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ORIGINAL RESEARCH ARTICLE

How Important is Healthcare-Contact Time to Systemic Treatment Decision-Making in Advanced Gastrointestinal Cancers: Developing Attributes to Include in a Discrete Choice Experiment

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Abstract

Background People receiving treatment for advanced cancer invest substantial portions of their survival time receiving healthcare, labelled the 'time toxicity' of treatment. Although qualitative research has examined the impact of time burden on patients and their caregivers, its influence on treatment decision-making is unclear.

Objective Our objective was to explore treatment decision-making with patients with advanced gastrointestinal cancer, their caregivers, and oncologists, and unmask the role of time burden in those decisions. The objective was to inform the design of a subsequent discrete-choice experiment (DCE) investigating the importance of time burden in treatment decision-making.

Methods A two-step process was used. Factors relevant to treatment decision-making were discussed as part of semi-structured interviews. Responses were analysed using thematic analysis with a focus on measurable themes relevant to the development of candidate attributes for a DCE. Second, we reviewed stated-preferences studies in the field of treatment decision-making in cancer and compared the results with the candidate attributes identified from interviews.

Results Interviews with 45 participants (20 patients, 10 caregivers,15 gastrointestinal oncologists; 53% metropolitan) revealed 4 themes and 6 candidate attributes: expected survival benefit of treatment, impact of physical side effects, effect on day-to-day functioning, route of administration, healthcare contact days, and planned length of the treatment course. Review of 45 published studies yielded no additional attributes.

Conclusions This study identified six candidate attributes for a forthcoming DCE on time burden in advanced cancer care. These findings support growing efforts to quantify and address time toxicity in cancer treatment decision-making.

Key Points for Decision-Makers

Australian patients, caregivers, and oncologists with advanced gastrointestinal cancers reported prioritising treatment effectiveness and physical toxicities over other considerations.

Time and logistical factors were frequently mentioned in qualitative interviews but were rarely the main drivers of decision-making.

A forthcoming discrete-choice experiment in a general population of people with advanced cancer will quantify the relative importance of healthcare contact time among other attributes, estimate willingness to trade healthcare contact time for survival time, and examine how demographic factors influence choice behaviour.

Janette L. Vardy and Richard De Abreu Lourenco have senior authorship shared.

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1 Introduction

Cancer care demands substantial investment of time and organisational resources from patients and their caregivers. Acknowledging the potential downsides of time spent in contact with healthcare ('contact days'), the time commitments of care have been labelled the 'time toxicity' of treatment [1]. The impact of contact days is believed to be most significant for people living with advanced cancers, with estimates suggesting adults with advanced solid tumours spend between 10 and 33% of their survival time in contact with the healthcare system [2–9]. Where the median survival benefit of treatment is minimal, some treatments may result in fewer 'home days' than supportive care alone [1, 10]. Prior knowledge of this may influence treatment decisions for some people with advanced cancer.

Qualitative studies have identified that many patients with advanced cancer and their caregivers associate receiving cancer treatment with a sense of performing unpaid physical labour [11–13]. These stakeholders identify opportunity costs associated with time-intensive tasks directly related to receiving care, such as attending frequent ambulatory appointments or commuting to care, as well as activities that are indirectly related to care, such as recovering from side effects or coordinating treatment activities [11–13]. As treatment options for cancer grow and become more complex, clinicians and patients will face increasingly difficult decisions about the value of further time spent undergoing cancer therapy. A deeper understanding of what shapes patient preferences is crucial for all stakeholders in healthcare, including clinicians, pharmaceutical developers, regulatory authorities, and reimbursement agencies. This knowledge can guide practices, policies, and innovations to better align treatments with patient priorities and societal expectations.

Discrete-choice experiments (DCEs) are a form of survey-based stated-preference research that allow for the quantification of individual preferences. DCEs require participants to choose between two or more hypothetical scenarios defined by varying attributes. They are widely used in healthcare and policy decision-making to infer the relative importance and willingness to trade attributes for one another [14]. To our knowledge, no prior DCE has specifically explored the role of contact days in treatment decision-making in advanced cancer. Compared with early stage illness, where the aim of treatment is cure, contact days associated with treatment may be more important to people living with advanced disease, where the aim of treatment is to prolong life and survival time is often limited. This article reports on the development of attributes for a DCE that will quantify the importance of healthcare contact days in a general population of people living with advanced cancer.

2 Methods

In line with best practice guidelines, a two-step approach was used to develop the attributes for the DCE [15]. As the role of contact days in treatment decision-making has not been extensively studied in quantitative preferences research, we first conducted semi-structured interviews about the impact of contact time, including an exploration of treatment preferences. Interviews were conducted with patients with advanced gastrointestinal cancers, their caregivers, and oncologists to learn about the experiences of those stakeholders. Second, a review of published stated-preference studies in the field of medical decision-making related to cancer care was conducted. Attributes arising from the literature review were compared with the candidate attributes identified from the qualitative research.

2.1 Qualitative Study

Qualitative semi-structured interviews were conducted to explore stakeholders' perspectives on the time spent in activities relating to cancer treatment. The results of patient and caregiver interviews have been published in full elsewhere [12]. Treatment decision-making factors, including healthcare contact time, were explored in specific parts of the interview guides (electronic supplementary material [ESM]-1). The study was approved by the Sydney Local Health District (Concord Repatriation General Hospital) Human Research Ethics Committee (ETH/00869). The methods and analysis were reported in accordance with the guidelines for reporting qualitative research informing the design of quantitative preference-elicitation instruments (ESM 2) [15].

2.1.1 Researcher Characteristics and Reflexivity

Interviews were conducted by SS, a Caucasian male medical oncologist. SS was a professional colleague of oncologist participants volunteering to be interviewed. He was not directly involved in the care of patients interviewed. As a medical oncologist, he is professionally trained to conduct medical interviews and respond sensitively to patient and caregiver emotional states. Additional practical training on qualitative interviewing was provided by JS, an experienced psycho-oncology and qualitative researcher. This included mock interviews and indirect feedback on interview style using audio recordings of interviews. SS will be the lead researcher for the forthcoming DCE.

