our set of questions brings these ways of understanding the body to questions of decision-making authority, competence, citizenry and values.

For example, the question 'How might the idea of intercorporeality (i.e. the relationships that exist between bodies) suggest or introduce perceived challenges to one's autonomy?' (Construct: Autonomy) highlights the implications of pregnancy and breastfeeding on the autonomies of mother and foetus (Scenario 3, Table 1; also see Appendix S1).<sup>56</sup> By illustrating such 'leaky' boundaries, 50 this set of exploratory questions invites researchers to consider how these relationships are conceptualized by researchers or their work. If these bodies are viewed as separate individuals, how might their respective health risks and benefits be in tension, or even in conflict? Conversely, viewing mother and foetus as an intrinsically connected dyad asserts the inseparability of their interests in the process and outcomes of health decision making.<sup>50</sup> This approach challenges notions of independent rational actors implicit in other theoretical frameworks such as the health belief model,<sup>57</sup> theory of reasoned action<sup>58</sup> and stages of change model.<sup>59</sup> Unlike our interdisciplinary approach, those theoretical frameworks do not examine the impact of oppression or emphasize factors such as ethnicity, education, employment, culture or gender.60,61

For example, the question 'In what ways might the stigmatized body be perpetuated by medical interventions, approaches to health research, and/or the presentation of research

evidence in this decision?' (Construct: Stigma) offers insight into the scenario of an Aboriginal sex worker who is choosing whether or not to be screened for HIV infection (Scenario 2, Table 1; also see Appendix S1). Her gender, occupation and ethnic identity intersect with structural inequities, historical and current experiences of discrimination, and stigma towards populations regarded 'at risk' of HIV infection. 61-63 While other discussions may refer to 'barriers' and 'facilitators' to HIV screening, assuming that screening is equally valued by all individuals is problematic. In this scenario, individuals from 'high-risk' groups might be further stigmatized by an HIV+ diagnosis, but those at 'high risk' who elect not to be screened may also be stigmatized for this choice. This assemblage of factors may influence powerfully whether or not this person decides to get screened for HIV.

By enriching how we understand decision makers (as singular, collective, rational, affective or a combination) and expanding traditional definitions of the body, we highlight less recognized factors affecting health decisions. Understanding why people appear to make 'bad', 'irrational' or arbitrary health decisions may be improved if decision-making models can distinguish the multiple bodies and paradigms within which people are living and making health-related choices.

# **Technologies**

Technologies entail questions of knowledge and information flow, availability and accessibility of options, and broad concepts of risks, benefits and costs. Tools, techniques and practices often shape not only the choices available but also the decision-making process itself.

Technologies are ubiquitous in health and medicine.<sup>44</sup> Body parts or functions can be supplemented or partially replaced by tools like prosthetic limbs, insulin pumps, kidney dialysis or skin grafts. Diagnostic, intervention and monitoring procedures play major roles in health delivery, and improved imaging technologies permit observation and interpretation of previously inaccessible body parts and processes.<sup>64,65</sup> Media, information and knowledge

technologies shape the flow and form of health data: electronic health records influence when and how individual information is recorded and used, wireless technologies deliver timely clinical evidence at the point of care<sup>66</sup> and medical information on the internet influences professional-patient interaction.<sup>67</sup>

Less obvious 'technologies' also influence health decision making. Ursula Franklin defines technology as 'not the sum of the artifacts, of the wheels and gears, of the rails and electronic transmitters. Technology is a system. It entails far more than its individual material components. Technology involves organization, procedures, symbols, new words, equations and, most of all, a mindset' (68 pp. 2 and 3). In health care, the Office of Technology Assessment defines technology broadly as 'the drugs, devices, and medical and surgical procedures used in medical care, and the organizational and supportive systems within which such care is provided'. 69 Using such definitions, meditation, prayer<sup>70,71</sup> and guided exercises such as counselling or cognitive behavioural therapy exemplify internalized, supportive techniques with the potential to help individuals suffering from mental illness or distress.<sup>72</sup> A broadened but critical understanding of technologies offers new possibilities for understanding often unrecognized contextual factors influencing health decision making.

Despite its promise, technology may not be in the hands of individuals who may require or benefit from it most.4 Barriers to health information or technologies are pervasive:<sup>73</sup> use or access may be obstructed by a variety of physical, cognitive, emotional, socio-cultural or situational factors. In health decisions, these factors are often highly individualized and contextual; in health policy decisions, some of these variables influence approaches within health technology assessment. 64,74,75 For example, the question 'What are the paradoxical and/or unintended effects of the technologies considered in this decision?' (Construct: Risks, Benefits and Costs), applied to the scenario of a university student deciding whether or not to seek treatment for depression (Scenario 4, Table 1; also

see Appendix S1), raises questions about the time required to participate in treatment and effects of medical interventions (e.g. medication) on academic performance. Understanding how the actual or perceived effects, availability, accessibility<sup>76</sup> and usability of technology<sup>77</sup> differ between stakeholders may elucidate their influence on individual decision making.

