

# Patients' preferences regarding information provision for chemotherapy

*A Discrete Choice Experiment*

## MASTER THESIS HEALTH SCIENCE

R.T.E. Terlouw

S2624419

March 3, 2025

University of Twente

Faculty of Science and Technology (TNW)

Master Health Science

Track: Optimization of Healthcare Processes

Isala Zwolle

Department Internal Medicine

Supervisors:

Dr.ir. A.G. Leeftink

Dr. J.A. van Til



UNIVERSITY OF TWENTE.

# Abstract

**Introduction:** This study aims to investigate the information preferences of patients undergoing chemotherapy in Isala hospital to optimize the information provision process and enhance patient-centeredness of the care process.

**Method:** This study follows a Discrete Choice Experiment (DCE) approach. Between December 2024 and January 2025 patients who were receiving chemotherapy at Isala Zwolle were invited to fill in a questionnaire. The questionnaire included an information letter and informed consent, background characteristics, 9 DCE choice tasks, and digital competence and health literacy scaling questions. A logistic regression and counting analysis were used with R studio to analyse patients' preferences.

**Results:** A total of 107 patients were invited to this study and 78 questionnaires were correctly filled in, which results in a responsive rate of 72.9%. All 5 attributes had a significant impact on patients' preferences ( $p < 0.05$ ). Support materials had a high relative importance (32.2%) and preparation of the patient low (11.3%). Patients showed a negative preference for podcasts ( $\beta = -0.904$ ,  $p < 0.001$ ) and videos ( $\beta = -0.616$ ,  $p < 0.001$ ) as support materials compared to text based formats. A shorter duration of the consultations is preferred than higher levels of consultation duration. Consecutive meetings, consultation 1 week before treatment and optional preparation of the patient for the meeting also had significant positive impact on the patients' preferences for the information provision for chemotherapy.

**Discussion:** Based on the results of this study and in consultation with the stakeholders, a revised information process is proposed. Including pre-consultation preparation, shorter consultation duration, and revised content information, to enhance the patient-centeredness of the care process. A pilot study is recommended to evaluate effectiveness of the revised process and ensuring accessibility of the process for patients with low digital competence or low health literacy.

**Conclusion:** Support materials were the most influential factor and patient preparation the least. All attributes significantly impacted patient preferences, with podcasts and audiovisual materials being least favoured compared to text based, though a combination of format may be beneficial. Patients preferred shorter consultations, as extended sessions can lead to information overload. Patients also favour receiving information as short as possible before treatment. Based on these findings a revised information provision process is proposed to enhance the patient-centered care.

# Table of Contents

<b>ABSTRACT .....</b>	<b>1</b>
<b>1. INTRODUCTION.....</b>	<b>3</b>
<b>2. METHOD .....</b>	<b>5</b>
2.1 STUDY DESIGN.....	5
2.1.1 <i>Identifying attributes and levels</i> .....	5
2.1.2 <i>Constructing the choice sets and the questionnaire</i> .....	6
2.1.3 <i>Data collection and analysing</i> .....	7
2.2 ETHICAL CONSIDERATIONS .....	8
<b>3. RESULTS.....</b>	<b>9</b>
3.1 ATTRIBUTES AND LEVELS.....	9
3.2 RESULTS PILOT STUDY .....	10
3.3 PATIENTS CHARACTERISTICS .....	10
3.4 RELATIVE IMPORTANCE .....	11
3.5 PREFERENCE WEIGHTS .....	11
3.6 SUBGROUP ANALYSIS .....	12
<b>4. DISCUSSION.....</b>	<b>13</b>
4.1 KEY FINDINGS .....	13
4.2 PRACTICAL IMPLICATIONS .....	13
4.3 LIMITATIONS AND FUTURE RESEARCH.....	14
<b>5. CONCLUSION.....</b>	<b>16</b>
<b>6. REFERENCES.....</b>	<b>17</b>

# 1. Introduction

Patient-centered care has become an increasingly recognized concept within healthcare, driven by technological advancements and shifts in the organization and financing of care [1]. The Institute of Medicine defines patient-centered care as “care that is respectful of and responsive to individual patient preferences, needs, and values.” [2]. Patient-centeredness is valuable across various aspects of healthcare, with communication, partnership and health promotion being recognized as its core components [3]. Within communication, this approach empowers patients to actively participate in their own care process, by prioritizing personalized attention, effective communication, patient advocacy, safety and high-quality services. Collectively, these principles contribute to better outcomes and higher patient satisfaction [3, 4].

In this context, patient-centered care is valuable when patients are informed about their treatment options. At this stage of their care pathway, patients often encounter substantial amount of complex information. When patients feel well-informed, they feel greater involvement in the decision-making processes, which leads to improved quality of care [5]. Healthcare providers play an important role in supporting patients through this process. Studies have shown that patients need a broad spectrum of information to make more informed decisions about their disease and feeling more prepared for their treatment journey [6]. Furthermore, patients with fulfilled information needs generally experience higher health-related quality of life, with reduced anxiety and depression [7].

For cancer patients, receiving a diagnosis is a highly stressful event that impacts both the physical and mental dimensions of their lives [8]. The treatment plan for many cancer patients includes chemotherapy [9]. This treatment of cancer, involving the use of cytostatic drugs, plays a crucial role in both curing and symptom relief of cancer, despite its associated drawbacks [10]. These drugs, in addition to having a cell-killing effect or inhibiting cancer cell division, may also damage healthy cells and may cause a lot of side effects [11]. This complexity creates a challenge for healthcare providers, who need to communicate complicated medical information in a way that is accessible and understandable to patients with different levels of health literacy [12]. Health literacy refers to the extent to which an individual has the skills “to obtain, process, and understand basic health information and services” [13].

