BD2Decide

Big Data and models for personalized Head and Neck Cancer Decision support

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EDITOR	A. Berlanga (MAASTRO)		
Contributors	Adriana Berlanga (MAASTRO), Scott Delbressine (MAASTRO), V. Tountopoulos (ATC)		
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1.	20-06-2017	E. Martinelli	Added abstract and corrected typos
1.1	26-06-2017	V. Tountopoulos	Revised version

Addressees of this document

The EU and all BD2Decide Consortium.

The document is public.

This document describes the Interactive Patient co-Decision Aid (IPDA) tool, a web-based application aimed at collaborative decision-making (patient and caring physician) concerning cancer treatment. The current application developed by MAASTRO is aimed at larynx cancer patients, for whom several treatment options may be followed.

This document is meant to the technical partners of BD2Decide Consortium (ATC, UPM in particular) who should verify the interoperability and integration potential into BD2Decide CDSS. It is also addressed to clinical partners who might experience it with selected patients to collect feedback and check the impact of the tool on treatment compliance.

For the general public, the tool described in this document constitutes a working proof-of-concept for the application of IPDA to other head and neck cancer types.

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Abbreviations and definitions

CDSS	Clinical Decision Support System
IPDA	Interactive Patient co-Decision Aid
IPDA-Standard	International Patient Decision Aid Standard
SDM	Shared Decision Making

Abstract

Treatment decision for cancer patients brings out a number of ethical aspects concerning patients' acceptance, compliance and full understanding of treatment pros, cons and consequences. These issues are addressed through a "participative medicine" approach, which involves patients and clinicians in a process of understanding (Q&A, what if) and clarifications (scientific background, explanation of the patient's treatment options).

In recent years, with the spread of wider communications (e.g. internet, social media), new methods of participative treatment decision have been experienced: the so-called Interactive Patient co-Decision Aids (IPDA). Through interviews with reference clinicians, animations explaining the disease and the different treatment options, the individual verification of treatment options vs. patients' preferences in terms of efforts required, quality of life and expected treatment outcomes derived from scientific evidence, patients can either independently or in presence of their caregivers, formulate their opinions and achieve a shared treatment decision.

In BD2Decide we experience this tool for a head and neck cancer that offers different treatment options (larynx), as a proof-of-concept of its effectiveness in increasing patients' awareness and compliance to treatment and to stimulate better response.

The tool developed by MAASTRO clinic for BD2Decide can be used as stand-alone or linked to the patient's data and prognostic models, thus becoming a personalized shared decision tool.

At this stage we present the stand-alone version of the IPDA; the integration into BD2Decide will be performed in the next period upon availability of validated models and of the complete patients' dataset.

1 ABOUT THIS DOCUMENT

This deliverable describes the development and validation of the interactive tool (IPDA) for larynx cancer patients (stage T3/T4). The IPDA presents the treatment alternatives as identified by the physician along with their rationale, curative effectiveness and impacts/side effects. The development of the IPDA was guided by the International Patient Decision Aid Standard (IPDAS-Standard) and user-center design principles. During this process relevant stakeholders have been be involved to provide the necessary input.

The deliverable also describes the resulting IPDA prototype and elaborates on future work.

2 SHARED DECISION MAKING

Shared decision-making (SDM) is the process of collaboration between clinicians and patients to evaluate all available information and reach the most ideal treatment decision taking into account the patient's preferences (Charles, Gafni, & Whelan, 1997).

Although SDM is associated with numerous benefits (Oshima Lee & Emanuel 2013), involving patients in clinical decision-making is a complex undertaking. Patients must not only weigh several treatment options in terms of benefits and harms but also absorb a large amount of medical information while dealing with the emotional and psychological aspects of their condition (Reyna, Nelson, Han, & Pignone, 2015). Lack of awareness about different treatment options can result in patients making choices that are not aligned with their values and can lead to decisional regret (Davison, So, & Goldenberg, 2007; Stacey et al., 2016).

2.1 Interactive Patient Decision Aids (IPDA)

Interactive Patient Decision Aids (IPDA) can be a valuable tool in empowering patients with information, improving care quality, reducing unnecessary procedures and consequently costs. Patients who use IPDAs are better informed about their treatment options, experience less decisional conflict and fewer comorbidities such as anxiety, depression, and fatigue (O'Connor et al., 2009). There is Level 1 evidence from a Cochrane study of 115 randomized controlled trials that IPDAs are beneficial for patients in different levels. Patients who use decision aids are better informed about their treatment options, are more likely to adhere to their treatments, are more involved in the decision process, and have more accurate risk perceptions (Stacey, D. et al., 2014).

IPDAs support patients by making their treatment decisions explicit, providing information about options and associated benefits/harms, and helping clarify congruence between decisions and personal values. Therefore these aids should provide information about the treatment options which illustrate the consequences of the treatment and effects on the quality of life of the patient.

To reach this goal, an IPDA should (see Fig. 1):

- Consider patient medical condition to present only relevant information
- Inform the patient about the different treatment options offered by the clinicians, as recommended by gold standard guidelines and good clinical practice, the pros and cons of these treatments, and their outcomes.
- Help patient to check if he/she understood the information about the treatments
- Assist the patient to identify their personal preferences and values
- Help the patient to compare the treatment options and support the patient to understand
- Provide a summary report, so the patient and doctor can communicate better during the decisional talk. This report should provide information about what is important for the patient, and what information needs to be explained further.

