



Role Preferences in Medical Decision Making: Relevance and Implications for Health Preference Research

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Abstract

Health preference research (HPR) is being increasingly conducted to better understand patient preferences for medical decisions. However, patients vary in their desire to play an active role in medical decisions. Until now, few studies have considered patients' preferred roles in decision making. In this opinion paper, we advocate for HPR researchers to assess and account for role preferences in their studies, to increase the relevance of their work for medical and shared decision making. We provide recommendations on how role preferences can be elicited and integrated with health preferences: (1) in formative research prior to a health preference study that aims to inform medical decisions or decision makers, (2a) in the development of health preference instruments, for instance by incorporating a role preference instrument and (2b) by clarifying the respondent's role in the decision prior to the preference elicitation task or by including role preferences as an attribute in the task itself, and (3) in statistical analysis by including random parameters or latent classes to raise awareness of heterogeneity in role preferences and how it relates to health preferences. Finally, we suggest redefining the decision process as a model that integrates the role and health preferences of the different parties that are involved. We believe that the field of HPR would benefit from learning more about the extent to which role preferences relate to health preferences, within the context of medical and shared decision making.

1 Introduction

When we perform health preference research (HPR), we often assume that a patient or consumer of a medical product or intervention is both willing to be involved in decision making and that their individual preferences are what drive their decisions. What if that's not true? What if preference researchers are missing a critical aspect of medical decision making, which would make their work more relevant to clinicians and patients? Consider situations where patients or consumers follow the advice of the healthcare provider willingly, even when their preference for treatment is different. Also consider situations where a proxy (i.e., a spouse, parent) is the one who actually drives the decision. In cases like these, our standard approach will still provide preference evidence, but not the evidence that matters for actual decision making.

Medical decision making (MDM) is defined as “the process in which a diagnosis or treatment plan is made based on the available information, often with the incorporation of known patient preferences” [1]. In MDM, there is a

movement towards shared decision making (SDM), which is defined as “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences” [2]. Understanding patient preferences is, thus, an integral component of MDM and SDM.

The relevance of patient preferences for MDM and SDM has led to an increased interest in HPR [3]. HPR is dedicated to “understanding the value of health and health-related goods and services” [4]. Thus, the aim of HPR studies is to inform providers and policy makers about the extent to which attributes of health-related goods, services, and health outcomes matter to patients. Preference information can be used to guide service design and delivery of health-related goods and services to improve uptake, adherence, satisfaction and, possibly, health outcomes [4, 5]. Many HPR studies also claim that their findings are relevant to SDM. Their reasoning may be that knowledge about patient preferences can be used to inform providers about patient preferences on the group level, different classes of patients with similar preferences, or even guide individual treatment decisions [6, 7].

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Key Points for Decision Makers

At present, HPR in the context of shared decision making rarely addresses the extent to which patients and other parties involved want to participate in decision making.

When role preferences are elicited in conjunction with health preferences, this can offer insight into the relevance of these health preferences to shared decision making, the extent to which health preferences are associated with role preferences and improve predictions of uptake based on health preferences.

Role preferences should be considered in formative research, inform the design of the preference instrument and the preference task, and be considered during statistical analysis, to better interpret the relevance of health preferences for medical and shared decision making.

However, research has shown that not all patients want to be actively involved in medical decisions [8, 9]. Role preferences are defined as “the degree of control an individual wants to assume when decisions are being made about medical treatment” [10]. In the most prominent models for SDM, patients’ decisional role preferences are discussed before, along with, or after patients’ health preferences, and individuals’ health preferences only influence the decision to the extent that their role preferences dictate [11–13]. To-date, role preferences have played a limited role in HPR in the context of SDM, which we feel is an oversight.

In this opinion paper, we first advocate for the routine consideration of role preferences of patients and others involved in decision making within HPR studies that focus on supporting SDM processes. Next, we provide three recommendations regarding the integration of role preferences into HPR and when this could be done. Finally, we argue that consideration of role preferences may also be relevant in HPR studies aimed to inform the design of services to improve uptake and adherence, providing treatment and care and focusing on patient-centric goal setting.