2.1.2 Study Participants and Recruitment

We recruited adults with advanced gastrointestinal cancer and their unpaid caregivers from one metropolitan and one regional cancer centre. Patient participants had to have received at least one cycle of palliative-intent systemic treatment to be eligible. Purposive sampling was used to recruit participants with a range of experiences of treatment, thereby increasing the generalisability for the forthcoming DCE. Potential patient and caregiver participants were approached by their treating clinician during routine appointments. Patients and caregivers could participate in dyads or as individuals; they were not interviewed together.

A convenience sample of gastrointestinal oncologists was recruited from participating sites, as above, as well as through email and social media advertising via the Australian Gastrointestinal Trials Group. Oncologists were included because of their central role in guiding treatment decision-making, shaping research priorities, and informing health policy.

2.1.3 Sample Size

Interviews were planned to continue until thematic saturation was achieved. A sample size of 15–20 patients, 15–20 caregivers, and 10 oncologists was initially estimated as sufficient to achieve thematic saturation considering the aims of the study, participant experience with treatment decision-making, the analysis method chosen, and sizes of similar studies [16, 17]. The initial sample size estimates assumed that thematic concerns would differ between groups. However, patient and caregiver interviews revealed similar thematic concerns, and saturation was confirmed after 20 patients and 10 caregivers were interviewed. In total, 15 oncologists were interviewed. All participants provided written informed consent using Research Electronic Data Capture (REDCap) eConsent [18, 19].

2.1.4 Data Collection

Before the interviews, participants self-reported demographic, treatment history (patients, caregivers), and professional background (oncologists) using a REDCap survey. Individual face-to-face or online semi-structured interviews were conducted between 5 October 2023 and 6 March 2025 using an interview guide developed by the research team in consultation with a patient advocate. Face-to-face interviews were conducted in a private clinical setting at the hospital; non-participants were not allowed in either interview format. Interview questions drew on the clinical experience of the research team, which included three medical oncologists, and existing literature on time and treatment burdens [20–22]. Questions were designed to be open ended to encourage rich discussion, exploring the sources, impact, and consequences of healthcare time. Specific questions exploring healthcare decision-making were incorporated within the interview guide to inform the development of the DCE. The interview guide was piloted with three participants in each group and amended iteratively (ESM 1). Interviews were digitally audio-recorded and transcribed verbatim using TRINT (www.trint.com), an AI-based online transcription tool, and corrected by researchers. Field notes were not used.

2.1.5 Data Analysis

Four members of the study team (SS, EE, IA, JS) independently reviewed the de-identified transcripts and developed an initial coding framework. The framework was independently applied to interviews (SS, EE) and coded using NVivo 14 software (QSR International; Melbourne, Australia). Disagreements were resolved through group discussion led by a senior researcher. Interview data were analysed using thematic analysis tied to a framework approach [23, 24] using an inductive, interpretivist approach based in grounded theory. Following coding, the study team reviewed the data, grouped codes and nodes, and identified broad themes.

Patient and caregiver interviews were analysed separately to oncologist interviews, given differing thematic concerns in the broad study. For the purposes of this study, data analyses focused on the extrinsic factors described by patients, caregivers, and oncologists as important in decision-making, as these are quantifiable and relevant to DCE attribute development.

2.2 Comparison with Attributes in Published Stated-Preference Studies

To ensure that all potentially relevant attributes were captured, we also reviewed studies that used stated-preference experiments (DCEs and conjoint analyses) in the fields of treatment preferences and medical decision-making regarding cancer treatments. The search terms were developed by the research team using the 'population, intervention, outcome' (PIO) framework, with a focus on adults with cancer receiving systemic treatments. The outcome of interest was treatment decision-making factors. To minimise the risk of omitting relevant studies, we initially adopted a broad search strategy, which included

all studies that focused on treatment decision-making for systemic therapies. Studies of curative-intent treatment were excluded during screening to focus on the population of interest. Specific search terms included are listed in ESM 3.

The initial search was conducted on 10 September 2024. All publication years were included. We searched SCOPUS, Medline (via EBSCO), and EMBASE (via Ovid). Results were imported into Covidence and screened for eligibility by one author (SS) with senior oversight from a senior author (RD). Studies were included if they used a stated-preference experiment to assess systemic treatment decision-making in advanced cancer and reported on the attributes and levels used. Study protocols were excluded.

These attributes were compared with candidate attributes arising from the qualitative research.

2.3 Approach to the Development of Attributes and Levels

Candidate attributes and levels for the subsequent DCE were derived through a structured, multi-step process informed by best practice in DCE methodology [25, 26]. Qualitative interviews were analysed using thematic analysis as outlined above, to capture the broad themes relating to participant treatment decision-making. Within each theme, prominent nodes were identified as potential attributes. A list of distinct nodes that could be operationalised as DCE attributes was populated by SS and RD in consultation with the group. These were then assessed alongside findings from the published literature on treatment preferences in advanced cancer to generate a preliminary list. Next, the research group refined this list to ensure both clinical relevance and feasibility, consolidating overlapping concepts into broader attributes where appropriate to generate a list of 6–10 attributes. Drawing on the group's clinical and DCE expertise, and informed by levels used in comparable preference studies, we then defined attribute levels to represent the plausible spectrum of patient experiences in advanced cancer. Finally, draft wording was iteratively reviewed within the group to maximise clarity and plausibility.

3 Results

3.1 Results of Qualitative Study

A total of 45 participants were recruited, including 20 patients with advanced gastrointestinal cancer, 10 caregivers, and 15 oncologists. Demographic characteristics are summarised in Tables 1 and 2.