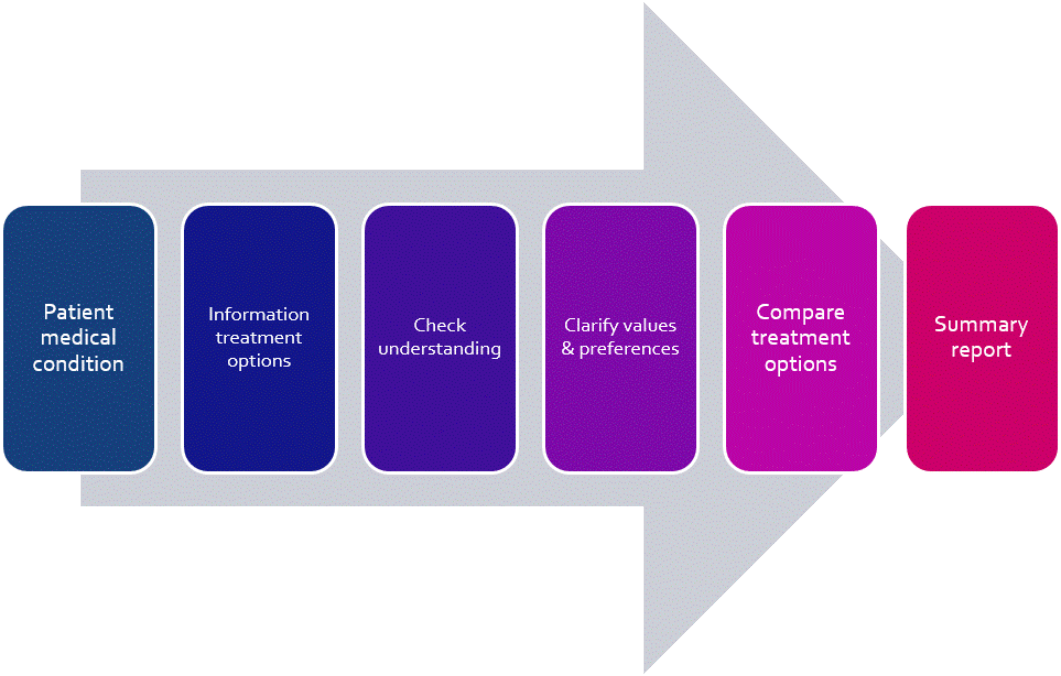


Fig. 1 – Design framework IPDA

It is important to point out that IPDA do not advise people to choose one option over another, nor are they meant to replace practitioner consultation. Instead, they prepare patients to make informed, values-based decisions with their practitioner.

2.2 Patient Decision Aid Standard (IPDAS)

The International Patient Decision Aid Standards Collaboration (IPDAS-Standard) has been established to enhance the quality and effectiveness of patient decision aids by defining an evidence-informed framework to improve their content, development, implementation, and evaluation.

Based on a review of relevant literature, the IPDAS-Standard proposed a systematic development process for IPDA ((see Coulter et al., 2013 and Fig. 2).

The key features of this process include scoping and design , the development of a prototype, ‘alpha’ testing with patients and clinicians in an iterative process (testing by stakeholders directly involved in the SDM process), and finally, ‘beta’ testing in ‘real life’ conditions, and production of a final version for use and/or further impact studies.

The specific details of how the prototype is developed, in particular how material for inclusion is reviewed and selected, are important elements that shape the final product. Less often are explicitly mentioned or studied barriers and facilitators of the implementation of IPDAs in the clinical practice.

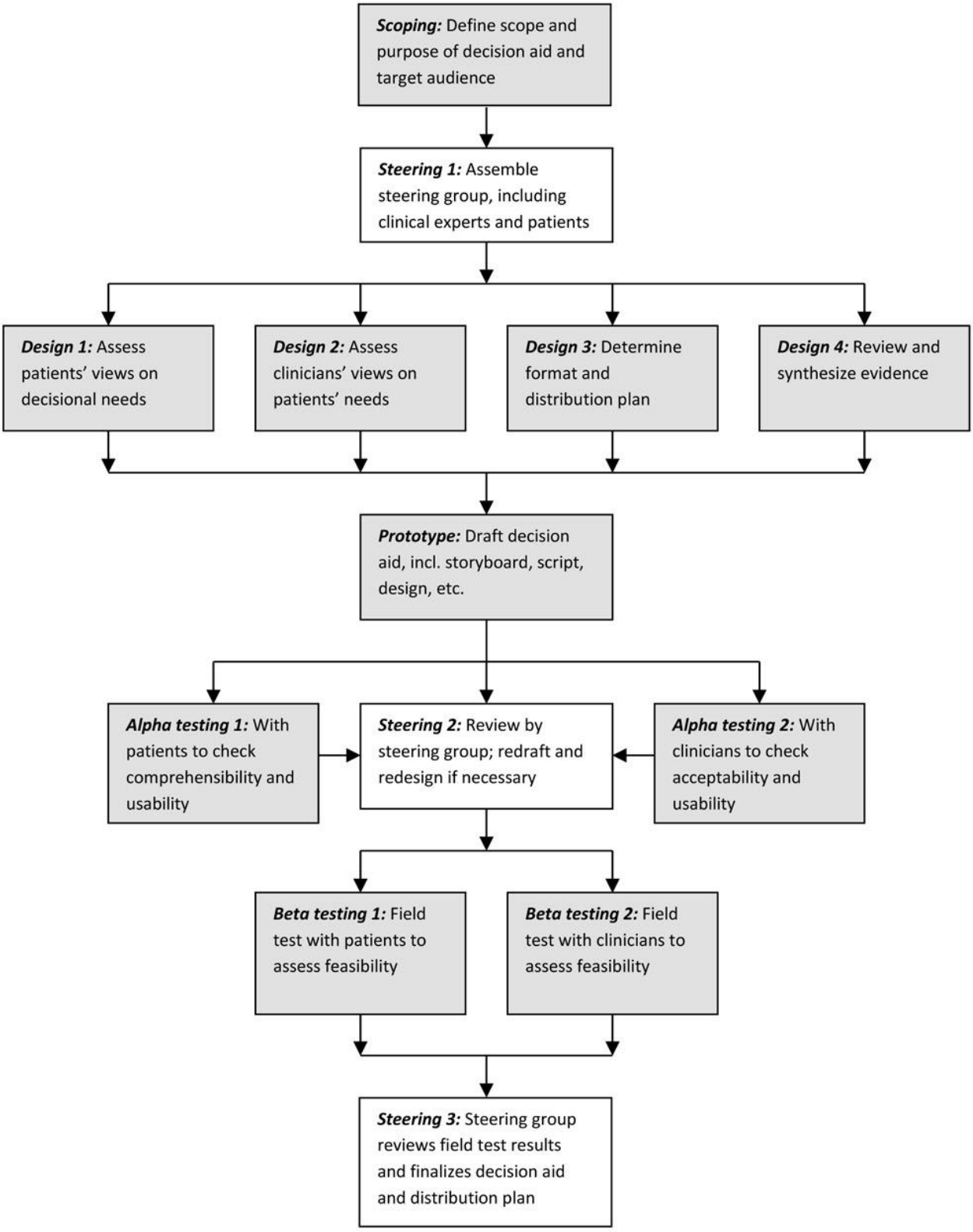


Fig. 2 –IPDAS-Standard (Ref. Coulter et al, 2013)

3 IPDA BD2DECIDE

3.1 Rationale for BD2Decide IPDA

Head and neck cancers are a heterogeneous type of tumor, where tumor sub-site (localization) implies fundamental differences in treatment options. For instance, oral cavity cancer has limited possibilities in terms of treatment selection, and in the majority of cases only one option (Surgery) is recommended according to gold standard guidelines; in this case IPDA would not be really useful for collaborative patient-physician decision making. Other subsites, and in particular larynx cancer, allow different treatment options that can be proposed by physicians to patients. The IPDA in these cases would be extremely useful to allow patients and their families to evaluate each option vis-à-vis the treatment impacts (e.g. toxicity) and benefits (e.g. outcome probability).