2 The Complex Landscape of Shared Decision Making

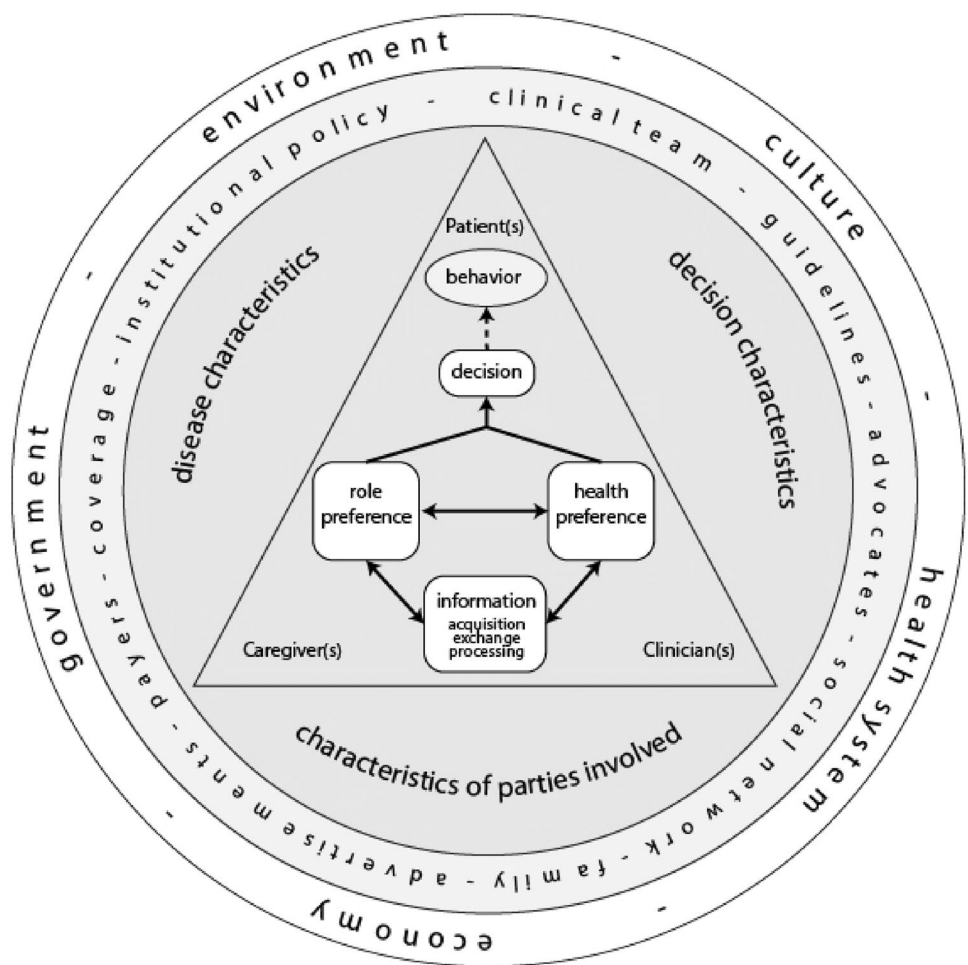
Shared decision making itself is a process that is extensively described in the literature [11–13]. Charles et al. categorize this process into three steps: information exchange, deliberation about options, and deciding on the option to implement [11]. Elwyn et al. revisit this model and emphasize

the importance of providing support to patients in understanding information, and eliciting patient goals to guide the decision-making process in the first step. They also discuss the need for strategies to compare and discuss trade-offs between favorable and unfavorable outcomes of interventions and emphasize that deliberation takes place based on informed preferences in the second step of the process [13]. Stiggelbout et al. split up the three step process into four steps, explicitly distinguishing the need to discuss the patient preferences for the options and the patient’s role in the decision [12]. The final stage of the decision is following up on the decision through actual behavior. We have depicted the shared decision-making process, with the interconnections between information, health preferences, and role preferences leading to decisions and subsequent behavior at the center of Fig. 1. Patient preferences for acquisition and exchange of information about available options, their preference for a specific option, and their desired level of participation in decision making can vary at different stages of the decision making process [14–17].

Most health preference studies focus on the perspective of the patient, which is the person affected by the disease or condition and for whom there is a need for intervention. However, many medical decisions involve multiple individuals beyond the patient themselves. The clinician’s role is obvious and often considered. Previous preference studies have captured the perspectives of clinicians, often to assess whether their preferences align with those of the patients [18]. In certain situations, decisions may involve the patient’s partner, such as in childbirth or live organ donation. Finally, there is also increasing evidence of the important role of caregivers in medical decisions [8, 19, 20]. The potential role of the different parties involved in the decision-making process being the patient(s), the clinician(s), and the caregiver(s), which includes partners and children, is depicted in Fig. 1 using a triangle. This triangular representation is derived from the TRIO framework [8].