At the Oncology Department of Isala there is a challenge in incorporating patient-centered approaches in the information provision process. Each year, approximately 2,500 new oncology patients are treated at Isala, with many undergoing chemotherapy as part of their treatment plan [9]. The current information provision process is predominantly focused on in-person information sharing. As depicted in Figure 1, this process starts with a consultation with the internist-oncologist, followed by an appointment with the oncology nurse coordinator. During the appointment with the internist-oncologist, which lasts a maximum of 30 minutes, the goal of the treatment, the most suitable treatment method for the patient and possible medication adjustments are discussed. This is followed by a maximum 60-minute session with the oncology nurse, who provides information about practical aspects, such as duration, time and location of the treatment, potential side effects and how to deal with them, and the provision of an information brochure, including contact details.

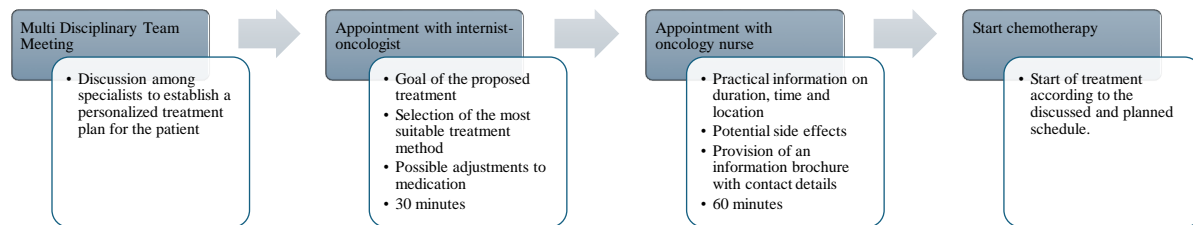


Figure 1: Current information provision process

Although this approach aims to cover all essential aspects of chemotherapy and the patient journey, it may not always align with the individual needs and preferences of the patients. Currently, healthcare providers often present a representative talk on exactly how the treatment works, whereas they would ideally make the transition to a conversation about integrating the treatment in the patient's daily life and personal circumstances [14]. This lack of personalisation can create a gap between the information provided and the information the patients personally need to go to their treatment effectively. A more patient preference-oriented approach is needed to bridge this gap and ensure information is not only medically accurate, but also relevant to the patient's personal circumstances. Strengthening this alignment by addressing these needs and preferences is essential for improving patient-centred care at Isala.

Previous research on cancer patients' information needs has primarily focused on the extent of information and their influencing factors, involving healthcare providers perspectives [15, 16]. These studies often did not consider the actual experiences and perspectives of patients, which can lead to a discrepancy between the information patients truly require and the services provided. Therefore, it is crucial to investigate patients' preferences to better align the information provision with their actual needs.

The goal of this study is to optimize the information provision process by making the care process more patient-centered. To achieve this objective, the information preferences of patients undergoing chemotherapy at Isala will be investigated. This leads to the following research question:

*What are the information preferences of patients regarding the information provision for chemotherapy?*

## 2. Method

To assess patient's preferences regarding the information provision process for chemotherapy, a patient preference method (PPM) was used. There are various PPMs, each with its own methodological characteristics [17]. For this study the selection of the most suitable method was guided by the following criteria:

1. Choice based approach: Patients should make choices between alternatives rather than ranking them, ensuring a realistic decision-making process that closely reflect real-world healthcare scenarios.
2. Trade-offs: The method should capture relative importance by requiring patients to make trade-offs between attributes providing insight into both preference direction and strength.
3. Statistical analysis: The use of an experimental design should enable robust statistical analysis ensuring reliable and valid estimations of patient preferences.

The following patient preferences methods met these criteria and were considered for this study [17].

- Discrete Choice Experiment (DCE): Participants repeatedly choose the most preferred profile between a set of option with varying attributes and levels [18].
- Best-Worst Scaling (BWS) Case 2: Participants select the most and least important attributes and their corresponding level from a fixed set [19].
- Best-Worst Scaling (BWS) Case 3: Participants choose the most and least preferred profile from a set of options [19].

These three PPMs were selected for a pilot study. In the pilot these three methods were evaluated for usability and comprehensibility with the aim of identifying the most suitable method for assessing patients' preferences regarding the information provision for chemotherapy. More information about the pilot is written in section 2.1.2.

### 2.1 Study Design

The study design of this research consisted of four steps: 1) identifying attributes and levels, 2) constructing choice sets, 3) data collection and analysing, and 4) summarizing results and give practical recommendations.

#### 2.1.1 Identifying attributes and levels

A crucial step in conducting a PPM is selecting the appropriate attributes and levels that are relevant to the research question. To establish this, a focus group with relevant healthcare providers, was organized. Healthcare providers were considered relevant if they were actively involved in the care process related to chemotherapy information provision. They were invited via email, and participation was voluntary (self-selection sampling). The aim of the focus group was to identify relevant attributes and levels from clinical practice. The focus group began with a brainstorm session where participants individually responded to the question: "When considering the key elements of information provision, which factors play the most important role in the patient experience" by writing their answers on post it notes. These factors were then discussed collectively and placed on the board. Next, these attributes were grouped into themes and eliminated by irrelevance or overlapping. Finally, they were asked to identify the most important attributes and relatively prioritize them from most to least important. This prioritization helped determine which factors had the biggest impact on the patients experience according to the healthcare professionals and should be included in the study.