The development of a scientifically and ethically correct IPDA implies an impressive work to provide all the scientific, medical and epidemiological information required to explain the treatment alternatives in simple and clear words. In this effort, developers must consider each treatment possibility for each patient/patient category and must be guided by the multidisciplinary team of physicians involved in treatment decision. Validation of the tool also implies an important effort of scientists (clinicians but also technical developers) and the involvement of patients. Given the limited resources available for this task in BD2Decide, the Consortium agreed to concentrate on a paradigmatic example, i.e. larynx cancer, for which different treatment options, including surgery, radiation, chemoradiation or combinations can be proposed and for which MAASTRO could organize a complete validation involving clinicians and patients, approved by local Ethics Committee.

3.2 Method

The development of an IPDA for larynx cancer patients (stage T3/T4) for the BD2Decide platform is based on a combination of the IPDAS-Standard and user-centered design principles (Abras, Maloney-Krichmar, & Preece, 2004). The process involved end-users (larynx cancer patients) and other relevant stakeholders (surgeons, radiation oncologists, oncology nurses) throughout all stages of development with an emphasis on meeting stakeholder needs at various levels. The resulting IPDA motivates patients to participate by providing personalized, useful and clear information about treatment options and a structured way to compare them. In addition, it helps clinicians to understand the characteristics and preferences of their patients by providing a printed report of the patient's preferences, questions, and a checklist of topics to guide the decisional talk. By engaging healthcare professionals in the process, we improved the IPDA's relevance, accuracy and usability and created awareness, and engagement among clinicians to promote its implementation.

3.3 Development and validation

Following the IPDAS-Standard, the development of the aid tool covered the phases of (1) assessing decisional needs of patients and clinicians and (2) Alpha testing of 2 versions of the IPDA.

3.3.1 Assess decisional needs of patients and clinicians

The goal of this phase is to elicit patients and clinicians' views on patient's information, expectations, and needs on decision support (Design 1 and 2 in Fig. 2).. The conclusions and recommendations are taken into account to create a revised version of the IPDA.

This phase started with the creation of a first draft of the IPDA, which was developed based on literature and feedback from a group of specialists in head and neck cancer. These were surgeons, oncologists and radiation oncologists, from two Dutch Institutes.

Their comments were incorporated to create a revised version of the IPDA, which was tested with a small group of ex-patients. Their comments and feedback were used to create a revised version of the IPDA (Alpha prototype, first version; "prototype" in Fig.2).

3.3.2 Alpha testing

The goal of this phase is testing patients' and clinicians' comprehensibility, acceptability and usability on the alpha prototype (Alpha testing 1 and 1 in Fig. 2). This is an iterative process. After each testing loop conclusions and recommendations are documented and considered to improve the prototype. This process repeats until the tool is comprehensible, acceptable and usable for both patients and physicians. We did two Alpha testing rounds. In these rounds we also explored the decisional needs of patients and doctors.

For Alpha testing we used a mixed method: qualitative research was conducting using structured interviews and think aloud methodology (Ahmed, 2009). Patients are asked about their decisional needs. We used a semi-standardized interview containing questions about their medical history, the treatment they have received, how they experienced the treatment, and how they experienced the SDM process (see Annex 1). The IPDA is then introduced and by means of a think-aloud protocol, and patients are asked to give comments on the tool and suggest improvements if necessary.

Quantitative research was done using questionnaires based on (a) the Unified Theory of Acceptance and Use of Technology (UTAUT; Venkatesh et al. 2013) and (b) the International Standard ISO-9242-11. These questionnaires (5-Likert) were used to measure to what extent the IPDA was easy to use, how patients and clinicians perceived its utility, effectiveness and efficiency for shared decision-making, as well as their satisfaction with the IPDA, and their intention to use it and recommend it to others (see Annex 2). Participants were asked to fill in these questionnaires after using the IPDA in the think-aloud protocol.

3.3.2.1 Alpha testing, first version IPDA

The first Alpha version of the IPDA was tested with clinicians (N=8) and patients (N= 12) from two Dutch hospitals.

Results showed (Berlanga et al., 2017) that patients and clinicians agreed on patient's difficulty to recall spoken information, to understand risk probabilities, and the preference for visual information. Patients preferred spoken information, which should be simple, visual, and presented in small chunks. Clinicians preferred the information adjusted to the psychosocial level of the patient.

Clinicians and patients mentioned the need of information about treatment options, side effects, and effectiveness. Patients also mentioned information about the preparations before and after treatment.

Patients were positive about the first Alpha version of the IPDA. All the criteria (satisfaction, effectiveness, clarity, usability, usefulness and intention of use) scored 4 ("agree"). Patients would like to have simpler terms in the tool, information about psychological effects, as well as the option of "no treatment".

These results were considered to create a second version of the IPDA (see Fig. 3). In this version the IPDA became a visual tool, which contains mainly videos with interviews with the clinicians, and animations to explain the treatments. The usability was also improved, and the content provided initially by clinicians was simplified into laymen's terms, and voice-over was included. The goal was to make the IPDA easier to understand also for patients with a lower medical literacy.