3.1.1 Factors Influencing Treatment Preferences

Four broad themes emerged from interviews relating to treatment decision-making: treatment efficacy, impact of physical toxicities, treatment logistics, and shared decision-making. Each theme is described with illustrative quotes in Table 3, referenced with patient/caregiver/oncologist (P/C/O), participant number, and regional or metro (R/M) [e.g. P1-M for patient, participant one, metropolitan location].

3.1.1.1 Treatment Efficacy Perceived treatment efficacy was raised by almost all interview participants. Efficacy often framed discussions about treatment decision-making:

> "I guess you start at, what is the treatment with the best evidence for efficacy … That's the starting point, and then you're working back from that." (O25-M)

Codes were grouped into three nodes: impact on overall survival, tumour shrinkage, and improved quality of life. For patients and caregivers, the efficacy of treatment was typically described in relation to the added survival benefit of the treatment: "I wanted to know how much time would this, sort of, buy me" (P-37R). This view was shared by oncologists, with many describing improvements in survival as the gold standard metric for treatment efficacy: "Overall survival is number one" (O65-M).

However, oncologist participants occasionally mentioned other considerations relating to tumour shrinkage, such as "improved progression-free survival" (O21-R) or response rate, which was perceived as having an impact on quality of life: "sometimes response rate is quite important for good quality time" (O65-M). These concepts were rarely raised as a treatment decision-making factor in patient or caregiver interviews, although some participants mentioned the importance of the absence of tumour growth on regular scans: "the biggest thing I want to see at this stage with the scans I've had, (is) there's been no growth of it." (P-23R)

Oncologists frequently mentioned improvements to quality of life as drivers of treatment decision-making recommendations: "live longer or feel better … that'll be my two big things that drive a lot of my decision-making" (O-55M).

Some patients and caregivers equated treatment with an improvement in quality of life:

> "Basically, I just wanted to know that the treatment that she was going to get was … going to prolong her life, and hopefully do it in a way that she still got, you know, quality as well … And hopefully … shrink it enough to have a sort of as normal life as you can have, I guess." (C24-R)

Table 1 Patient and caregiver demographics in qualitative interviews

Characteristic	Group	Patients	Caregivers	Total
Gender	Male	12 (60)	3 (30)	15 (50)
	Female	8 (40)	7 (70)	15 (50)
	Non-binary	0 (0)	0 (0)	0 (0)
Age bracket, years	18–34	1 (5)	2 (20)	3 (10)
	35–54	3 (15)	2 (20)	5 (17)
	55–74	13 (65)	5 (50)	18 (60)
	≥75	3 (15)	1 (10)	4 (13)
Geographic location	Metropolitan	10 (50)	5 (50)	15 (50)
	Regional	10 (50)	5 (50)	15 (50)
Born in Australia	Yes	16 (80)	6 (60)	24 (80)
English spoken at home	Yes	18 (90)	8 (80)	26 (87)
Relationship status	Single	3 (15)	1 (10)	4 (13)
	Married/de facto	14 (70)	9 (90)	23 (77)
	Separated/divorced	3 (15)	0 (0)	3 (10)
	Widowed	1 (5)	0 (0)	1 (3)
Level of education	High school	10 (50)	5 (50)	15 (50)
	Diploma	7 (35)	2 (20)	9 (30)
	Bachelor's degree	1 (5)	2 (20)	3 (10)
	Master's degree	2 (10)	0 (0)	2 (7)
	Doctoral degree	0 (0)	1 (10)	1 (3)
Time since diagnosis, years	<1	4 (20)	3 (30)	7 (23)
	1–5	14 (70)	6 (60)	20 (67)
	>5	2 (10)	1 (10)	3 (10)
Primary site	Oesophagus	2 (10)	1 (10)	3 (10)
	Stomach	0 (0)	0 (0)	0 (0)
	Hepatobiliary or pancreatic	6 (30)	3 (30)	9 (30)
	Large intestine	11 (55)	6 (60)	17 (57)
	Other	1 (5)	0 (0)	1 (3)
Currently on treatment	Yes	19 (95)	9 (90)	28 (93)
Lines of treatment	One	6 (30)	3 (30)	9 (30)
	Two	6 (30)	4 (40)	10 (33)
	Three or more	8 (40)	3 (30)	11 (37)
Caring responsibilities	No	13 (65)	0 (0)	13 (43)
	Yes	7 (35)	10 (100)	17 (57)
Relationship to person	Child	0	2 (20)	2 (7)
	Parent	3 (15)	1 (10)	4 (13)
	Spouse/partner	3 (15)	7 (70)	10 (33)
	Other	1 (5)	0 (0)	1 (3)

Data are presented as *n* (%)

However, quality of life arose more frequently in relation to treatment side effects (Sect. 3.1.1.2).

3.1.1.2 Impact of Physical Toxicities All three groups frequently discussed the importance of physical toxicities from treatment to treatment decision-making. Codes were categorised into two nodes: (1) perceived impact on short-term well-being and (2) overall physical function. Short-term well-being concerns predominantly focused on acute physical toxicities: "what side effects am I going to have? Are they different? Because the first ones were pretty full on … am I going to get the neuropathy? Am I going to get the rash?" (P17-M).

Patients frequently raised lived experiences of treatment toxicities when discussing treatment decision-making priorities. In contrast, most oncologists used more generic terminology such as "side-effect profile" (O19-M), "safety" (O20-R), or "tolerability" (O25-M), though some discussed tailoring treatment recommendations to the patient's desired side effect profile: "their preference for side effects. So, some

Table 2 Oncologist demographics in qualitative interviews

Characteristic	Interview cohort
Gender	
Female	7 (47)
Male	8 (53)
Non-binary	0 (0)
Primary role	
Medical oncologist	15 (100)
Medical oncology trainee	0 (0)
Years of experience	
<5	4 (27)
5–10	5 (33)
11–20	5 (33)
>20	1 (7)
Tumour subspecialty[a]	
Breast	4 (27)
Central nervous system	3 (20)
Genitourinary	5 (33)
Gynaecological	4 (27)
General	5 (33)
Head and neck	4 (27)
Lower gastrointestinal	11 (73)
Lung	6 (40)
Melanoma/skin cancer	1 (7)
Sarcoma	2 (14)
Upper gastrointestinal	12 (80)
Other	3 (20)
Location of practice	
Metropolitan	9 (60)
Regional	5 (33)
Both	1 (7)
Sector of practice	
Public	8 (53)
Private	0
Both	7 (47)

Data are presented as *n* (%)

[a]All participants treated gastrointestinal malignancies; 10 reported in interviews that this was their dominant tumour subspecialty

people don't want hair loss, above all else. For other people, it's other things that they want to avoid. Maybe nausea, for example" (O58-M).