Based on the outcomes of this focus group, the included attributes and levels were created with additions or modifications from existing literature. This sequential approach ensured that the clinically relevant attributes and levels that were selected during the focus group were also evidence based. This set was then presented back to two healthcare providers of missing specialties to ensure that all perspectives were included. The outcomes of the focus group and the final list of attributes and levels are presented in section 3.1.

### 2.1.2 Constructing the choice sets and the questionnaire

To identify the most suitable PPM, a pilot study was conducted. The goal of the pilot was to assess the comprehensibility of different patient preference elicitation methods, including Discrete Choice Experiments (DCE), Best-Worst Scaling Case 2 (BWS 2), and Best-Worst Scaling Case 3 (BWS 3). Patients were asked to verbalize their thoughts while completing the questionnaire. They were also asked to indicate which method they found most easy to understand. In addition to evaluating comprehensibility of the different PPMs, the pilot also helped identify ambiguities, unclear wording, or other potential issues within the questionnaire. Feedback gathered during the pilot informed subsequent revisions to ensure the questionnaire was clear, user-friendly, and suited to the target population. The outcomes of the pilot are presented in section 3.2

After the results from the pilot, a Discrete Choice Experiment (DCE) approach was chosen to assess patient preferences regarding information provision for chemotherapy. DCEs are a widely recognized quantitative method for eliciting preferences, particularly in healthcare contexts [20, 21]. This method evaluates preferences by presenting participants two (or more) hypothetical scenarios of information provision process, known as *choice sets*, in which each alternative (*profile*) is defined by a set of characteristics (*attributes*) with varying levels. Respondents are asked to choose the alternative they prefer from the choice set, enabling researchers to quantify the relative importance of specific attributes [18, 20].

To create the choice sets of the DCE, an experimental design was created in R-studio. An orthogonal approach was generated, using the *DoE.base*, *Idefix* and *Survival* packages to ensure an orthogonality and balance in the design. This means that the attributes and levels are statistically independent, minimizing multicollinearity and allowing for an unbiased estimation of preferences. The final design consisted of 9 choice sets, each containing two alternatives. All levels were equally presented in the choice sets. An opt-out option was not included in this study to focus on direct comparisons between the presented alternatives. An example of a DCE choice set is shown in Table 1.

	<b>Profile A</b>	<b>Profile B</b>
<b>Information providers</b>	Consecutive conversations with the internist-oncologist provides broad overview and the nurse for details	Combined conversation with internist-oncologist about the treatment plan
<b>Consultation duration</b>	De total duration of one or two conversation is maximum of 60 minutes	De total duration of one or two conversation is maximum of 45 minutes
<b>Moment of information provision</b>	Information session takes place 2 weeks before the first treatment	Information session takes place 3 weeks before the first treatment



<b>Support materials</b>	Text and images on paper or digital	Visual materials like videos or animations
<b>Preparation of the patient</b>	Support material is given prior to consultation, and patient is asked to prepare it	Patient receives support materials prior to consultation but all the information will be explained from the basics

Table 1: Example of a DCE choice set

After creating the experimental design, the final questionnaire was created. The final questionnaire is provided in Appendix 7.3 and consisted of the following four components:

1. *Information letter and informed consent.* The questionnaire begins with an explaining the study procedures followed by an informed consent form where patients provide their consent to participate. More information about this topic can be found in section 2.2.
2. *Background characteristics.* This section gathers relevant background information about the participants, including gender, age, disease type.
3. *Choice-tasks.* In this section the 9 DCE choice tasks are presented.
4. *Health literacy, digital competence and patient-centeredness.* The last section of the questionnaire consists of a screening scale for health literacy, digital competence and on overall satisfaction question of the patient-centeredness. The health literacy scale was developed by Chew and consisted of three questions [22]. Chew's questionnaire is validated and therefore convenient to use. The original English version of Chew's questionnaire was translated into Dutch and reviewed by multiple healthcare experts to ensure accuracy. The screening scale for digital competence is transferred from the health literacy questionnaire. To conclude an overall satisfaction question about the information provision process and the patient centeredness is asked on a 10-point scale.

### 2.1.3 Data collection and analysing

Convenience sampling was used from 9 December 2024 to 7 January 2025. Patients receiving chemotherapy at the day admission department in Isala Zwolle were invited. They were informed about the study, and asked if they are willing to voluntary participate in the study. After agreeing the patients were provided with information about the subject matter, objective, and method for completing the questionnaire. They were told explicit that they can withdraw from the study at any time without explanation. Patients could only participate once in the study. The questionnaire was offered on an iPad, non-digitally skilled patients were offered a paper questionnaire.

The inclusion criteria were as follows:

- Diagnosed with cancer
- Currently undergoing chemotherapy (9 December 2024 – 7 January 2025) or had undergone chemotherapy in the past
- Receiving or had received chemotherapy treatment at Isala Hospital.
- Age 18 years or older
- Cognitive ability to complete the questionnaire independently or under guidance
- Fluent in the language in which the questionnaire is conducted (Dutch)

The exclusion criteria were as follows:

- Missing information or pages in the questionnaire form



- Did not provide informed consent
- Had severe medical or psychological conditions preventing them from completing the questionnaire

The sample size was determined based on Orem's rule of thumb with the following formula:  $n > 500c / (t \times a)$ , where  $t$  represents the selection task,  $a$  denotes the number of choices, and  $c$  represents the maximum number of levels for any attribute. In view of this study with  $c = 3$ ,  $t = 9$ , and  $a = 2$ , the number of respondent ( $n$ ) should be 83.