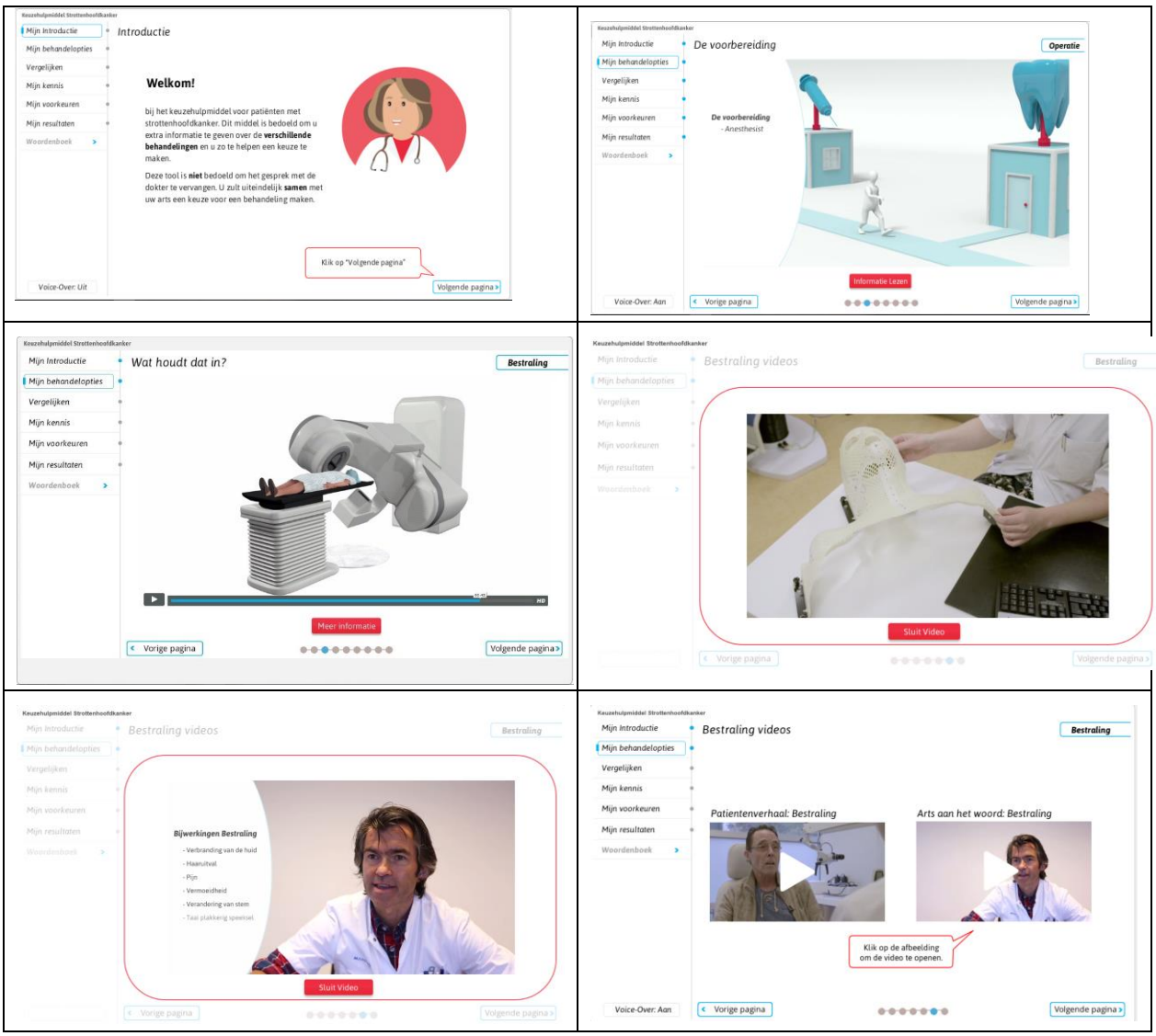


Fig. 3 –IPDA Larynx Screenshots

3.3.2.2 Alpha testing, second version IPDA

The second Alpha version of the IPDA was also tested by clinicians and patients.

For the evaluation with clinicians a qualitative method was used, using the same questionnaires than in the first round of testing. 13 clinicians from 2 Dutch institutes (N=6, N=5) participated in the evaluation.

The IPDA scored high in all criteria. Again, all the criteria (satisfaction, effectiveness, clarity, usability, usefulness and intention of use) scored higher than 4 ("agree"). Fig. 4 shows the results of the evaluation. Specialists scored the tool 7.7 out of 10. They liked specially the animations and videos, and the structure of the tool. They recommended to improve the result form and to minimize the clicks needed to navigate thru the tool

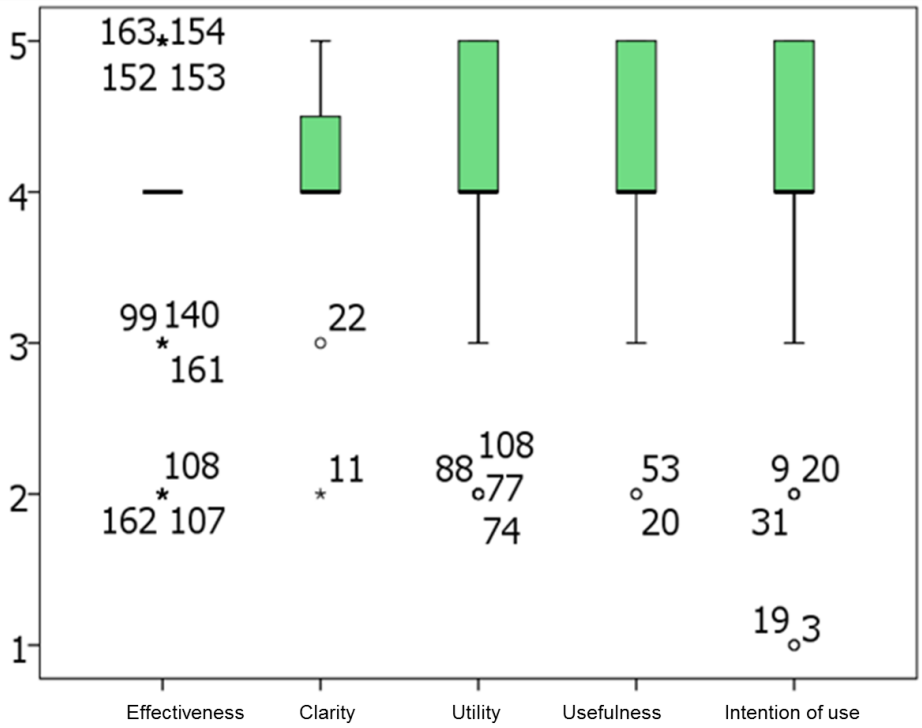


Fig. 4 – Results evaluation Alpha version clinicians

To minimize the number of clicks, information about treatment options was combined in single animations.

A new result page has been included to enable a better comparison between treatments and to communicate clearer the results of the IPDA (see Fig. 5). These results are structured in the same way as a checklist so the clinician can use it to conduct the decisional talk with the patient, as part of the Shared Decision Making process. The checklist is based on the guidelines proposed by (Elwyn et al., 2012).

This new version has been tested amongst ex-patients (n=10), who have had radiotherapy, chemo-radiotherapy or surgery. The same methodology was used than in the previous evaluation: interview and think-aloud protocol (see Annex 1) combined with questionnaires (see Annex 2) regarding user satisfaction and usability.

Preliminary results show that all patients are satisfied with the IPDA and see it as an improvement to the regular care. The content of the IPDA is positively evaluated, patients find it easy to navigate through. Furthermore, patients think it would not only help in medical decision making, but can also function as a reminder of expected side effects when the treatment has started. Regarding recommendation to others, only one patient will not advise new patients to use the tool.

The overall survival percentages could be very confronting, about half of the patients said they might not want to see them. They did not suggest to remove the overall survival information from the IPDA, but to include a button so patients could decide if they want to see this information or not. This is actually the most important outcome of the evaluation, and it will be incorporated into the IPDA to create a final version.

3.4 Description Interactive Larynx Patient Decision Aid

The current version of the IPDA for larynx cancer patient is available here https://goo.gl/bMoRhY.

The IPDA is composed of several sections:

1. Introduction
2. My Profile
3. My Treatments Options
    a. Surgery
    b. Radiotherapy
    c. Chemo-radiotherapy
4. My Comparison
5. My Knowledge (important to remember)
6. My Preferences
7. My Results

Below we describe how the patient will navigate and interact with the IPDA.

1. Introduction

The first page consists of a welcome video that introduces the concept of shared decision-making and the aim of the tool to the patient. The patient can navigate to the next page by pressing the button in the right bottom corner.	