The second node relating to treatment toxicity concerned global physical functioning, frequently framed as 'quality of life': "top of the list … am I still going to be able to do stuff?" (P35-R). As highlighted in Sect. 3.1.1.1, patients and caregivers raised concerns regarding detriments to quality of life from treatment toxicities more often than potential benefits due to disease control.

> "These side effects tipping over into the other things that I do to keep myself well … You know, getting in the water and swimming at the beach … when stuff started to get in the way of that … that was time to pull up stumps …" (P44-M)

This view was also held by oncologists, who similarly reported that treatment discussions often touched on the impact of toxicities on everyday function: "from a quality-of-life perspective, people generally tend to talk about the restrictions in activities from the toxicities." (O20-R)

3.1.1.3 Treatment Logistics Treatment logistics were frequently raised as an important treatment decision-making factor. Codes related to three nodes: (1) frequency of healthcare contact, (2) route of drug administration, and (3) total duration of the treatment course. Although considered valuable overall, treatment logistics were usually discussed as secondary to effectiveness and physical toxicities in treatment decisions:

> "For me, the goal really is, you know, what's the best treatment that I can manage that's going to keep this thing sorted? Having said that, I mean, you have to come every three weeks for half an hour, is so much better than coming every two weeks for the whole day." (P44-M)

However, for some patients and caregivers, treatment logistics or the frequency of physical contact days was a very important factor: "How is it going to impact my work, and how am I going to organise that around the treatment requirements? That's seriously the main thing." (P46-M).

Mode of treatment administration and planned duration of the treatment course were also important to patient and caregiver participants: "the (5-fluorouracil infuser) bottle is something we've got to watch because my son is so young … We will have to be extra cautious with mum when she's got that bottle" (C7-M) and "I asked her how long do I have to carry on like this" (P11-M).

Oncologists described the importance of logistical factors as being context dependent. For example, regional oncologists often described offering non-standard treatment options to accommodate the challenges of geographic isolation: "we have made odd treatment decisions, based on remoteness and what we can deliver in these remote video-assisted chemotherapy spots. But the flip side to that is that people would elect not to get treatment at all" (O21-R).

Frailty, older age, social isolation, medical comorbidities, and poor prognosis were also described as influencing the importance of logistic considerations.

Table 3 Verbatim quotes regarding treatment decision-making derived from interviews

Theme	Quote	Contributed to Attribute*
Treatment Efficacy	"I guess you've got a choice: do nothing or try something. Let's try something to see if it…. Extends my lifetime here and gives me more time with the people I care about." (P5-M) "Really, what my chances of survival (are) because I have a family." (P14-M) "I'd wanna know how effective the treatment was number one." (P35-R) "How much time would this, you know, sort of buy me" (P37-R) "How much time does it buy?... How much time does it extend?" (C13-M) "Getting a five-year efficacy" (C16-M) "Basically, we just wanted to know that the treatment was going to get was…. obviously, its' going to…. Prolong her life." (C24-R) "If they can do stuff to keep him a lot longer, this is what we're going to do." (C30-R) "I would talk about the treatments with the best evidence in terms of efficacy outcomes, understanding that best or better is different to each patient." (O18-M) "Finding evidence-based treatment that we think will work to, ideally prolong their survival and having treatment that's either logistically feasible for them and has a side effect profile that would be tolerable for them." (O20-R) "I think overall survival is number one…. but in advanced GI settings, sometimes response rate is important for good quality time." (O65-M)	Median Survival Benefit from Treatment
Physical Toxicities	"If it wasn't doing me any good… Like, just to suffer and be sick all the time. You know, I would probably, you know.... Stop." (P1-M) "I was scared of all the aftereffects and the side effects of this treatment." (P11-M) "I think that we changed the drugs the second time. So, side effects were in my mind what side effect am I going to have? Are they different? Because the first ones were pretty full on as well." (P17-M) "Knowing that it's terminal, I've just got to assess quality of life going forward…. if I get to the stage where I'm stuck in a in a hospital bed or, you know, stuck in the lounge chair and not doing anything, but just the health deteriorating…." (P43-R) "These side effects tipping over into the other things that I do to keep myself well…. So, when stuff started to get in the way of that, that was, that was time to pull up stumps on those things for me." (P44-M) "Possible side effects that might be more long lasting." (C16-M) "we're not going to make it that he's going to be a nothing like a vegetable type thing. So, we want quality of life, not quantity." (C30-R) "the sickness that he's going to go through worrying about that, because you hear of cancer treatment and people are so ill…." (C38-R) "So often it's, um, more intense treatments that come with more side effects, um, that cause more health care contact time because, um, they end up getting side effects that then they need to call nurses or call me for advice about will end up coming into hospital." (O18-M) "But below (efficacy) will be factors, which is about the side effect profile. So, what is our expected toxicity." (O19-M) "Side effect profile is very important." (O63-M)	Toxicity Effect on day-to-day functioning
Treatment Logistics	"When I had the radiation, it was every second day and it was like: 'driving here, driving home.' And like, I don't really want to go through that." (P4-M) "I'd almost rather have the (5-Fluorouracil) bottle. The tablets were terrible, and they went for such a long time… I had two weeks of tablets, I think, every day. They're like horse tablets, they're massive; there's 7 or 8 of them a day; they taste disgusting." (P10-M) "There was there was like not knowing how much longer it was going to take…. doing six months of chemo is long and then having six months off just kind of coming back for scans, getting that.... That call back for more chemo, was it... It just made everything unsure of how much long is it going to take? How much longer am I going to have to do chemo for? One cycle or ten years?!" (P17-M) "Thing that goes through my head is how is it going to impact my work, and how am I going to organise that around the treatment requirements? That's seriously the main thing." (P46-R) "It's your life… If you sacrifice a couple of years and hopefully keep living, so be it." (P35-R) "The routine is a big one because the routine can change, you know, the family dynamics as well... we have to work out in amongst work schedules. You know how Mum's getting there. Who's going with Mum? You know, things like that. So, yeah, I guess routine is a big one." (C7-M) "that's probably a rule that's generally applicable to most of the practice here, which is that often if they live at a distance, we would favour, regimen like CAPOX, which involves them coming in once every three weeks and able to accommodate an oral treatment or an intravenous treatment, and avoiding the need to actually stay locally for 48 hours to then get the infuser unhooked." (O27-R) "So then obviously, during that discussion, I actually asked …. whether they would arrive at having, for example, oral chemotherapy or, infusional chemotherapy." (O28-R) "There is a clear time difference which is involved with the, um, XELOX, complete with, uh, FOLFOX…. So definitely I would consider that." (O19-M)	Route of Administration Healthcare Contact Days Total Length of Treatment Course