R studio was used to analyse the background characteristics, DCE data, health literacy scores and digital competence scores. To determine the relative importance of the attributes, a counting analysis was conducted by aggregating the frequency of attributes levels wins across the experiment. This method provided insight into the rank and weight of attributes that influenced patients' decisions. Additionally, a logistic regression model was used to evaluate the patient preferences for the different attributes, giving an estimation of the likelihood of the attribute levels. The attributes were dummy coded on their first level and statical significance was defined as  $p < 0.05$ .

Finally, subgroup analyses were performed to compare preferences across patient groups, including patients with low health literacy; patients with low digital competence; patients receiving treatment for breast cancer. These groups were selected based on factors that could influence their information preferences. Patients with low health literacy or digital competence may experience greater challenges in processing medical information or prefers different formats [22]. The mamma oncology group was selected because their department already providing patients with a podcast about chemotherapy before their consultation. Since these patients have prior experience with this format, it was hypothesized that they might have a different view of the use of audio-based materials and the preparation before consultation.

## 2.2 Ethical considerations

The Ethics Committee of the University of Twente granted approval for this study (application number 240854). Approval has also been received by the Isala Academy's Innovation & Science Department for conducting a non-WMO study. Before conducting the survey, all participants received and information letter (Appendix 7.1) outlining the purpose of the study, activities involved and the expected time commitment. The information also highlighted that participation is voluntary and they have the right to withdraw at any time without consequences. No information was withheld from the participants. Furthermore, participants were asked to sign informed consent form (Appendix 7.2) if they choose to participate, by ticking the boxes in the survey. This form confirmed that they understand the study's aim, activities and potential burdens and that they agree to participate voluntarily. The study could not proceed if the participant did not obtain their explicit consent. Participants were able to ask questions to clarify any concerns before and during the survey and reminded that they could withdraw from the study at any time. Data were anonymized and securely stored within Isala. All study findings and data do not contain any identifiable information to maintain patient confidentiality.

### 3. Results

This section presents the results of the focus group, the pilot study and the questionnaire. The findings include the identified attributes and levels from the focus group with healthcare providers. The outcomes from the think-aloud interviews during the pilot study to select the most suitable PPM and identify ambiguities. Patient characteristics are described to give context on the study population. The results of the questionnaire highlight the relative importance and the preference weights of the different attributes. Lastly, the subgroup analysis explores differences in preferences among patient groups.

#### 3.1 Attributes and levels

The focus group included one internist-oncologist and three oncology nurses from the fields of neurological oncology, urologic oncology and haematology. During the brainstorming session 25 factors were identified. The most important attributes were selected and relatively ranked from most to least important: 1) Setting: how information is provided 2) Moment of information provision 3) Planning 4) Knowledge of the caregiver 5) Support materials 6) Content of information 7) Social network 8) Characteristics of the patient.

After the literature review and input from the unrepresented specialities, a total of five attributes with each three levels, were identified. The five attributes included information providers, consultation duration, moment of information provision, support materials, preparation of the patient. Table 2 provides a description of the included attributes and their levels.

Attributes	Levels	Description
Information providers	Separated consultations	Separated consultations with internist-oncologist about medical information and with directional nurse about practical information
	Combined consultation	Combined conversation with internist-oncologist about the treatment plan
	Consecutive conversation	Consecutive conversations with the internist-oncologist provides broad overview and the nurse for details
Consultation duration	45 minutes	De total duration of one or two conversation is maximum of 45 minutes
	60 minutes	De total duration of one or two conversation is maximum of 60 minutes
	90 minutes	De total duration of one or two conversation is maximum of 90 minutes
Moment of information provision	3 weeks	Information session takes place 3 weeks before the first treatment
	2 weeks	Information session takes place 2 weeks before the first treatment
	1 week	Information session takes place 1 week before the first treatment
Support materials	Text	Text and images on paper or digital
	Podcasts	Podcasts or other audio files
	Audio-visual material	Visual materials like videos or animations
Preparation of the patient	No preparation	All information is explained from the basis and the patient receives support materials after the consultation
	Optional preparation	Patient receives support materials prior to consultation but all the information will be explained from the basics
	Mandatory preparation	Support material is given prior to consultation, and patient is asked to prepare it

Table 2: Descriptions of the identified attributes and levels

### 3.2 Results pilot study

Four patients participated in this pilot study using the think-aloud method, in which participants were asked to verbalize their thoughts while completing the questionnaire. All four patients incorrectly completed the BWS Case 2 due to a knowledge gap of the other comparative levels. Two of the four patients expressed a preference for the DCE, while the other two indicated a preference for either BWS Case 3 or DCE. One patient interpreted the questions as an attempt to align responses as closely as possible with the current process, rather than their individual preference. The perception of the amount of information varied among patients; one patient found it overwhelming, while the other three did not. However, no participants reported a complete lack of understanding or an inability to complete the questionnaire independently. Finally, minor language errors and alignment inconsistencies were identified and corrected.

### 3.3 Patients characteristics

In this study a total of 107 patients were invited and 78 questionnaires were correctly filled in, which results in a responsive rate of 72.9%. Reasons for non-response included a refusal to participate in the study, being too fatigued or anxious due to chemotherapy, or a low cognitive ability to comprehend the questions. 64.1% of the respondents who completed the questionnaire were women. The mean age was 61 years. Mammary oncology, pulmonary oncology, and gastrointestinal and liver oncology were the most common among the participants. An overview of all the background characteristics of the study population is given in Table 3.