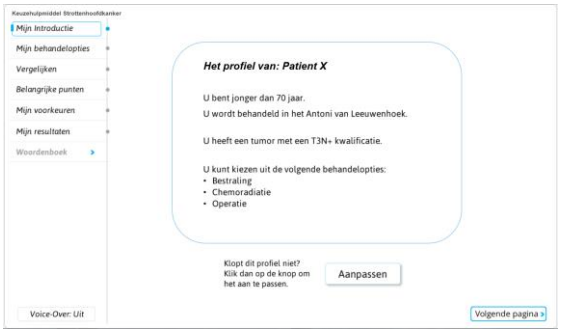
Help

In the next page, the patient can decide if s/he wants to get an introduction of the navigation of the tool or to go directly to “My Profile”	

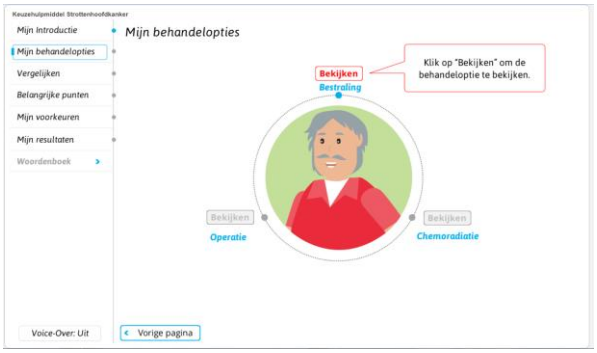
2. My Profile

After the introduction, the patient needs to fill in his/her profile. The IPDA uses this profile (age, hospital and tumor size) to personalize the information and presents only the information about the treatments that are relevant for the patient.	

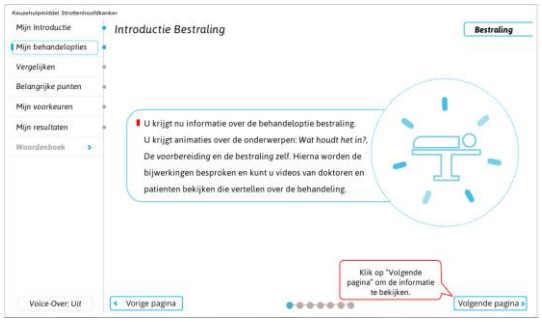
My Profile (check)

The tool shows the profile the patient filled in. The patient can make changes if s/he wants. This screen also shows which treatments options are available to the patient.	

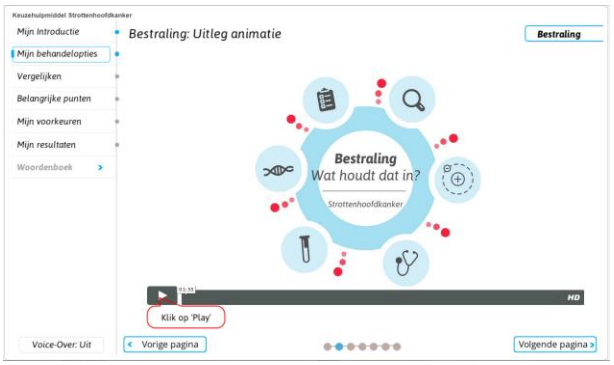
3. My Treatment Options

Next, the patient can start with the section "My Treatment Options". In this section, the treatments that are applicable to the patient (according to the profile) are explained. The patient needs to go thru all the treatment options available for him/her before the IPDA opens the rest of the sections.	

3.1 Description of treatments: Starting page

Each treatment includes a starting page that mentions the topics that will be described.	

3.2 Description of treatments: Explain treatment

The explanation of the treatment starts with an animation, which gives an introduction about the treatment.	

3.3 Description of treatments: Complications

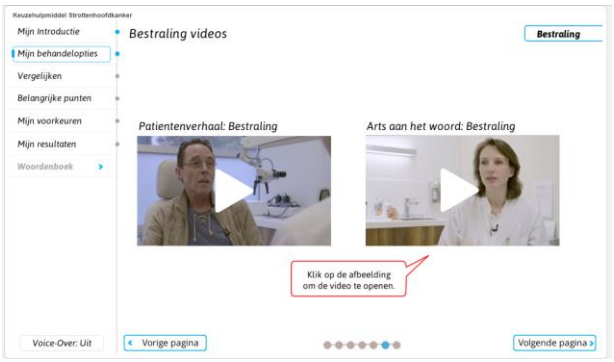
After the introduction to the treatment, the complications of the treatments are visualized and described in short sentences.

3.4 Description of treatments: Advantages, disadvantages per treatment

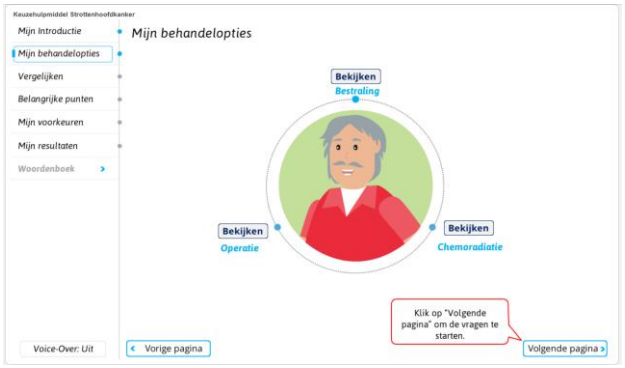
For each treatment, the advantages and disadvantages are presented.

3.5 Description of treatments: More information

Each treatment contains videos of former patients describing their experience and doctors explaining the local procedures.



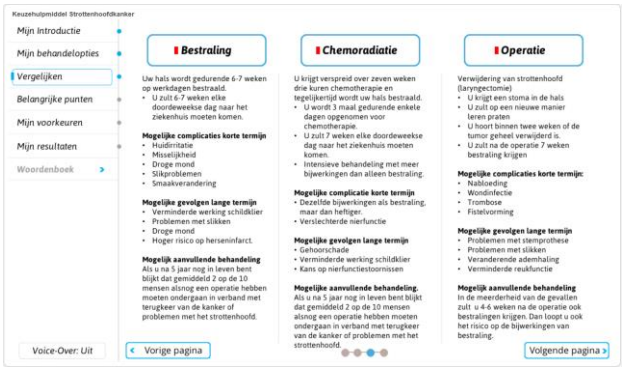
4. My Comparison

If the patient saw all the information about the treatments, the section “My Comparison” becomes available.	