Table 3 (continued)

Theme	Quote	Contributed to Attribute*
Shared Decision-Making: Stakeholder Views	"Well, to be honest, it was.... We're just going to do what we're going to do. Like if (they) told me I have to eat 6 red beans a day, well, that's what I'd be doing." (P23-R) "Basically, we were directed by the medical team" (C16-M) "Me and (patient) talked about it and between us we decided to do whatever they sort of suggested." (C30-R) "He gave us the driving seat. So, he laid out all these options. But it was the patient's choice." (C45-M) "My general treatment philosophy is to understand what factors matter how much to a particular patient and apply that metric to what I think will happen to the patient based on their comorbidities, stage and so forth, and then come up with something that fits their metrics the best." (O56-M) "Their preference for side effects. So, some people don't want hair loss above all else. For other people, it's other things that they want to avoid. Maybe nausea, for example. I don't know. People have different preferences about what kind of side effects they would prefer to have." (O58-M)	N/A

*Unlabelled attribute names listed.

3.1.1.4 Shared Decision-Making: Stakeholder Views Despite this hierarchy of decision-making, there was an acknowledgement that treatment decision-making was shared. Patient and caregiver participants frequently mentioned that their oncologist's recommendation was an important factor in their decisions: "You see, you're a patient. There is no point being a patient if you're not going to follow doctor's advice" (P11-M).

Caregivers prioritised the needs of the person they cared for: "it's always been his decision because he's the one doing the fight" (C12-M). Further, oncologists frequently mentioned patient preferences as a driving factor of their final recommendations for treatment: "at the end of the day, it is the patient who makes that decision about, whether or not they want to take on that treatment" (O18-M).

3.2 Development of Candidate Attributes

Based on the themes related to treatment decision-making from the interviews, a list of candidate attributes was developed for use in a subsequent DCE (Table 4). This DCE will assess the importance of information about healthcare contact time in treatment decision-making for advanced cancer. These attributes were then discussed and refined by the team according to whether they could be quantified for the purpose of DCE choice tasks as follows: (1) from theme one (treatment efficacy), the median survival benefit of treatment attribute was derived; (2) from theme two (physical toxicities), two attributes were derived: toxicity, and effect on day-to-day function; (3) theme three (treatment logistics) resulted in three attributes: route of administration, healthcare contact days, and total length of treatment course. No attributes arose from the final theme (shared decision-making), as it was believed that this was not treatment related and could dominate preferences. Several additional considerations were identified during interviews as relevant to treatment decision-making, including expediency of treatment commencement, the degree of personalisation or novelty of treatment, out-of-pocket financial costs, and potential effects on fertility. However, they did not emerge as standalone themes. These factors were nonetheless considered in attribute development. These factors are discussed further in Sect. 3.3.

3.3 Results of Literature Review

A total of 44 studies were included in the literature review (Figure 1; ESM 3; studies with a healthcare time domain are further summarised in ESM 4). In total, 40 (89%) were conducted in high-income countries, and 4 (11%) were conducted in upper middle-income countries (China and Brazil). No studies focused on the specific role of healthcare contact days in treatment decision-making. Of the candidate attributes derived from the qualitative study, treatment toxicity and treatment effectiveness were attributes in 43 papers retrieved (98%). Toxicity was commonly described in terms of specific side effects (e.g., neuropathy), with many studies including multiple different side effects to evaluate their relative importance. Effectiveness was conceptualised in terms of survival benefit or surrogate measures (e.g., progression-free survival, response rate). Often, several measures of efficacy were included within the same DCE (e.g., overall survival and progression-free survival). In studies containing more than one measure of efficacy (n=5), overall survival was consistently identified as more important than putative surrogates in decision-making. Overall quality of life or impact on physical functioning was an attribute in 14

studies (32%). This was commonly described as impact on functioning. Studies frequently contained attributes describing treatment logistics, including route or mode of administration (26 studies [59%]); this was often combined with treatment scheduling information (18 studies [41%]). However, only two of these studies contained attributes that could be considered a standalone measure of contact days healthcare contact time (5%). Total length of treatment course was an attribute in five studies (11%). Other attributes related to logistical considerations that were mentioned in interviews included out-of-pocket financial expenses of treatment (14 studies [32%]) and expediency of treatment or review (four studies [9%]). Attributes that were not mentioned explicitly in interviews but identified in the literature review included treatment 'convenience' (five studies [11%]) and distance to the treatment centre (two studies [5%]).