Characteristics	N (%)	Mean (SD)
<b>Sex</b>		
Male	28 (35.9)	
Female	50 (64.1)	
<b>Age</b>		61.2 (12.9)
<b>Tumour type</b>		
Gynaecologic oncology	6 (7.7)	
Haematology	12 (15.4)	
Pulmonary oncology	14 (17.9)	
Gastrointestinal and liver oncology	14 (17.9)	
Melanoma oncology	3 (3.8)	
Mammary oncology	24 (30.8)	
Neurological oncology	1 (1.3)	
Urologic oncology	3 (3.8)	
Soft tissue oncology	0	
Other	1 (1.3)	

Table 3: Basic characteristics of the included patients (N = 78)

### 3.4 Relative importance

Figure 2 shows the results of the relative importance of each attribute. The attribute that is most important by patients are support materials (32.2%). Followed by moment of information provision (21.5) and duration of the consultation (20.6%). Information providers (14.5%) and preparation of the patient (11.3%) were the least important attributes for selection information provision during chemotherapy. The calculation of the relative importance is presented in Appendix 7.4.

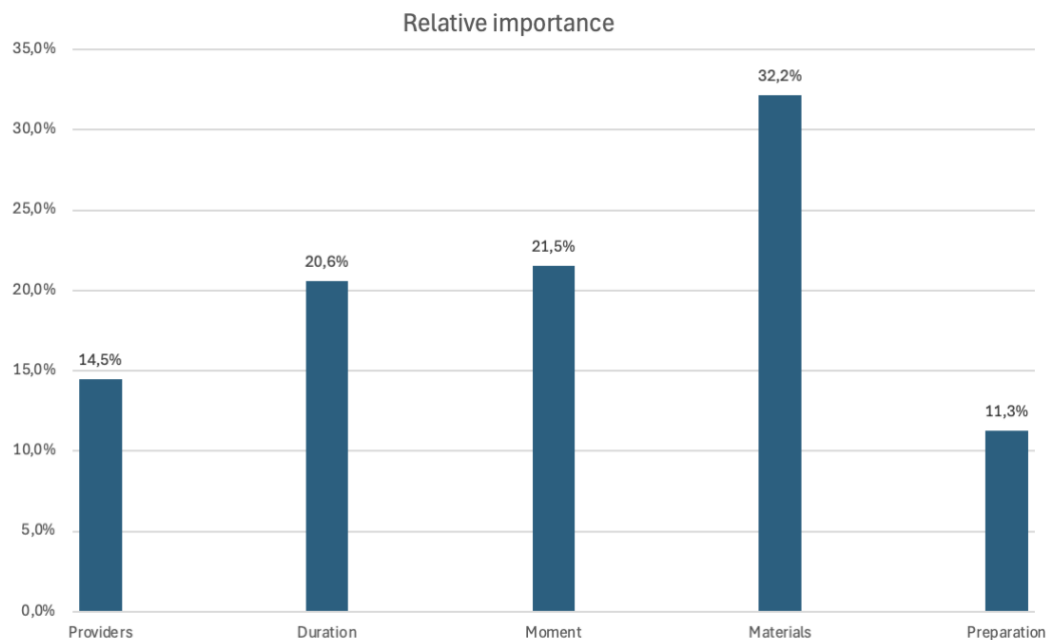


Figure 2: Relative importance of the attributes

### 3.5 Preference weights

The logistic regression model showed that all the attributes have a significant impact on the patients' preferences ( $p < 0.05$ ). Patients preferred receiving support materials about information of chemotherapy in text-based information formats over audio-visual materials ( $\beta = -0.616$ ), which, in turn, were preferred over podcasts ( $\beta = -0.904$ ). A shorter duration of the consultations is preferred than higher levels of consultation duration, especially a total of 90 minutes consultations ( $\beta = -0.578$ ) had a strong negative effect compared to 60- or 30-minutes consultations. Other significant factors were consecutive consultations ( $\beta = 0.334$ ) and moment of information provision 1 week before treatment ( $\beta = 0.411$ ) Patient preparation had the least influence, where optional preparation had a small positive effect. The levels combined consultations, 60 minutes consultation duration, moment of information provision 2 weeks prior treatment or mandatory preparation of the patient, had no significant influence.

Attributes	$\beta$	SE	z-value	Pr(> z )
Intercept	0.389	0.181	2.145	0.032 *
Information providers (reference level: separated consultations)				
Combined consultations	-0.066	0.137	-0.477	0.633
Consecutive consultations	0.334	0.136	2.460	0.014 *
Consultation duration (reference level: 45 minutes)				
60 minutes	-0.007	0.135	-0.050	0.960
90 minutes	-0.578	0.136	-4.246	2.18 e-05 ***
Moment of information provision (reference level: 3 weeks)				
2 weeks	-0.190	0.135	-1.412	0.158
1 week	0.411	0.137	3.010	0.003 **
Support materials (reference level: text)				
Podcasts	-0.904	0.138	-6.546	5.90 e-11 ***
Audio-visual material	-0.616	0.136	-4.542	5.58 e-6 ***
Preparation of the patient (reference level: no preparation)				
Optional preparation	0.319	0.135	2.359	0.018 *
Mandatory preparation	0.138	0.135	1.019	0.308

Significant codes: 0 '\*\*\*\*' 0.001 '\*\*\*' 0.01 '\*\*' 0.05 '.' 0.1 ' ' 1

Table 3: Logistic regression analysis of patient preferences for information provision

### 3.6 Subgroup analysis

Logistic regressions were also performed for the following subgroups: inadequate health literacy, inadequate digital competence, and mamma oncology. The results are presented in Appendix 7.5. Due to small patient subgroups (low health literacy n=4, low digital competence n=8), few significant results were found. These few findings did not differ from the results from the overall study population.