4.1 Introduction My Comparison

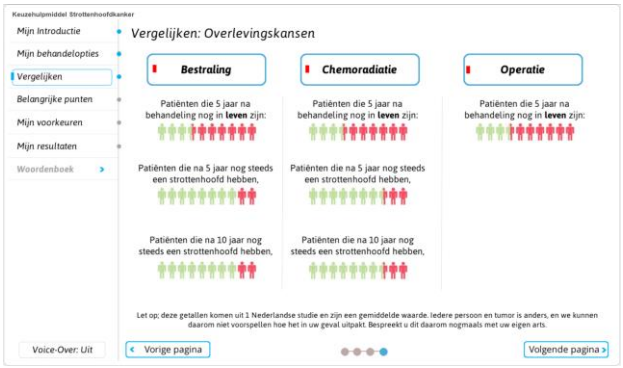
The comparison section starts with a video explaining how the medical team usually decides which treatment to choose.	

4.2 Comparison, side by side

The next page shows the characteristics of the treatment options (for the selected profile), side by side. This overview enables a clear comparison.	

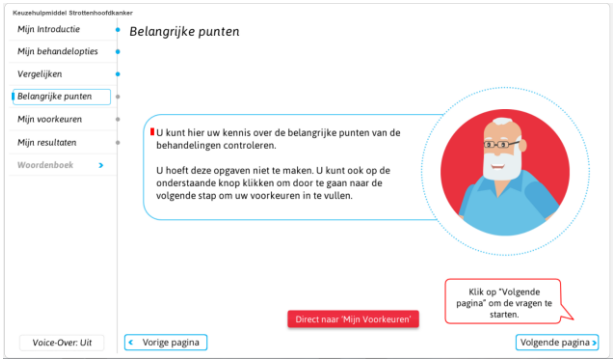
4.3 Prediction outcomes per treatment, side by side

The next page shows the prediction outcomes of the each one of the treatments.



5. Important to remember (My knowledge)

After the section “My Comparison”, a new section “Important to know” is available. This section is a short self-test to help the patient to recap if s/he understood the information about the treatments.



Per treatment option, five true/false statements are presented. The patient needs to answer the questions to check if s/he understood the information.

After each answer, the IPDA tells the patient whether the answer was correct or not. If the answer was wrong, the correct answer is provided.

6. My Preferences

The next section that becomes available is “My Preferences” section.

This section helps the patient to clarify her/his values and preferences.

For every treatment, five statements about complications (side effects) or treatment characteristic (treatment experience) are presented. The patient can assess how big the impact on her/his (quality of) life would be.

The statements are meant to trigger patient’s thinking of what would be acceptable for her when choosing a treatment. The patient can choose between: small impact, big impact but can cope with it, or big impact cannot cope with it.

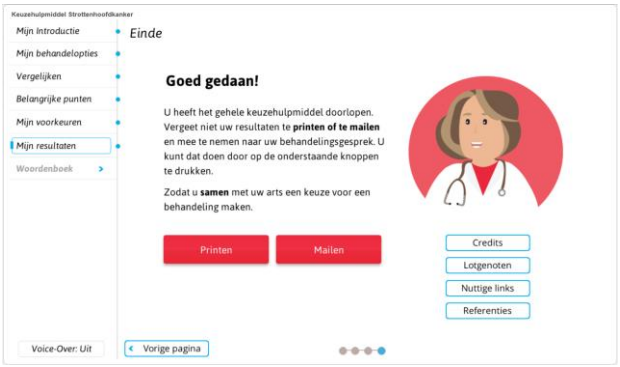
7. My Results

The last section is “My Results”. This section shows the answers of the patient in the sections “My Preferences” and “Knowledge test”, and allows to print a summary report.

7.1 Extra questions

The patient has also the possibility to include extra questions to be discussed with the clinician. The patient can write down extra questions, and/or chose questions from a list, which are based on frequently asked questions.	

7.2 Print summary report

In the last part of this section, the patient can print the summary report of her results of the IPDA, and take them to the consultation with the doctor.	

7.3 Summary report

Fig. 5 shows the summary report. The report summarizes the preferences of the patient per treatment. It shows per treatment --Radiotherapy ("Radiotherpie"), Chemo-radiotherapy ("Chemoradiate") and Operation ("Operatie")--, how the patient evaluated them by using three circles. One full circle means "low impact", two full circles mean "medium impact", and three full circles mean "high impact".

The topics the report includes are ("Onderwerp"):

- Duration (Duur)
- Treatment (Behandeling)
- Side-effects in the long term (Gevolgen lang termijn)
- Side-effects in the short term (Gevolven korte termijn)
- Follow up

The report also shows per topic, answer the patient gave. It shows if the answer of the related question was correct, incorrect or no-answer was given.

The structure of the topics is ordered in the same way as the SDM consultation recommended by the literature review. The goal is that the clinician and the patient can use this summary report to guide the decisional talk.

Behandeloptie Gesprek Formulier: Patient X

U heeft een T3N+ tumor en wordt hiervoor in het Antoni van Leeuwenhoek ziekenhuis behandeld.

Voor u zijn de volgende behandelopties beschikbaar: Radiotherapie, Chemoradiatie & Operatie.

Bij iedere behandeloptie heeft u over enkele onderwerpen gelezen. Waarschijnlijk wil u meer weten over:
Duur van Radiotherapie,Gevolgen Korte Termijn van Radiotherapie,Follow-Up van Radiotherapie,Follow-Up van Chemoradiatie,Gevolgen Korte Termijn van Operatie,Follow-Up van Operatie

U heeft de volgende vragen nog opgeschreven voor de dokter:

In uw voorkeuren heeft u aangegeven dat deze onderwerpen zeer belangrijk voor u zijn:
Duur van Radiotherapie,Follow-Up van Radiotherapie,Gevolgen Lang Termijn van Chemoradiatie,Follow-Up van Chemoradiatie

Uw resultaten stellen dat u deze aspecten minder belangrijk vindt:
Behandeling van Radiotherapie,Gevolgen Korte Termijn van Chemoradiatie,Duur van Operatie

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Legenda:

Correct	✓	Lage Impact:	●○○
Incorrect	×	Medium Impact:	●●○
Niet ingevuld	?	High Impact:	●●●

Onderwerp:	Radiotherapie:	Chemoradiatie:	Operatie:
Duur	× ●●●	✓ ●●○	✓ ●○○
Behandeling	✓ ●○○	✓ ●●○	✓ ●●○
Gevolgen Lang Termijn	✓ ●●○	✓ ●●●	✓ ●●○
Gevolgen Korte Termijn	× ●●○	✓ ●○○	× ●●○
Follow-Up	× ●●●	× ●●●	× ●●○

Wat moet ik nu met deze informatie?

Het is de bedoeling dat u deze resultaten print en mee neemt naar uw arts. Uw arts kan op basis van deze gegevens behandelopties nogmaals uitleggen.Daarnaast geeft de tabel inzicht in wat u belangrijk vindt in een behandeling. Niet tevreden?U kunt de voorkeuren nog aanpassen en (opnieuw) printen door de vragen opnieuw in te vullen.

Fig. 5 - Summary report

4 FUTURE WORK

The future steps for the IPDA are (a) to personalize it by using the prognostic models that are developed in WP4; and (b) to translate and validate it with the clinical consortium partners.