In Fig. 1, we also acknowledge that the process of MDM does not occur in isolation. Both health and role preferences of the parties that are involved in the decision-making process may be directly influenced by other factors, actors, or influences, depicted in the different rings. The characteristics of the parties involved, for instance demographic characteristics such as age, gender, ethnicity, and educational level, socio-economic characteristics such as income and net worth, personality traits including dispositional optimism, attitudinal characteristics such as worry and trust in the healthcare system, appraisals such as perceived control and risk perception, and prior experience with similar or related decisions [21–23]. Disease characteristics include the type of disease or condition, its nature (acute versus chronic), perceived severity, and its course and prognosis, as well as patients’ perceptions

Fig. 1 Schematic overview of the medical decision-making process, with different actors and influence(s). Within the central triangle, the medical decision-making process is depicted as a process in which information is first acquired by, exchanged between, and processed by the different parties involved (usually patient(s) and/or caregiver(s) and/or clinician(s)). All parties involved have both role and health preferences, and the extent to which different parties want to be involved determines the extent to which their health preferences influence the decision. A decision is then followed by behavior. The middle ring indicates the direct influence of the characteristics of the parties involved, the decision that needs to be made, and the disease of the patient on the health and role preferences of the involved parties. The second and third rings indicate the indirect influence of the decision context and environmental context on the decision process



of the burden, controllability, and duration of the disease [24–27]. Decision characteristics include characteristics such as the number and type of alternatives available to the patient, the complexity, uncertainty, and reversibility of the decision and the time available to make the decision.

In the middle ring of Fig. 1 there are influences and influencers that can affect the information, valuations, and behaviors of the involved parties indirectly. For instance, clinical guidelines or payers might restrict access to alternatives [25, 28], and advocacy groups and media may have a strong influence on the information that is available [29]. To be exhaustive in Fig. 1, we also recognize the influence of government regulation, the health system, the economy, culture, and the impact of the natural environment on preferences for health and healthcare. However, assessing their influence on preferences is usually outside the scope of HPR.

The elements comprising the decision-making process within a health preference study typically include information about the available alternatives, the attributes that factor into the treatment or care decision, and the trade-offs between various attributes related to health, treatment,

or care (referred to as health preferences). The extent to which patients want to be involved in the decision is often not considered. We believe that incorporating patient role preferences into the preference instrument is essential for a range of health preference study types, but especially those examining individual preferences as part of shared decision making. Their inclusion can enhance the relevance of HPR to SDM for the following reasons:

1. Role preferences can vary among patients, diseases, and decisions. Recognizing this heterogeneity in role preferences informs the target audience of HPR studies about the relevance of the preferences for a particular decision. For example, patients with cancer may desire a greater involvement in decision making regarding treatment than those with other chronic conditions [30].
2. Role preferences may be interconnected with health preferences. Patients who want to have certain treatments, for instance palliative care instead of life-prolonging treatment, or more risky treatment with higher potential benefit, may require more active role preferences to get

their needs met. This is an area of study that has not been explored much and may be an area for future work.

3. Role preferences may determine the extent to which health preferences should be considered when estimating or predicting decisions, which can be part of the aim of some HPR studies. Predictions of treatment patterns may be improved if decision making style is also taken into account [31].

In addition to the role preference of the patient, we also believe that the interpersonal exchange of information between all parties that are involved in the decision (patient, clinician, and possibly caregiver) and their willingness to participate or relinquish control in the decision (role preferences) are important components of the medical decision-making process that can be considered in HPR. Moreover, the factors, actors, and influence(r)s depicted in Fig. 1, especially those in the inner and middle ring, may influence both health and role preferences and therefore should be of interest to health preference researchers. However, to maintain manageability in our work as health preference researchers, we recommend beginning by identifying the individuals involved in decision making early in the design phase of an HPR study and determining their desired roles in the health preference instrument. In the following sections, we will provide recommendations on how to approach this in practice.

3 Recommendation 1. Explore Role Preferences in Formative Research for HPR

The first, foundational stage of HPR is formative research [32]. Qualitative methods are often used because they are well-suited to the exploratory nature of formative research and this phase presents an opportunity to explore important context-specific questions related to both role and health preferences prior to the study.

