Improving value of care for renal cell carcinoma patients: development of 2 Dutch decision aids

C.C. Bresser[1,2,3] , H.H.E. van Melick[2], P.B. van der Nat[1,3], M.M. Garvelink[1,3]

[1] Department of Value Improvement, St. Antonius Hospital, Nieuwegein, The Netherlands
[2] Department of Urology, St. Antonius Hospital, Nieuwegein, The Netherlands
[3] IQ Healthcare, Radboudumc, Nijmegen, The Netherlands

INTRODUCTION

- Every year, 2700 people in the Netherlands are diagnosed with kidney cancer. Renal cell carcinoma (RCC) occurs in 90% of the cases. Depending on the stage of the disease, there are various treatment options that differ between hospitals, contributing to practice variation.
- It is important that patients are properly informed about the treatment options and that they are involved in treatment decisions with their healthcare professional (HCP) about the most appropriate treatment option in their situation.
- Decision aids (DA) can support the decision-making process by providing information about options, pros and cons and eliciting personal preferences.
- **Aim:** to develop two Dutch decision aids for RCC: one for localized (T1) and one for metastatic disease.

METHODS

The development of the DAs were two **co-creation processes** with HCPs, patients and a patient representative, consisting of two phases (Figure 1):

1. **Needs assessment:** Patients treated for RCC were interviewed about their experiences with the care process and treatment decision-making. HCPs involved in RCC care completed a questionnaire about their preferences and needs for the DAs.
2. **Acceptability and usability testing:** Assessment of the compatibility of the DAs using the IPDAS- criteria. Both DAs were tested during think-out-loud sessions with 9 patients and interviews were held with 24 HCPs who have used them.

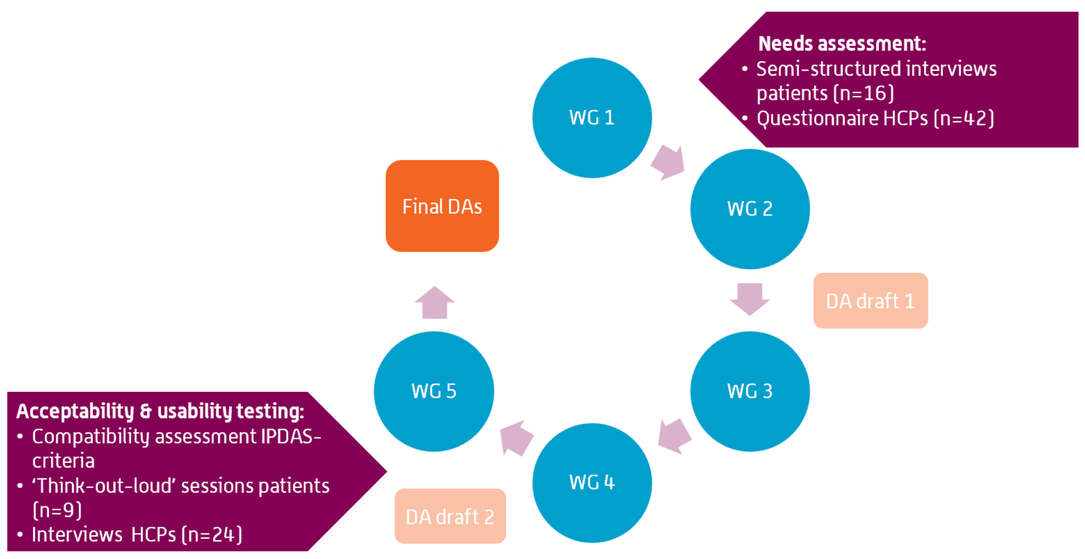


Figure 1. Development process of the DAs. WG = working group session, DA = decision aid, HCP = health care professional, IPDAS = International Patient Decision Aids Standards

During **five working group sessions** HCPs involved in RCC care from several Dutch hospitals and a patient representative determined the goal, target groups, content, and design of the DAs. During these sessions, the results from phases 1 and 2 were used.

RESULTS

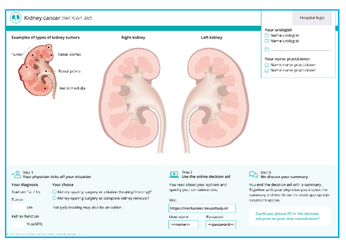
Both phases of the development process have been completed. There was a high need for DAs in both patients and HCPs (n=42) (phase 1). 16 Patients (100%) indicated a need for DAs. HCPs were asked whether a DA was desirable in a survey, in which 19 HCPs (51%) answered 'desirable' and 9 (24%) 'very desirable'.

Five working group sessions (n=18) were needed to arrive at two final concept DAs, which were positively received by patients and HCPs (phase 2). The DAs were positively received by all patients (n=9) and there were no HCPs who did not want to use the DAs.

The DAs consist of three components (Figure 2):
1) a **decision aid handout** containing an overview of treatment options,
2) an **online patient decision aid** containing information on RCC and treatment options and value-clarification and preference-elicitation exercises, and
3) a personal **decision aid summary** sheet containing the answers of these exercises.

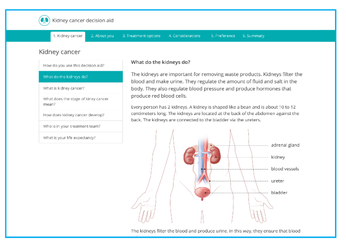
Currently, the DAs are being authorized by several professional associations. With the development of the DAs, we meet the needs of both patients and HCPs and contribute to improvement of care.

1. Health care professional hands out decision aid



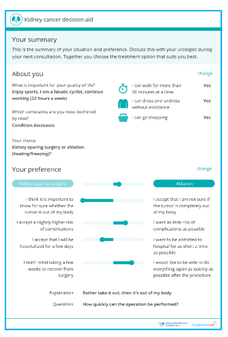
The health care professional explains the patient's diagnosis and treatment options using the decision aid handout. This sheet contains a unique login for the online patient decision aid.

2. Patient uses decision aid



The patient reads information in the online patient decision aid and lists their goals, considerations and treatment preferences.

3. Shared decision-making



The patient and health care professional discuss the patient's goals, considerations and preferences supported by the decision aid summary. Together they decide about the most suitable treatment.

Figure 2. Overview of the three components of the localized RCC DA.
RCC = renal cell carcinoma, DA = decision aid

CONCLUSION

- We expect that the DAs will be launched by the end of 2023.
- The existence and use of these two RCC DAs will contribute to high-quality, patient-centered and appropriate care for RCC patients in the Netherlands.
- As a next step, the effect of the DAs on the quality of the decision-making process and the decision itself will be studied in a pre-post study in six Dutch hospitals (SDM-RCC study).

Cato Caroline Bresser MD, PhD-candidate
St. Antonius Hospital Nieuwegein, The Netherlands
c.bresser@antoniusziekenhuis.nl