3.4 Refinement of Candidate Attributes

A set of candidate attributes and levels was developed for the proposed DCE and is presented in Table 5. The list includes six attributes derived from the qualitative research and were frequently included in other studies identified in the literature review. Given the themes emerging from the qualitative research, and as supported by the literature, we chose to include attributes describing added survival time, physical toxicities, effect on quality of life, mode of administration, healthcare contact days, and total length of treatment course.

Based on the results of the qualitative interviews, we regarded baseline survival time (expected illness trajectory) as being relevant to choices about treatment. However, we considered it as being independent of treatment choice so will include separate scenarios for baseline survival as vignettes in the DCE. Accordingly, vignettes for 3 months and 12 months of baseline survival without treatment will be included to reflect decisions for 'poor' and 'good' prognosis advanced cancers, respectively.

The levels of each attribute were developed based on plausible ranges, considering relevant literature and the experiences of clinicians in the research group. For the added survival time attribute, we considered the available research on the median added benefits of palliative cancer therapies in high-income nations, which suggests a median survival improvement of 2–3 months [27–30]. Toxicities were described in generic terms reflecting severity and duration. The function attribute reflected the commonly used Eastern Cooperative Oncology Group performance score [31]. Levels for attributes reflecting logistics (administration, healthcare contact time, and total length of treatment course) were designed to reflect clinical practice, with consideration given to the applicability of levels used in other stated-preferences literature as summarised in ESM 3. Given that the subsequent DCE aims to quantify whether healthcare contact time independently drives treatment choice, treatment logistics were separated into distinct attributes to test their individual effects on treatment decision-making,

Several factors influencing treatment decision-making were identified during interviews but were not included as discrete attributes in the DCE. These included the expediency of treatment initiation, the degree of personalisation or novelty of treatment, out-of-pocket costs, and fertility preservation. The primary rationale for their exclusion was to preserve statistical power by limiting the number of attributes. In addition, the attributes selected were those the research team judged to be most reflective of the concerns commonly expressed by the intended DCE population. For example, many cancer histologies lack personalised treatment options, and 'personalisation' or 'novelty' may overlap with other attributes or be difficult to operationalise. Expediency of treatment initiation, although raised in interviews, is often driven by external system capacity factors rather than intrinsic properties of the treatment itself. Fertility preservation may be highly influential for some individuals of childbearing age but is emotionally sensitive and may cause distress among a broader population living with advanced cancer. Finally, although out-of-pocket costs were noted in the literature, this attribute was infrequently raised by participants in our qualitative study. Moreover, as we did not intend a priori to estimate marginal willingness to pay, we did not include a cost attribute.

4 Discussion

This study presents work informing the design of a DCE aimed at understanding how information about healthcare contact time influences treatment decision-making in a general population of people with advanced cancer. In qualitative analysis, interviewed patients, caregivers, and oncologists reported that treatment efficacy and toxicity were the main drivers of their treatment selection. In this study, participants reported that treatment logistics, such as contact days, mode of administration, and length of the treatment course were 'modifiers' of treatment choices. A literature review revealed the most frequently occurring attributes to be treatment tolerability, efficacy, logistics, and out-of-pocket costs. Refinement of candidate attributes led to the development of six attributes to inform the design of the DCE, which will allow quantification of relative attribute importance, preference behaviours, and marginal willingness to trade with respect to time when making decisions about treatment in the advanced cancer setting.