To-date, most qualitative formative research in HPR has not directly addressed role preferences—instead it is implicitly assumed that the patient values the role as a sole or shared decision maker and has autonomous preferences for their health or healthcare. When role preferences are directly discussed in qualitative research, it is often with regards to the patient's preference for the clinician's role [33]. Some researchers indicate that their qualitative data collection instrument inquired about role preferences, but there is little description of role preferences reported in the results [34]. In other cases, authors discuss findings regarding role preferences, but do not indicate whether this information was actionable or contributed to the HPR study design [35–37].

The objectives of formative qualitative research in relation to role preferences in HPR would be to first explore for situations in which patients may be reluctant to accept an

active decision-making role, thereby diminishing the relevance of evidence they provide about health preferences. A second objective could be to look for situations in which there are other parties involved in the decision, who may have different roles and health preferences. If so, there may be a need to also elicit their preferences. Finally, formative research could also be used to explore which characteristics of the disease and/or the decision and of the parties involved, influence role and health preferences.

Addressing these questions during formative research may impact the research questions, the design of survey instruments, and/or the interpretation of preference evidence in HPR. Furthermore, as we learn more about which characteristics are related to specific role preferences, we can better target qualitative inquiry for a particular population or context.

4 Recommendation 2. Considering Role Preferences in Meaningful Ways in the Design of the Health Preference Instrument

If we consider measurement of role preferences in the design phase of the health preference instrument, it would be possible to study associations between role and health preferences. To do so, one or more of the options discussed in the following paragraph may be considered.

4.1 Recommendation 2a. Include a Measure to Assess One or More Role Preferences

To understand whether there is a relationship between role preferences and health preferences, we need to include a measure of respondents' preferences for their own roles in decision making in a health preference instrument. The objectives of eliciting role preferences along with health preferences would be (1) to identify the degree of heterogeneity in role preferences in the study population, (2) to aid in the interpretation of heterogeneity in health preferences, and (3) to determine weights to apply to the preferences of all parties involved for assisting the medical decision.

Choosing an appropriate measure of role preferences may be difficult. Jerofke-Owen and colleagues provided a systematic review of the instruments measuring patient preferences for involvement in health care decisions. They concluded that among the instruments they identified there were none that demonstrated adequate evidence for methodological and/or measurement quality [38].

We suggest that, given the paucity of evidence and the lack of validated instruments, HPR researchers could start by including as little as a single stand-alone question, designed for their specific study. Most examples in current literature

are adaptations of the control preference scale [10]. For instance, Peay and colleagues asked participants to rate their preferences regarding participating in treatment decisions with options ranging from “I prefer to make the decision about which treatment I will receive” to “I prefer to leave all decisions regarding treatment to my doctor” [10, 39]. Some studies also assess preferences for the role of others in the decision (such as family and caregivers), to understand the interactions within the patient–caregiver–clinician triad [40].

To advance studies into the relationship between role preferences and health preferences in MDM, we call for the development of validated and reliable instruments that elicit preferences of patients and other involved parties for their involvement in medical decisions, which is applicable in different stages of decision making and can be used across disease areas. Cunningham and colleagues included role preference and role perception attributes within their descriptive system of decision alternatives to identify the degree to which patients wanted to be involved in their health decisions and the nature of involvement [41]. Ideally, instruments would be sensitive to differences in role preferences between individuals, and changes in role preferences over time [42]. Inspiration for the domains of an instrument can be drawn from existing instruments that focus on access to medical information and treatment alternatives [43–50], communication with clinicians [46–48, 50], descriptive expectations [10, 45, 48–51], and normative expectations about the roles of patients and others in medical decision making [15, 43, 44, 51].

4.2 Recommendation 2b. Include Decision Making Role(s) in the Framing of the Preference Elicitation Task

In the design of a preference instrument, it is also important to consider whether and how the role in decision making is part of the framing of the preference task, and whether more description is required. In a typical health preference study, the preference elicitation task is introduced by explaining that the decision is sensitive to preferences for different attributes of the decision alternatives, and that a better understanding of the respondent’s preferences could help inform an actual decision. The relationship between preferences that are elicited from the respondent and the decision to be made is often implicit. Instead, we argue that the respondent’s role in the decision may be prescribed or aligned with their preferred role.