## 4. Discussion

### 4.1 Key findings

The results of this study stated that support materials are the most important factor in patients' preferences regarding information provision for chemotherapy and text and images on paper or digital were preferred to podcast or audio-visual. Krontoft also states that text-based information is the preferred material, over podcasts and video's [23]. She shows that patients prefer a combination of written, audio, and video materials, rather than a single format. Similarly, Goodman and Lambert state that written material remains popular, especially among older patients, although many patients prefer a multidisciplinary approach of combining different formats [24].

Another finding of this research is that patients have a negative preference against consultation sessions lasting 90 minutes. In the current situation, the information provision process consists of two appointments: a 30-minute consultation with the internist-oncologist followed by a 60-minute session with the oncology nurse. However, the results indicate that this current structure is not preferred by patients. Literature states that extended consultations can lead to information overload, what can lead to reduced engagement and increased anxiety [25, 26]. This phenomenon where patients are feeling overwhelmed by the amount of information is called cancer information overload. Research supports that cancer patients prefer shorter consultations when receiving information about treatment options. Hermann et al. found that most patients and their support persons favoured two shorter consultations, allowing time to process information [27]. Hitz et al. found that high satisfaction with treatment decision could be achieved with a 30-minute consultation [28].

Furthermore, the most preferred timing for information provision was one week before the first chemotherapy treatment. This suggests that patients generally prefer to receive treatment as early as possible. Existing literature support this statement, that patients often express high satisfaction with rapid diagnosis and treatment, even when the process feels overwhelming [29, 30]. However, patients' preferences may vary based on different factor such as depression, anxiety and expected survival time [31]. Therefore, healthcare providers should inform about their treatment options and services early on, while considering patient's capacity to process information at each stage [29, 32].

Finally, the last key finding was that the preparation of the patient before the consultation was the least important attribute among the factors analysed. This result suggest that preparation of the patient does not impact the consultation process a lot. Currently, patients do not have to prepare their information consultation. Nevertheless, the logistic regression indicates that some patients value receiving information about chemotherapy in advance.

### 4.2 Practical implications

Based on the results of this study and in discussion with the stakeholders of the internal medicine department, a revised information provision process is suggested in Figure 3. In this process, three key adjustments compared to the current information provision process, based on patient preferences and existing literature, have been made:

1. **Pre-consultation preparation:** Informational material about chemotherapy will be provided before consultation via the BeterDichtbij app. These materials will allow

patients to familiarize them with the key information in advance, what will improve patient engagement.

2. **Reduced consultation duration:** The consultation with the oncology nurse can be reduced from 60 to 30 minutes. Patients expressed a preference for shorter consultations, which aligns with the research that long consultations may lead to information overload [26].
3. **Content of information:** Since the patient receives information in advance and the consultation time with the oncology nurse is reduced, the content of the consultation will change slightly. By providing patients with materials covering standardized topics, such as potential side effects, essential knowledge can be addressed beforehand and does not need to be discussed during the consultation, allowing more time to focus on individual questions and concerns.

These adjustments aim to enhance patient-centered care for the information provision. A pilot study should be conducted to assess whether the revised process is successful. This should evaluate its impact on patient outcomes, satisfaction, and consultation efficiency. However, this revised process may not be suitable for patients with limited health literacy or digital competence. In practice these subgroups already receive a different information provision format.

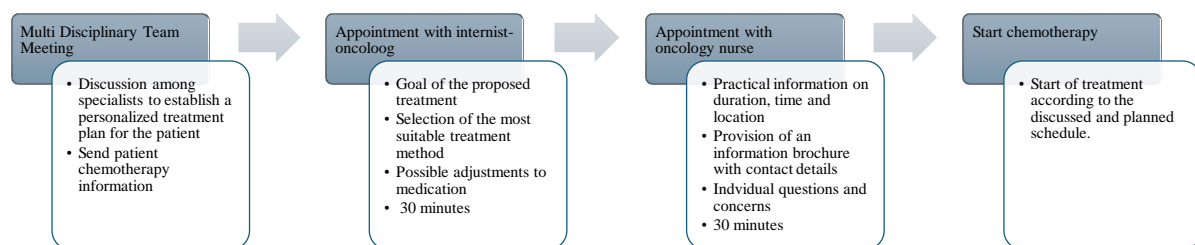


Figure 3: Revised information provision process

Another practical implication includes prioritizing text-based formats as the primary source of supplementary information while offering audio or video resources to enhance accessibility. Literature indicates that many patients prefer a multidisciplinary approach of combining different formats, ensuring more effective and accessible information [23, 24].

### 4.3 Limitations and future research

The questionnaire included a total of five attributes, which was based on input from a focus group with relevant healthcare providers with additional literature research. But these five attributes may not fully capture other important factors influencing patient preference regarding information provision for chemotherapy. Attributes such as presence of family members, knowledge content, and supplementary services may also play a significant role [33]. These factors were not included in the current study, due to practical constraints. Incorporating a broader range of attributes would require a larger experimental design and a larger study population to achieve significant results or it would increase the number of questions for the current study population. To keep the questionnaire concise and manageable, the five most relevant attributes were selected by the healthcare professionals during the focus group. Future research should incorporate a broader range of attributes for a discrete choice experiment, along with the use of different qualitative approach, to gain deeper insights.