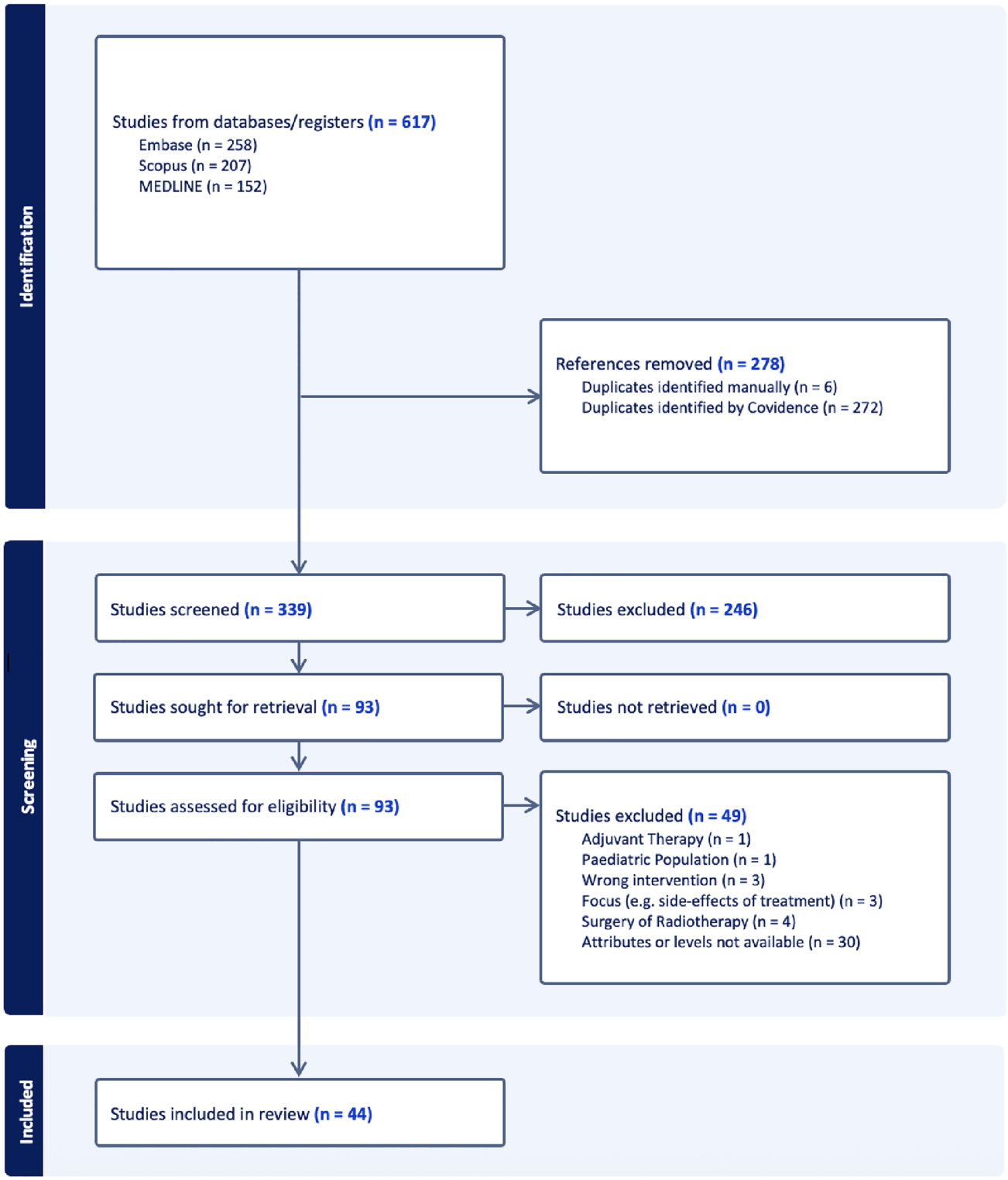

Fig. 1 Preferred reporting items for systematic reviews and meta-analyses (PRISMA) diagram from literature review

Table 4 List of candidate attributes derived from qualitative interviews compared with attributes identified in literature review

Attributes derived from qualitative interviews	Results of literature review		
	Studies reporting attribute (n)	Frequency of attribute inclusion	References
Treatment toxicity	43	103	[35–52, 54, 55, 57–79]
Effectiveness of treatment	43	68	[35–45, 47–52, 54, 55, 57–80]
Route/mode of administration	26	24	[35–37, 39–48, 50, 52, 54, 58, 60, 63, 67, 70, 71, 77–79, 81]
Healthcare contact time, including frequency of administration	18	21	[35–52]
Overall quality of life (physical functioning)	14	16	[35, 47, 49, 50, 52, 55, 62–64, 68, 69, 73, 75, 78]
Out-of-pocket financial costs	14	12	[36, 41, 46, 57, 58, 63, 64, 66, 67, 69, 70, 73, 76, 79]
Total length of treatment course	5	5	[40, 43, 45, 49, 70]
Expediency of treatment/review	4	2	[45, 66, 72, 82]
Personalisation/novelty of treatment/mode of action	3	4	[61, 66, 69]
Patient preference	1	1	[65]
Effect on fertility	1	1	[69]
Oncologist recommendation	Not observed	Not observed	
	Additional attributes derived from literature reviews		
Other logistics, excluding administration or time/frequency domains (e.g., distance to treatment centre)	8	9	[45, 48, 57, 62, 65, 69, 80, 82]

Table 5 Candidate attributes and levels

Attribute	Label (seen by respondent)	Attribute levels
Survival benefit	Additional survival time with this treatment	(a) 1 month (b) 4 months (c) 8 months (d) 12 months
Toxicity	Physical side effects of the treatment	(a) Mild side effects that persist for a few days after treatment (b) Mild side effects that are present every day (c) Moderate side effects that persist for up to 1 week after treatment (d) Severe side effects that persist for more than 1 week after treatment
Function	How the treatment affects your day-to-day life and ability to work/study	(a) Fully active, able to carry out all usual activities, including remain at work (b) Mildly weak and tired, restricted with strenuous activity but able to do light housework or office work and all self-care activities (c) Quite weak and tired, unable to work and resting for up to half of the day due to fatigue, but able to dress and shower self with effort (d) Severely weak, having to rest for more than half of the day, requiring assistance for basic tasks like showering and dressing self
Administration	How the treatment is given (administered)	(a) Oral treatment (b) Intravenous treatment, given in hospital (c) Tablet and intravenous treatment, given in hospital (d) Intravenous treatment given in hospital and then for a period of time at home
Healthcare contact time	Days per week receiving healthcare	(a) 3 hours per week, on 1 day per week (b) 6 hours per week, delivered on 1 day per week (c) 6 hours per week delivered on 2 separate days (d) 12 hours per week, delivered on 3 separate days
Total treatment course	Total length of treatment course	(a) Up to 6 months (b) Indefinite treatment with no planned breaks

Compared with early stage disease, where adjuvant systemic treatment given for a limited time course aims to increase the proportion of patients cured of their disease, palliative systemic treatments for advanced cancers are usually given indefinitely with the aim of improving quantity and quality of life [32]. In the adjuvant context, curative treatment is usually associated with many years of life gained [33, 34]. However, the median benefit of novel systemic therapies approved for use by the US Food and Drug Administration is approximately 2.8 months, many of these in the palliative setting [27]. It is on the background of these incremental gains that the time spent commuting to, receiving, and coordinating cancer care can amount to a substantial portion of a person's remaining survival time. In addition, time spent on treatment has been reported in qualitative research as partitioning patients' lives into short segments whereby they can take part in 'normal' activities [12]. The volume and frequency of healthcare contact can therefore amount to a substantial burden for many people [11].

Multiple stated-preference studies in oncology and haematology have examined the impact of logistics on treatment preferences. To date, few studies have studied contact days, and none have assessed the importance of contact days to decision-making in a broad advanced cancer population. Most commonly, existing literature examines treatment logistics through the combined lens of 'route and frequency of administration' [35–48]. One study examined healthcare time via treatment type following the surgical management of breast cancer (e.g., need for radiotherapy, chemotherapy vs endocrine therapy) [49]. These studies commonly report attributes related to efficacy as having the highest attribute importance, with route and frequency of administration playing a less important role. Overall, participants tend to prefer less healthcare contact where possible, often favouring oral treatments over subcutaneous or intravenous treatments, and less frequent, shorter durations of healthcare contact [35, 37, 40, 41, 43–45, 47, 50]. As observed in our qualitative analysis, several studies show high heterogeneity in preferences for contact time between participants, with classes of participants expressing a preference for treatments with less healthcare contact [36, 40–42, 46]. In advanced solid tumours, there was a preference for more convenient treatments with advanced cancer and increasing lines of treatment [36, 42].