Prescribing a role to patients may be especially applicable in situations where there are clear prior expectations about the relationship between health preferences and decision making, for instance when the respondent is expected to take an active, consumer role in health care decisions. Examples include deciding whether to get a vaccination or a screening test, the use of direct-to-consumer products, and choosing

whether, when, or which health care service to access (e.g., selecting a clinical site or provider, making appointments, etc.). In other situations, where the patient’s roles depend on their role preferences, the role description in the framing of the task could be adapted to match what was elicited by the role preference instrument (i.e., role alignment).

Aligning the role described in the framing of the task with the respondent’s stated role preference will increase the face validity of the task to the respondent. It will also ensure that preferences are elicited within the role with which the respondent feels most comfortable, thus ensuring that the elicited health preferences are valid within that role. This is also true for situations where a role is prescribed, as long as it reflects the role that the respondent has, or can plausibly assume, in actual life. An example of an introduction to the preference task in which the role is explicitly described can be found in Text Box 1.

A third option may be to include a respondent’s preferred role in the decision as an attribute of the alternatives themselves, thereby using the study to understand trade-offs between role and health attributes. For example, patients may prefer a more active role if benefits are substantial and certain and the risks are low, and a more passive role if benefits are uncertain and risks are high. Alternatively, patients may be willing to wait longer for an appointment if that allows them to play a more active role in decision making. There are multiple examples of role–health tradeoffs in preference studies that include role as one or more attributes [52–56]. Some examples of role attributes and attribute levels that are drawn from these examples are presented in Text Box 2.

5 Recommendation 3. Integrate Role and Health Preference Evidence into Quantitative Analysis

When role preferences are measured (using an instrument such as the control preference scale [10]) and health preferences are elicited (using a health preference method such as a discrete choice experiment), there are three possible findings. First, role preferences do not vary significantly within the respondent sample and health preferences are simply reported for consideration. Further analysis can be performed to explore whether heterogeneity in health preferences, if present, is explained by characteristics of the individual. Second, role preferences vary, but health preferences do not, in which case the implications of heterogeneous role preferences may need to be addressed. Third, the respondents within a sample have both heterogeneous role and health preferences. If so, conventional analytical methods may not be adequate. Heterogeneity of role preferences

Text Box 1 Example of the introduction of a preference task

In these questions, you will answer questions about your preferences for treating disease X. When you answer these questions, please imagine that you are telling your clinician about which treatment you prefer. After understanding your treatment preferences, together you and the clinician would make a shared decision about what choice is best for you.”

Text Box 2 Examples of four level, three level, and two level adjectival statements that have been used as either attribute levels within a DCE to elicit trade-offs between role preferences and other attributes of the alternatives

Which process do you prefer?

- “the doctor chooses the treatment for you”,
- “the doctor chooses the treatment considering your opinion”,
- “you and the doctor make a joint decision”, or
- “you choose considering the doctor's opinion”

(example taken from Scott and colleagues, 1999).

Who chooses treatment?

- “doctor chooses”,
- “patient chooses”
- “both choose”

(example taken from Longo and colleagues, 2006).

What is your preferred decision process?

- “the doctors advise and help me decide what treatments I get”
- “the doctors advise me, and I would decide what treatments I get”

(example taken from Tobin and colleagues, 2021).

may be included as a covariate in an interaction analysis to understand whether a portion of the heterogeneity in health preferences can be explained by heterogeneity in role preferences or heterogeneity in the scale factor. For example, Peay and colleagues used the responses to the control preference scale as a covariate to explore individuals’ maximum acceptable risk of death in return for a non-curative gene therapy [39]. A more common approach for HPR researchers is to incorporate heterogeneous role preferences into their choice models either using random parameters or latent classes. The aim would be to study whether role preference subgroups systematically overlap with health preference subgroups. Two approaches are commonly applied to identify subgroups or segments with different preferences: (1) obtain parameters for individual subjects using hierarchical Bayesian analysis and segment on their random parameters and, perhaps, covariates, and (2) conduct latent class analysis, which assigns each subject a likelihood of belonging to a

class such that the members of each class share common parameters (i.e., within-class homogeneity) [57]. Both procedures have been used before to understand preference heterogeneity within HPR studies [58].

6 Understanding Role and Health Preferences Across Individuals, Diseases, and Different Types of Decisions

The aim of HPR in the context of SDM and MDM is to inform decision makers about the extent to which attributes of alternatives matter to patients and their relationship with their choices. When multiple parties are engaged in decision-making, conducting health preference studies that assess the health and role preferences of all individuals involved, such as the patient, a primary caregiver, and the clinician, can reveal heterogeneity in both role and health

preferences within and among these parties. To improve our understanding of whether and how these preferences influence actual decisions and behavior, innovative methods to integrate health and role preferences become essential.