For example, the question 'In what ways does the acceptability of each technology differ between individuals, groups and institutions in this decision?' (Construct: Availability and Accessibility of Options) offers insight into the situation of a woman unsure whether or not to participate in a workplace influenza immunization programme following exposure to conflicting information in popular media (Scenario 1, Table 1; also see Appendix S1). Such information sources may lack acceptability for public health officials due to perceived low credibility, but remain popular among laypersons<sup>78</sup> who may judge credibility differently.<sup>79,80</sup> Exposure to accessible and influential media suggesting vaccinations are harmful can create uncertainty about the value and purpose of immunization programmes, and may comprise a powerful contextual factor affecting health decision making.

Technologies are not simply tools applied within health settings: they play an integral role in determining how we understand health, disease and decision making.81,82 By recasting technologies as medical interventions with powerful social and historical significance, we can recognize and systematically explore these phenomena as potential factors influencing health decision making.

#### Place

As health decisions occur in increasingly diverse contexts, decisions are shaped by the availability and accessibility of options, social organization and individual perspective or 'placement'. The third theme of this set of questions, Place, describes how decision making is influenced by the location(s) in which it occurs.

The relationship between place, health and medicine has long been a topic of enquiry. Hippocrates's *On Airs, Waters, and Places* (ca 400 BC) first recognized that the cause and distributions of disease could be explained by understanding the geography of places. <sup>83</sup> More recently, a range of academic disciplines (including health geography, architecture, anthropology, social work, sociology and health administration) have investigated ways in which place affects health practices, access and decision making.

The issues of place range widely in scale. A community's demographic profile regarding race, immigration status and income<sup>84</sup> may affect risk of illness and access to care. 4,25,85 At a much smaller scale, the physical design of a hospital ward affects decision making by facilitating patients' access to staff and information, providing privacy and creating spaces that encourage interprofessional team members to consult with one another.86,87 Architectural design shapes the experiences of providing or receiving care in a hospital as well as the meaning given to those experiences. 87-89 Rhetorical theories and discourse analysis encourage us to consider the placement, or points of view, of all agents affecting a decision-making scenario, as well as those of analysts studying the decision-making process.<sup>90</sup>

Thus 'place' is not confined to physical, material and geographical locations. Rather, place conveys an interrelated set of meanings. As much as place has been understood simply as material locations or coordinates in space, humanities and social science research has tended to regard place as additionally comprised of a phenomenological-existential reality, or a 'sense of place', 91,92 often understood in relation to practices of power and control. Power is enacted through patterns of social meaning, interaction and division, which often become naturalized and taken for granted by stakeholders located within and outside these situated or placed relationships. As centres of personal and social meaning, places encapsulate ideas about what is right, just and appropriate; in this sense, place is a moral landscape. 93 As healthrelated decisions, work and experiences become increasingly distributed away from clinical settings, place provides a site for negotiating between objective and material concerns on the one hand, and subjective or social concerns on the other. 94

Consider the question 'What is the meaning and value of a "safe" place in this situation? How does safety and place pertain to this decision?' (Construct: Risk Attitudes) in the case of a woman choosing between a repeat caesarean section, VBAC (vaginal birth after caesarean) in hospital, or VBAC at home (Scenario 3, Table 1; also see Appendix S1). Obstetrical care providers might judge the hospital as a 'safe' place because potentially life-saving interventions are close at hand in the case of uterine rupture. The woman, however, might perceive home as a safer place because of a previous negative hospital birth and postpartum experience.

Attending to questions of place allows us to recognize the impact of where health decisions occur, what decisions are available, how a decision places its stakeholders and how such placements are perceived. The symbolic, geographical, historical, economical, social, physical and formal connotations of place articulate a range of contextual factors that may influence individual preferences in health decision making.

# Work

Technological, social and political shifts in health provision have dramatically altered the nature of health-related work and its role in decision making.<sup>43</sup> The final theme highlights the multiple and complex dimensions of Work as a factor in individual health decision making.