To personalize the IPDA, the outcomes of the larynx models will be used. This will be done through a dynamic link generated by the clinician in the CDSS that will be send to the patient by e-mail. The link will include information about the patient (e.g., age, stage of disease), and the outcomes of the models (e.g. overall survival and local control). The IPDA will use this information to automatically personalize the information that is presented to the patient and, therefore, the patient will not need to fill in a profile within the tool.

The IPDAS will be translated into English so that the other clinical partners can profit from it. A German version will be also created and eventually validated with clinicians in UDUS. The same methodology used to validate the Dutch IPDA will be followed.

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6 ANNEXES

6.1 Annex 1

Studie: "Evaluatie van tweede versie keuzehulptool voor gevorderd larynxcarcinoom"

Vragenlijst voor de onderzoeker

Control number:*(In te vullen door onderzoeker)*

A. Vraag aan de patiënt de volgende.

Kruis het rondje aan bij het juiste antwoord of vul het juiste antwoord in.

1	*Wat is uw geboortedatum?*	……	(dd/mm/jj)
2	*Bent u gehuwd?*	0 Gehuwd of samenwonend	0 Alleen-staand
3	*Heeft u kinderen?*	0 Ja	0 Nee
4	*Wonen u kind(eren) nog thuis?*	0 Ja	0 Nee
5	*Wat is de <u>hoogste</u> opleiding die u hebt genoten?*	*Voltooid met een diploma:*	*Gestopt, zonder diploma:*
	a. Lager algemeen onderwijs/ basisschool of een gedeelte hiervan	0	0
	b. Lager beroepsonderwijs, bijvoorbeeld: LTS, LHNO, LEAO, VMBO, detailhandelschool, lager landbouw- en tuinonderwijs	0	0
	c.Middelbaar beroepsonderwijs, bijvoorbeeld: MEAO, MTS, UTS, MBA, SPD-1, ULHNO, MHNO, MSPO, kleuterkweekschool, horecaschool, opleiding tot verpleegkundige	0	0
	d. Algemeen voortgezet onderwijs, bijvoorbeeld: 5-jarig HBS, MMS, gymnasium, lyceum, VWO, HAVO (vanaf de vierde klas)	0	0
	e. Hoger beroepsonderwijs, bijvoorbeeld: HTS, HEAO, sociale academie, HBO-V, kweekschool, SPD-2/3, NIMA B/C, AMBI	0	0
	f. Wetenschappelijk onderwijs, bijvoorbeeld: universiteit, promotie	0	0
7	*Heeft u een computer, laptop of tablet (iPad) in uw bezit?*	0 Ja	0 Nee
8	*Heeft u thuis of elders toegang tot internet?*	0 Ja	0 Nee
9	*Maakt u gebruik van internet?*	0 Vaak 0 Soms	0 Nooit
10	*Vindt u dat u goed met internet om kan gaan?*	*0 Ja*	*0 Nee* *0 Matig*

Zie de volgende pagina

B. Open Vragen

Medische geschiedenis

1. Kunt u me iets vertellen over uw strottenhoofdkanker?
2. Kunt u me iets vertellen over uw behandeling voor strottenhoofd kanker?
3. Kunt u me iets vertellen over uw gezondheid nu?
4. Kunt me beschrijven welke mensen betrokken waren tijdens uw behandelingsproces? Welke relatie had u met hen?

Impact op het dagelijks leven

1. Hoe heeft uw strottenhoofdkanker uw dagelijks leven veranderd?
2. Wat mist u het meest van de tijd voordat u behandeld werd voor strottenhoofdkanker?

Diagnose en informatie

1. Begreep u alle informatie die u kreeg van uw behandeld arts?
    a. Waar had u meer over willen weten t.a.v. uw ziekte?
    b. Welke arts speelde een belangrijke rol in dit proces (bijvoorbeeld uw huisarts, de hoofd-hals chirurg, de radiotherapeut?)
    c. Heeft u tegenstrijdige informatie gekregen?
2. Welke onderdelen van informatie zijn het belangrijkst voor u (bijv. voor of nadelen behandeling, duur van behandeling, etc.) en waarom?
    a. Vond u dat er informatie ontbrak? Zou u misschien meer technische informatie willen of meer emotionele ondersteuning? Toegang tot bepaalde informatie bij het zikenhuis of thuis?
3. Heeft u zelf nog voor aanvullende informatie gezocht?
    a. Waarom wel of waarom niet?
    b. Welke soort informatie heeft u opgezocht en waar heeft u deze opgezocht?
    c. Wat vond u prettig aan deze informatie?
    d. Heeft u contact gehad met een lotgenoten vereniging?
4. Op welke manier zou u meer informatie willen krijgen over de verschillende soorten behandelingen? (tekst, video, etc.)

Behandelingskeuze

1. Was u betrokken bij het maken van een behandelingskeuze?
    a. Zo ja, hoe verliep dit proces?

b. Zo niet, waarom heeft u geen rol gespeeld in het maken van een beslissing?

2. Wat was het moeilijkst aan betrokken zijn bij het maken van een beslissing?
3. Wat was de rol van uw familie en vrienden in het proces van een keuze maken?
4. Als u drie dingen kon verbeteren in het proces van een behandelingskeuze maken, wat zouden deze zijn?
5. Wat zorgde ervoor dat u gekozen hebt voor de uiteindelijke behandeling?
6. Welk advies zou u geven aan iemand die net gediagnostiseerd is met larynxkanker?

Computervaardigheden

1. Zou u toegang willen hebben tot een computerprogramma die u kunt gebruiken in het proces van een behandelingskeuze maken? Waarom?

B2. Start keuzehulp middel

Laat patiënt na een korte toelichting het keuzehulp middel zien. Vraag de patiënt om het menu door te lopen terwijl opmerkingen worden genoteerd en ten minste de volgende algemene vragen worden gesteld:

Algemeen

1. Wat is uw eerste indruk van het keuzehulpmiddel?

2. Vind u het keuzehulp middel makkelijk te gebruiken?

3. Kunt u de tekst goed begrijpen?

6.2 Annex 2

Studie: “Evaluatie van tweede versie keuzehulptool voor gevorderd larynxcarcinoom”

Schriftelijke vragenlijst voor de patiënt

Control number: _____

Geachte heer/ mevrouw,

In deze vragenlijst staan vragen over het gebruik van het keuzehulpmiddel die u helpt bij het maken van uw behandelkeuzes en het bespreken van uw keuze met uw arts.

De vragen worden voorafgegaan door een korte instructie. Lees deze instructie zorgvuldig door. Het is voor het onderzoek van belang dat u zelf de vragenlijst invult en op alle vragen antwoord geeft. Na het invullen van deze vragenlijst kunt u de vragenlijst afgeven aan de onderzoeker.