One approach was demonstrated by Ozdemir and colleagues. In this study, patients and caregivers first complete preference elicitation tasks separately, and then together they repeat the tasks that had received different answers [59]. This approach could be used both on the group level, to understand the preferences of different parties that are involved separately and jointly, and on the individual level, to elicit preferences for and support individual medical decisions [6].

Integration methods from other disciplines may also be considered for this purpose. For instance, the analytic hierarchy process (AHP) addresses decisions based on subjects' preferences of multiple attributes [60]. In SDM, Dolan and colleagues did seminal work using the AHP in individual decision support [61, 62]. The Analytic Network Process (ANP) was developed to integrate dependence and feedback in multiple criteria multiple person decisions using network structures [63]. A combination of AHP and ANP may be helpful in identifying and quantifying the hierarchy of influence among parties (Fig. 2) even though actual integration of potentially heterogeneous role and health preferences among the different parties is beyond the scope of most HPR studies.

Finally, exploring role preferences and their relationship with health preferences may also be an avenue to a greater understanding of the influence of the characteristics of the parties involved in the decision, the specific diseases or disease area and that of different types of decisions on the way patients and other parties want to be involved in the decision and the extent to which attributes of treatment matter to patients, caregivers, and clinicians.

Beyond their relevance to medical decisions where there is the potential for shared decision making, we believe that accounting for role preferences and their heterogeneity may also be relevant in HPR studies that aim to inform the design of services to improve uptake and adherence and provide recommendations on treatment and care. For that aim, the definition of role preference may be slightly adjusted to “the degree of influence an individual wants to have when decisions are being made about service design, delivery, and/or care planning.” A patient could prefer an active role, but also could defer authority over clinical policy to a professional association. Another may prefer a less active role or to not defer authority. The questions central to the significance of role preferences in this context are similar to those in HPR to support SDM. Preferences for involvement in policy decisions within a sample of respondents may also impact aspects of the service design, delivery, and planning. If role and health preferences are present and heterogeneous, it

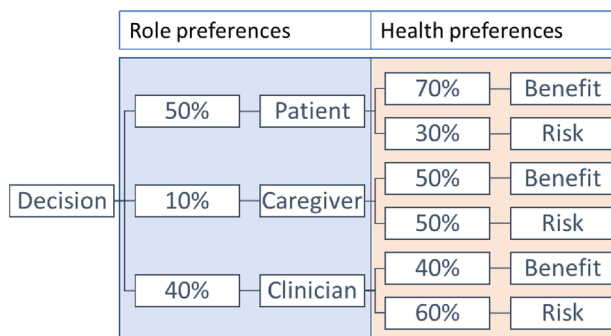


Fig. 2 Possible hierarchy of influence (role) of different parties that are involved and their heterogeneous health preferences

raises inquiries about the extent to which the modifications stemming from the outcomes of a health preference study affect uptake, adherence, and satisfaction on the group level.

7 Summary and Conclusions

By failing to consider role preferences and their heterogeneity in the design, execution, and analysis of HPR studies, HPR researchers are leaving out important opportunities to increase the impact of health preference evidence on medical decisions and decision makers. In this paper, we highlight the relevance of understanding health preferences in the context of the role preference of the patient for MDM and SDM and provide recommendations on how role preferences can be considered in the different stages of HPR, including design, elicitation, analysis, and interpretation.

We suggest that health preference researchers conducting preference studies with the goal of informing a medical decision consider role preferences in any formative research prior to conducting a health preference study and use the evidence collected in the formative stage to inform the design of their instrument and preference elicitation task and the analysis of their evidence.

We call for methodological work to: (1) develop generic instruments to measure role preferences within the context of HPR and demonstrate its validity and reliability, (2) understand the influence of different framings of roles in the preference elicitation tasks and its effect on trade-offs between health attributes of the alternatives, and (3) develop strong methodologies for the integration of health and role preferences across all parties that are involved. This work is essential in advancing HPR methods to truly be informative for SDM and MDM.

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Declarations

Conflict of interest Janine van Til, Alison Pearce, Semra Ozdemir, Holly Peay, Ilene Hollin, Albert Wu, Jan Ostermann, Ken Deal, and Benjamin Craig declare that they have no conflict of interest.

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