Health professionals such as physicians and nurses continue to play a dominant role in conducting health work. However, contemporary health care is increasingly characterized by *inter*professional work that complicates traditional professional categories. 95–98 Part of the structural work done by health professions includes maintaining boundaries around professional domains and between professionals and patients. 98,99 Recent decades have shown a shift towards greater reliance and responsibility

on the part of the care recipient and/or unpaid caregiver; this shift, enabled by technology and financial restraints, recasts these boundaries as sites of competition. For example, the internet has enabled the production of 'expert patients' with unprecedented access to and literacy in health information. 100,101 In spite of potential advantages for health decision outcomes, patient expertise introduces new tensions in patientprofessional relationships 102 by equating patient experience with professional expertise. 19,103 Moreover, as the expert patient is increasingly assumed as a dynamic actor in health decision making, a considerable burden is added to an individual's 'work' associated with managing illness. 104

Conceiving of the human body as a site of health care renders the 'owner' of that body a full or part-time health worker:105 a concept taken up by recent reconceptualizations of informed patients as 'reflexive consumers' 106 or as an 'active' or 'informed' citizenry. 107,108 Diet, exercise, and other healthy lifestyle choices which lessen health resource burden – are often challenging, time-consuming, and expensive. Terms like adherence, regimen and 'doctor's orders' reinforce the work demanded of patients (and their families) diagnosed with acute, chronic and terminal illnesses, as well as that of lay individuals who are encouraged to diet, exercise and make healthy lifestyle choices. Moreover, the Western biomedical model of health can clash with religion, culture and other philosophical worldviews, challenging the extent to which the average person successfully meets the criteria of a 'good' health worker.

The questions 'To what extent does the responsibility of caregiving work confer decision-making authority in this situation? Would everyone agree? Is it possible to recognize and/or work with such differences within the context this health decision?' (Construct: Burden, Duty of Care) highlight divergent views in the case of a man with end-stage prostate cancer choosing between traditional Chinese and allopathic pain medication (Scenario 5, Table 1; also see Appendix S1). The father and son's respective opinions of appropriate treatment

demonstrate contested decision-making authority within a family caregiving relationship. The son's role as a caregiver means that he bears the burden of caring for his father; he may prefer to do 'everything possible' within the allopathic system and feel that the caregiving role confers decisional authority on this matter.

The relationships between Work and decision making occur at multiple conceptual levels: structural (i.e. governmental or policy decisions regarding health care, clinic openings/closures, pay allocation, scientific research); institutional (i.e. hospital structure, occupational hierarchies); and individual (i.e. decisions of worker, patient, primary caregiver). Awareness of how questions of Work factor into health decision making is critical, as such awareness can illuminate existing dynamics that serve to marginalize both health workers and their patients.

# **Discussion**

Health decision making is often a nonlinear, multi-factorial, iterative process. Although many disciplines and theoretical domains provide insight into this process, integrating interdisciplinary insights better reflects complexity of health decisions. 109-111

By translating conceptual understandings of BTPW into questions that can be asked of particular situations, the BTPW tool highlights a range of contextual factors relevant to decision making. Furthermore, these questions provide a systematic tool to help health professionals and researchers identify contextual factors that might be affecting particular decisions. Carefully considering contextual factors may improve the decision-making process by suggesting new choices or revealing hidden constraints that need to be addressed before optimal decision making is possible. Moreover, considering decisions within their broader contexts may enrich our conception of a 'good' decision: i.e., a choice that appears irrational from one perspective may simply take different factors into consideration.

Previous research has also articulated nonmedical factors in health decision making (Table S1). Our work aims to expand this range of contextual factors to include relevant concepts and theories from disciplines outside traditional health sciences. We present an extensive list of exploratory questions framed within the conceptual categories of BTPW that transcend professional, para-professional and lay boundaries. This model is versatile and applicable to a range of decision-making domains.

Given our large and diverse interdisciplinary group, our iterative development process and complexity of the topic, this set of questions is a generative and inclusive - but potentially unwieldy – tool. We chose to use our collective resources and training in interdisciplinary enquiry to yield as many insights as possible, rather than placing pragmatic limits on those insights. We recommend that potential users identify aspects of the tool most appropriate to their projected line of research or questioning. For example, a researcher could employ questions under the 'Stigma' construct to explore possible effects of stigma on the uptake of a preventative health programme; a practitioner might employ the Technologies theme to explore cases where professionals, patient and family hold different perspectives on the best choice of assistive device. Accordingly, the questions may be applied wholly or partially in the context of clinical practice, policy development and healthrelated research. The tool offers an early step towards creating a shared language with which to discuss the challenging interdisciplinary issues that emerge in health decision-making processes.