This study was conducted with a limited sample size of 78 patients undergoing chemotherapy. However, the results of this study may also be applicable to patients receiving immunotherapy, as their information provision process is similar to that of patients who will receive chemotherapy. To strengthen the external validity, comparative studies between chemotherapy and immunotherapy patient could provide deeper insights into similarities and differences between these pathways, ensuring tailored and effective patient education for both patient groups.

Due to the small subgroup populations in this study, no definitive conclusions can be drawn. In practice, these patient groups may already receive an alternative approach. Alternative strategies should be explored to support patients with limited digital access or literacy, ensuring equitable information provision.

Another limitation of this study is the small subgroup population among patients with low health literacy ( $4/78 = 5.1\%$ ) and low digital competence ( $8/78 = 10.2\%$ ). The limited sample size restricts the ability to draw conclusion about these groups. This can be partly explained by exclusion of patients with language barriers and low cognitive abilities from the study, due to difficulties in understanding the DCE-methodology. This misunderstanding leads to a limitation of the generalizability of the findings. The limited representation of these groups, this study does not capture the preferences of these vulnerable groups, who may require tailored information strategies. However, patients with severe language barriers or cognitive inability often already receive a different approach to information provision from the healthcare providers, which may partially reduce their exclusion from this study. Future research should aim to include a larger and more diverse study population to ensure sufficient representation of patients with varying literacy levels and digital competence. Additionally, qualitative methods such as interviews could provide deeper insights into specific information needs and help to develop more inclusive and tailored information provision process.

Lastly, in this study data were analysed using count analysis to determine the relative importance of attributes and logistic regression to calculate preference weights. Ideally, a DCE analysis would be performed using a conditional logit model. In a conditional logit model, coefficients (preference weights) and their corresponding standard errors are estimated for all but one level of each attribute. As demonstrated by McFadden [34], the conditional logit model aligns with random utility theory, which assumes that individuals faced with a choice will select the alternative that maximizes their personal utility. However, due to insufficient trade-off information in the choice sets, it was not feasible to apply a conditional logit model in this study. This limitation arose, because the choice sets lacked balance and orthogonality, which are crucial for simultaneously estimating preference weights for multiple attributes in a conditional logit model. Due to this limitation, a logistic regression was resorted, which calculates preferences weights for each attribute individually. While the logistic regression provides a useful alternative estimate of preference weights, it may give less nuanced estimates compared to the conditional logit model. Therefore, caution is warranted when interpreting the current results, as the estimates may not fully capture the complex trade-offs between attributes. To address this limitation in future research, it is recommended that the experimental design incorporate a greater number of choice sets and utilize blocking to distribute choice sets across a larger sample of respondents. This approach would provide sufficient trade-off information to enable the application of a conditional logit model and produce more robust estimates of preference weights.

## 5. Conclusion

In conclusion, this study investigated the information provision preferences of patients undergoing chemotherapy in Isala, by calculating the relative importance of relevant attributes and using a logistic regression. The results show that support materials are the most influential factor (32.2%) and preparation of the patient (11.3%) the least influential factor in patients' preferences. The logistic regression analysis showed that all attributes had a level that significantly impacted patient preferences ( $p < 0.05$ ), with podcasts and audiovisual materials being the least preferred formats for support materials.

Based on these findings, a revised information provision process is proposed to enhance patient-centered care. Three key adjustments have been made: 1) pre-consultation preparation through BeterDichtbij app 2) shorter consultation duration with oncology nurse 3) shift in consultation content. A pilot is needed to assess the impact on patient satisfaction.