A. Vragen die gaan over het gebruik van de Treatmentchoice.

Bij de vragen 1 t/m 17 ziet u cijfers staan die oplopen van 1 tot 5.

Aan beide kanten staan twee uitersten (“Helemaal niet mee eens” en “Helemaal mee eens”). Wilt u aangeven in welke mate het eens bent met onderstaande uitspraken?. Het is de bedoeling dat u het cijfer omcirkelt die het beste uw mening weergeeft..

	Helemaal niet mee eens	**Niet mee eens**	**Geen mening**	**Mee eens**	**Helemaal mee eens**
1. Ik heb geen hulp van anderen nodig bij het doorlopen van het keuzehulpmiddel.	1	2	3	4	5
2. De instructies van het keuzehulpmiddel zijn duidelijk.	1	2	3	4	5
3. Het doel van het gebruik van het keuzehulpmiddel is duidelijk.	1	2	3	4	5
4. Het keuzehulpmiddel is een goed hulpmiddel voor het geven van informatie.	1	2	3	4	5
5. Het keuzehulpmiddel heeft een prettige vormgeving.	1	2	3	4	5
6. De geschreven informatie over de behandelingen is goed te begrijpen.	1	2	3	4	5
7. De video fragmenten over de behandelingen zijn goed te begrijpen.	1	2	3	4	5
8. De geschreven informatie over de behandelingen is nuttig.	1	2	3	4	5
9. De video’s over de behandelingen zijn nuttig.	1	2	3	4	5
10. De informatie over de bijwerkingen is goed te begrijpen.	1	2	3	4	5
11. De informatie over de bijwerkingen is nuttig.	1	2	3	4	5
12. Het keuzehulpmiddel laat duidelijk de voor- en nadelen van de operatieve behandeling zien.	1	2	3	4	5
13. Het keuzehulpmiddel laat duidelijk de voor- en nadelen van de chemoradiatie zien.	1	2	3	4	5

14. Het keuzehulpmiddel laat duidelijk de voor- en nadelen van de bestraling zien.	1	2	3	4	5
15. Het keuzehulpmiddel helpt mij in het maken van mijn behandelkeuze.	1	2	3	4	5
16. Door het keuzehulpmiddel heb ik meer inzicht gekregen in wat ik belangrijk vind.	1	2	3	4	5
17. Ik zou iedere patiënt met larynxkanker aanraden om het keuzehulpmiddel te gebruiken als hulpmiddel bij het kiezen van een behandeling.	1	2	3	4	5
18. Get keuzehulpmiddel neemt te veel tijd in beslag.	1	2	3	4	5
19.De informatie over de behandelingsmogelijkheden gaf geruststelling.	1	2	3	4	5
20. Ik zou het keuzehulpmiddel thuis op de computer bekijken.	1	2	3	4	5
21. Hoeveel tijd heeft u nodig gehad om het keuzehulpmiddel te doorlopen? (Zelf invullen)	……. Minuten				
22. Welk rapportcijfer van 1 tot en met 10 zou u het keuzehulpmiddel willen geven? (Zelf invullen)	……. Rapportcijfer (1-10)				
23. Is er een onderwerp dat u miste? (Zelf invullen)	0 Nee 0 Ja, namelijk……				

Zie de volgende pagina

B. TREATMENTCHOICE

Bij de vragen 1 t/m 17 ziet u cijfers staan die oplopen van 1 tot 5.

Aan beide kanten staan twee uitersten (“Helemaal niet mee eens” en “Helemaal mee eens”). Wilt u aangeven in welke mate deze uitersten op u van toepassing zijn. Het is de bedoeling dat u het cijfer omcirkelt dat het beste uw mening weergeeft tussen deze 2 uitersten.

	Helemaal niet mee eens	**Niet mee eens**	**Geen mening**	**Mee eens**	**Helemaal mee eens**
1. Over het algemeen ben ik tevreden over het keuzehulpmiddel	1	2	3	4	5
2. Ik denk dat het keuzehulpmiddel de kwaliteit van patiëntenzorg kan helpen verbeteren.	1	2	3	4	5
3. Ik denk dat het keuzehulpmiddel patiënten kan motiveren actief deel te nemen in hun behandelkeuze.	1	2	3	4	5
4. Get keuzehulpmiddel functioneert goed.	1	2	3	4	5
5. Over het algemeen vind ik het keuzehulpmiddel gemakkelijk te gebruiken	1	2	3	4	5
6. Het keuzehulpmiddel leren gebruiken is gemakkelijk	1	2	3	4	5
7. Navigeren in het keuzehulpmiddel is gemakkelijk	1	2	3	4	5

	Helemaal niet mee eens	Niet mee eens	Geen mening	Mee eens	Helemaal mee eens
8. Het is duidelijk en gemakkelijk te begrijpen hoe het keuzehulpmiddel moet worden gebruikt.	1	2	3	4	5
9. Ik denk dat het keuzehulpmiddel een nuttig keuze hulpmiddel is.	1	2	3	4	5
10. Ik denk dat het keuzehulpmiddel me zal helpen makkelijker en meer over de behandel mogelijkheden te leren.	1	2	3	4	5
11. Ik denk dat het keuzehulpmiddel me zal helpen een goed overwogen beslissing te maken over mijn behandeling.	1	2	3	4	5
12. Ik zou anderen het keuzehulpmiddel aanraden	1	2	3	4	5
13. Ik zou het keuzehulpmiddel graag gebruikt hebben wanneer deze vooraf aan mijn behandeling beschikbaar was geweest.	1	2	3	4	5
14. Ik vind dat elke patiënt in het zikenhuis het keuzehulpmiddel zou moeten kunnen gebruiken.	1	2	3	4	5
15. Get keuzehulpmiddel geeft voldoende details over elke behandeling om een keuze te kunnen maken.	1	2	3	4	5
16. De inhoud van het keuzehulpmiddel is duidelijk en makkelijk te volgen.	1	2	3	4	5
17. De informatie in het keuzehulpmiddel is begrijpelijk en	1	2	3	4	5

correct.					
18. Het keuzehulpmiddel zal een dokters bezoek langer laten duren.	1	2	3	4	5

Zie de volgende pagina

C. ALGEMENE FEEDBACK - OPMERKINGEN

Benoem de punten van het keuzehulpmiddel die u **goed** vindt.

1.

2.

3.

Benoem de punten van het keuzehulpmiddel die u **niet goed** vindt.

1.

2.

3.

Heeft u verbeter punten? Dit onder andere kunnen veranderingen, toevoegingen of functionaliteiten zijn.

1.

2.

3.

Wilt u betrokken zijn bij toekomstige evaluaties van het keuzehulpmiddel? Zo ja, dan kunt u hier uw contact gegevens noteren.

Hartelijk dank voor het invullen van de vragenlijst.

Controleer even of u alle vragen heeft ingevuld.