However, only two studies included attributes that focused on the influence of contact days on treatment choice. Ivanova et al. [51] assessed the importance of contact days per treatment cycle in advanced soft-tissue sarcoma in adult patients and oncologists. Healthcare contact was the least important attribute in decision-making in both groups, though patients expressed a strong preference to avoid hospitalisation because of side effects and weak to moderate preferences to avoid contact days. In willingness-to-trade analysis, the number of additional contact days that patients would accept to gain 1 month of survival time was surprisingly low: 1.4 days for patients and 4.7 days for oncologists [51]. However, this analysis did not separate contact days from other logistical burdens and may lack generalisability because of the rare cancer type, the predominantly female (75%) population, and the recruitment strategy, which was via patient advocacy groups (85%).

In another analysis, Zeidan et al. [52] assessed various measures of logistic convenience, including the number of visits, alongside measures of efficacy and toxicity in patients receiving hypomethylating agents for myelodysplastic syndrome. Although efficacy and toxicity had the highest relative attribute importance, the number of visits involved with treatment was more important than the mode of treatment administration, duration, or frequency of visits. This aligns with qualitative work that suggests that, of all the logistical considerations of cancer treatment, physical contact days may be the most important consideration, as patients are forced to 'work their lives around' any treatment activities [13, 53].

Foundational literature in the field of time toxicity has proposed 'contact days' as a comprehensive, patient-centred, and pragmatic measure of the impact of treatment-related time burdens on people undergoing cancer treatments [1, 13]. As interest in and literature describing time toxicity grows, it is important to understand the importance of information about contact days on treatment decision-making. Oncologists interviewed as part of our qualitative work expressed significant uncertainty about the value their patients placed on time toxicity [12]. To our knowledge, our DCE will be the first to specifically focus on the impact of information about contact days on treatment choices in a broad population of people with advanced cancers. The primary outcome of the forthcoming study is to evaluate the importance of information regarding contact days for treatment decision-making. Like Zeidan et al. [52], we included contact days among other measures of logistical burden to evaluate its importance in treatment choices independent of other logistical concerns such as mode of administration and length of the planned treatment course.

The six attributes chosen for inclusion are well supported by qualitative work and existing stated-preferences studies. All stakeholders strongly valued information about treatment efficacy and toxicity in treatment decision-making interviews. Furthermore, these were drivers of decision-making in the majority of the stated-preference studies reviewed. Regarding efficacy measures, interview participants frequently mentioned added survival time. Surrogate measures of efficacy, such as progression-free survival and response rate were mentioned by several oncologist interview participants and identified in a number of stated-preferences experiments [36, 41, 44, 54, 55]. However, prior qualitative work and five DCEs included in the literature review suggest that these metrics are not

as important to patients [36, 41, 44, 54–56]. As this DCE is planned to be run in a patient and general community population, we have not included surrogate measures of efficacy.

Further, toxicity is commonly included in the treatment preferences literature [26–43, 46–70]. Unlike in some studies identified in the literature review, specific side effects (e.g., alopecia, or sexual dysfunction) were not commonly mentioned [38, 46]. As this study will be conducted in a broad cohort of patients with advanced cancer, we have chosen to describe toxicity in generic terms, split between a wellbeing-focused attribute ('physical side effects of treatment') and a function-focused attribute ('effect on day-to-day functioning').

4.1 Limitations

This qualitative study was limited to patients with advanced gastrointestinal cancers who had received at least one cycle of palliative treatment, their caregivers, and oncologists, and recruited from public healthcare settings in New South Wales, Australia. The views expressed by participants may not be generalisable to other patient cohorts or healthcare systems. For example, patients who choose not to have cancer treatment because of logistical burdens were not included in this study. Conversely, given their generally poorer prognosis, this patient group may place greater importance on logistical considerations. However, the views expressed by participants were representative of those in other stated-preferences studies, with the exception of out-of-pocket healthcare costs. This was a less frequent concern for participants in our study compared with the broader literature, which may limit the generalisability of these findings beyond healthcare settings with similar healthcare financing arrangements.

5 Conclusions

This study identified a set of measurable candidate attributes for use in a future DCE. This study and the resultant DCE will clarify the importance of information about contact days to patients making choices about palliative systemic treatments in a general population of people with advanced cancer.

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Declarations

Conflicts of Interest Richard De Abreu Lourenco is an editorial board member of *The Patient*. He was not involved in the selection of peer reviewers for the manuscript nor any of the subsequent editorial decisions. All other authors declare no conflicts of interest.

Ethics Approval The Sydney Local Health District Human Research Ethics Committee–Concord Repatriation General Hospital approved the conduct of this study (2023/ETH00869). The study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Consent to Participate All participants provided written informed consent for study participation.

Data Availability Statement The data underlying this article cannot be shared without compromising the privacy of individuals who participated in the study. The qualitative nature of the interviews and experiences of clinicians are personal, so even if identifying information is removed from individual transcripts, it may still breach confidentiality.

Author Contributions Samuel Stevens, Richard De Abreu Lourenço, Deborah Street, Christopher Booth, Joanne Shaw, and Janette Vardy contributed to the study conception and design. Writing and revision of the interview guide was completed by Samuel Stevens, Richard De Abreu Lourenço, Christopher Booth, Joanne Shaw, and Janette Vardy. Interviews were conducted by Samuel Stevens. Interview analysis was performed by Samuel Stevens, Ella El-Katateny, Isaac Addo, and Joanne Shaw. The literature search was conducted by Samuel Stevens. The final attribute list was developed by Samuel Stevens, Richard De Abreu Lourenco, Deborah Street, Christopher Booth, Joanne Shaw, and Janette Vardy. The first draft of the manuscript was written by Samuel Stevens. All authors reviewed and revised additional drafts of the manuscript and approved of its final form.

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