## 6. References

1. Greene SM, Tuzzio L, Cherkin D. A framework for making patient-centered care front and center. *Perm J*. 2012;16(3):49-53. doi: 10.7812/tpj/12-025.
2. Institute of Medicine Committee on Quality of Health Care in A. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington (DC): National Academies Press (US) Copyright 2001 by the National Academy of Sciences. All rights reserved.; 2001.
3. Constand MK, MacDermid JC, Dal Bello-Haas V, Law M. Scoping review of patient-centered care approaches in healthcare. *BMC Health Serv Res*. 2014;14:271. doi: 10.1186/1472-6963-14-271.
4. Reynolds A. Patient-centered Care. *Radiol Technol*. 2009;81(2):133-47.
5. van Vliet LM, de Veer AJE, Raijmakers NJH, Francke A. Is Information Provision about Benefits and Risks of Treatment Options Associated with Receiving Person-Centered Care?: A Survey among Incurably Ill Cancer Patients. *Journal of Palliative Medicine*. 2019;22(7):797-803. doi: 10.1089/jpm.2018.0591.
6. Chua GP, Tan HK, Gandhi M. What information do cancer patients want and how well are their needs being met? *Ecancermedicalscience*. 2018;12:873. doi: 10.3332/ecancer.2018.873.
7. Husson O, Mols F, van de Poll-Franse LV. The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Ann Oncol*. 2011;22(4):761-72. doi: 10.1093/annonc/mdq413.
8. Li PWC, So WKW, Fong DYT, Lui LYY, Lo JCK, Lau SF. The information needs of breast cancer patients in hong kong and their levels of satisfaction with the provision of information. *Cancer Nursing*. 2011;34(1):49-57. doi: 10.1097/NCC.0b013e3181ef77a0.
9. Isala. *Samen sterk en vertrouwd*. Zwolle: Isala; 2019.
10. Nygren P. What is cancer chemotherapy? *Acta Oncol*. 2001;40(2-3):166-74. doi: 10.1080/02841860151116204.
11. Isala: Behandelwijzer chemotherapie (PID). <https://www.isala.nl/patientenfolders/6686-behandelwijzer-chemotherapie-pid-h1-inhoudsopgave-inleiding/> (2021). Accessed.
12. Allen-Meares P, Lowry B, Estrella ML, Mansuri S. Health Literacy Barriers in the Health Care System: Barriers and Opportunities for the Profession. *Health Soc Work*. 2020;45(1):62-4. doi: 10.1093/hsw/hlz034.
13. Institute of Medicine Committee on Health L. In: Nielsen-Bohlman L, Panzer AM, Kindig DA, editors. *Health Literacy: A Prescription to End Confusion*. Washington (DC): National Academies Press (US) Copyright 2004 by the National Academy of Sciences. All rights reserved.; 2004.
14. Epstein RM, Fiscella K, Lesser CS, Stange KC. Why the nation needs a policy push on patient-centered health care. *Health Aff (Millwood)*. 2010;29(8):1489-95. doi: 10.1377/hlthaff.2009.0888.
15. Rutten LJF, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980–2003). *Patient Education and Counseling*. 2005;57(3):250-61. doi: <https://doi.org/10.1016/j.pec.2004.06.006>.
16. Kalyani A. Types of information needs among cancer patients : a systematic review. *Library and Information Science Research E-Journal*. 2005;15(2):1-25. doi: doi:10.32655/LIBRES.2005.2.1.
17. Soekhai V, Whichello C, Levitan B, Veldwijk J, Pinto CA, Donkers B, et al. Methods for exploring and eliciting patient preferences in the medical product lifecycle: a literature review. *Drug Discovery Today*. 2019;24(7):1324-31. doi: <https://doi.org/10.1016/j.drudis.2019.05.001>.
18. Szinay D, Cameron R, Naughton F, Whitty JA, Brown J, Jones A. Understanding Uptake of Digital Health Products: Methodology Tutorial for a Discrete Choice Experiment Using the Bayesian Efficient Design. *J Med Internet Res*. 2021;23(10):e32365. doi: 10.2196/32365.
19. Louviere JJ, Flynn TN, Marley AAJ. *Best-worst scaling: Theory, methods and applications*. Cambridge University Press; 2015.
20. Mangham LJ, Hanson K, McPake B. How to do (or not to do) ... Designing a discrete choice experiment for application in a low-income country. *Health Policy Plan*. 2009;24(2):151-8. doi: 10.1093/heapol/czn047.
21. Ellis AR. *Improving Methods for Discrete Choice Experiments to Measure Patient Preferences*. 2021.

22. Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. *Fam Med*. 2004;36(8):588-94.
23. Krøntoft A. How do patients prefer to receive patient education material about treatment, diagnosis and procedures?—A survey study of patients preferences regarding forms of patient education materials; leaflets, podcasts, and video. *Open Journal of Nursing*. 2021;11(10):809-27.
24. Goodman C, Lambert K. Scoping review of the preferences of older adults for patient education materials. *Patient Educ Couns*. 2023;108:107591. doi: 10.1016/j.pec.2022.107591.
25. Epstein RM, Street R. L. *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*. National Cancer Institute, NIH; 2007.
26. Trevino KM, Prigerson HG, Maciejewski PK. Advanced cancer caregiving as a risk for major depressive episodes and generalized anxiety disorder. *Psychooncology*. 2018;27(1):243-9. doi: 10.1002/pon.4441.
27. Herrmann A, Holler E, Edinger M, Eickmann S, Wolff D. A qualitative study on patients' and their support persons' preferences for receiving one longer consultation or two shorter consultations when being informed about allogeneic hematopoietic stem cell transplantation. *BMC Health Serv Res*. 2021;21(1):623. doi: 10.1186/s12913-021-06632-9.
28. Hitz F, Ribi K, Li Q, Klingbiel D, Cerny T, Koeberle D. Predictors of satisfaction with treatment decision, decision-making preferences, and main treatment goals in patients with advanced cancer. *Supportive care in cancer*. 2013;21:3085-93.
29. Junge AG, Risør MB, Toustrup K, Grau C. [Head and neck cancer patients' experiences with accelerated diagnostic and treatment programs]. *Ugeskrift for læger*. 2010;172 4:274-8.
30. Petersen GS, Knudsen JL, Vinter MM. Cancer patients' preferences of care within hospitals: a systematic literature review. *International Journal for Quality in Health Care*. 2015;27(5):384-95. doi: 10.1093/intqhc/mzv059.
31. Hagerty RG, Butow PN, Ellis PA, Lobb EA, Pendlebury SC, Leighl NB, et al. Cancer patient preferences for communication of prognosis in the metastatic setting. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2004;22 9:1721-30.
32. Singer S, Kojima E, Deppisch L, Taylor K, Wickert M, Riedel P, et al. What is the best time for psychosocial counselling from the perspective of cancer patients and their relatives? A multi-centre qualitative study. *Counselling and Psychotherapy Research*. 2021.
33. Li L, Liu X, Zhou W, Zhang Y, Zhang X. Information needs preferences of Chinese colorectal cancer patients receiving chemotherapy: A discrete choice experiment. *Asia-Pacific Journal of Oncology Nursing*. 2024;11(9):100551. doi: <https://doi.org/10.1016/j.apjon.2024.100551>.
34. McFadden D. Conditional logit analysis of qualitative choice behavior. 1972.