# Interrelationships between themes

Although each BTPW theme provides a distinct perspective, many questions are conceptually linked to multiple themes. Two constructs, 'Knowledge and Information Flow' and 'Scope of the Decision,' are conceptually linked across all four themes. This outcome is not surprising as knowledge, information and the complexities encompassed by decision making implicate considerations that may fall under any or all of these themes. 'Autonomy', 'Ethics, Legality, Professional and Social Standards' and 'Risks, Benefits and Costs' were also strongly linking

constructs, each shared by three of four BTPW themes. Rather than suggesting artificial boundaries between themes, this work asserts the conceptual and practical fluidity of these contextual factors and their potential sites of influence on decision making. Similar interrelationships have been described elsewhere: 'technologies are embedded in relations of other tools, practices, groups, professionals, and patients and it is through their location in these heterogeneous networks that treatment, or any other action, is possible in health care'. <sup>69</sup> p104

Within-theme constructs help to internally organize the exploratory questions encompassed by each BTPW theme. For example, within the Bodies theme, risk attitudes are linked to 'Risks, Benefits and Costs', 'Knowledge and Information Flow' and 'Concepts of Self'. Likewise, 'Natural' bodies are conceptually linked to subthemes of 'Autonomy', 'Social Organization' and 'Stigma'. Articulating sub-theme constructs demonstrates the applicability of these questions to a range of disciplines; health researchers and policy-makers may investigate constructs relevant to their particular interests or discipline within a structured set of questions that explicitly articulates the probable overlap between contextual factors affecting health decision making.

# Strengths and limitations

This study contributes to decision-making knowledge both in its content and interdisciplinary research approach. By beginning to organize the multifaceted array of personal, social and structural considerations affecting health decision making, we offer a strategy for systematically eliciting factors which have proved difficult to articulate in a strictly biomedical paradigm. This work may help to integrate a wider range of non-clinical factors into the decision-making literature.

Furthermore, developing and employing hypothetical scenarios permitted a constant translation of theoretical concepts to the individual case level. By developing scenarios and thematic questions in tandem, our iterative approach effectively stitches together common concerns and complementary knowledge of disparate academic disciplines. This approach is consistent with studies suggesting that multiple disciplinary thinking is more likely to achieve new insight for complex problems than disciplinary approaches that share similar epistemological assumptions. 112

In addition to further articulating non-medical factors in health decision making (Table S1), we offer a set of exploratory questions that build on previous work in several ways. As a tool for structuring or directing research, Engel's biopsychosocial model of health 113 has encouraged medical professionals to incorporate psychosocial factors into patient care. Our questions complement this by integrating and emphasizing domains not traditionally considered in psychosocial examinations (e.g. technology). This integration benefits from sociological investigations of how technologies shape healthcare practices. 114 Second, our questions provide a systematic means for researchers or health professionals to further question the context surrounding health decisions. Third, these questions complement the structural violence framework for understanding the impact of structural and social influences on health<sup>4</sup> and address sociocultural and equity issues highlighted as integral to anti-oppressive practice in social work. 115

There are several limitations associated with this approach. First, the questions are built on hypothetical scenarios with individuals who are aware of their options<sup>3</sup> and who wish to participate in health decision making at some level. This is not always, or even often, the case. 116 Second, although iterative tool development helped to generate a list of investigative questions deemed useful and interesting within the boundaries of this work, further research and application of this tool may be required to determine the utility of the questions among researchers and clinicians less familiar with this interdisciplinary approach and the literature referenced. If our set of exploratory questions helps illuminate under-examined issues in health decision making or generate hypotheses for researchers or clinicians unfamiliar with these

literatures or concepts, we will have achieved our goal of translating theoretical knowledge into an accessible set of exploratory questions. Further research will be required to validate the set of questions by applying them to other health decision-making scenarios, determining which questions are most useful, and possibly reducing the number of questions associated with this tool. We also acknowledge that this work was conducted in a predominantly Western context, and that other global placements may provoke different questions and concerns within these themes. Nevertheless, our exploratory questions permit health researchers, professionals and policy-makers to direct focus towards one theme or construct and elicit information about factors affecting individual preferences in a variety of health decision-making contexts.

# Conclusion

Unprecedented shifts in the demographics, technologies, settings, and structure of health and social care systems require health researchers and professionals to integrate the complexity of health decisions into decision-making models. Health research has only recently begun to attend to the pertinence of work in academic disciplines (including philosophy, sociology, literature, history and geography) that address emergent relationships between technologies, providers, recipients and places used for health care. The BTPW tool comprises an approach for exploring complex factors affecting decision making in the contexts of clinical practice, policy development and health-related research. By integrating scholarship from fields outside traditional medical decision-making fields, we present an innovative and accessible interdisciplinary toolkit capable of identifying contextual factors unaddressed by single or limited disciplinary approaches.

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### Conflict of interest

None.

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# Ethical approval

Not applicable.

# **Supporting Information**

Additional Supporting Information may be found in the online version of this article:

**Figure S1.** Small working group assignment to each Bodies, Technologies, Place, Work theme and hypothetical scenario as organized on project wiki.

**Table S1.** Previous work describing contextual factors relevant to health decisions or decision making.

**Table S2.** The Bodies, Technologies, Place and Work set of exploratory questions.

**Appendix S1.** Complete hypothetical scenarios developed in tandem with Bodies, Technologies, Place and Work tool questions.

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