Decision Aids to Assist Icelandic Men with PSA Testing and Prostate Cancer Treatment Decision-Making

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Abstract

Prostate cancer (PC) is the second most common cancer among men globally and the most common cancer among Icelandic men. Early detection of PC is possible with a prostate-specific antigen (PSA) test. Before making a decision about PSA testing and before deciding which treatment to choose for localized PC, shared decision-making (SDM) is encouraged as many uncertainties are associated with those decisions and it is important that patients understand the pros and cons of all options before making a decision. Decision aids (DAs) have been found to enhance SDM by, for example, affecting patient involvement and patient-physician communication. While it is known that Icelandic men, newly diagnosed with PC, lack information about the pros and cons of different treatment options, no study to date has examined how much information Icelandic men receive about the pros and cons of PSA testing prior to undergoing PSA testing. Furthermore, DAs for PSA testing decision and PC treatment decision are not available in Icelandic. To address these limitations, the aims of the current Thesis were to; 1) establish the need for an Icelandic PSA testing DA, 2) translate and culturally adapt a pre-existing PSA testing DA for Icelandic men, and 3) develop, culturally adapt and extend an interactive DA to assist men, diagnosed with localized PC, to make a treatment decision.

In Paper I, all Icelandic men diagnosed with PC from 2015 to 2020 were invited to participate in a quantitative study evaluating how much information men receive about the pros and cons of PSA testing prior to undergoing a PSA test. Participants were 471 men aged 51 to 95 (M = 71.9, SD = 7.3). In Paper II, a pre-existing DA for PSA testing decision was translated and culturally adapted, and usability was tested in a mixed-methods study, first in a qualitative study and then in a quantitative study. Ten men, aged 51 to 66 (M = 59.9, SD = 5.6) participated in the qualitative study using a semi-structured interview and a questionnaire. Minor modifications were made to the DA following the qualitative study, whereafter, a quantitative study was conducted among 135 men aged 50 to 70 years (M = 59.7, SD = 5.2) to evaluate the final version of the DA. In Paper III, a DA for localized

PC treatment decision was culturally adapted, modified and extended. The usability of the DA was evaluated in a mixed-methods study, first in a qualitative study and then in a quantitative study. The qualitative study included semi-structured interviews and a usability scale and participants were 12 men, aged 58 to 80 years (M = 70.66, SD=6.58), diagnosed with PC. A thematic analysis of the interviews led to minor revisions of the DA. Then a quantitative evaluation of the usability of the final version of the DA was conducted among 11 newly diagnosed men with PC, aged 60 to 74 (M = 66.18, SD = 4.79).

Findings from Paper I underscored the need for an Icelandic PSA testing DA as Icelandic men lack information before making a PSA testing decision. Half of the participants received information about the pros and cons of PSA testing, a third did not receive any information and 22.2% did not even know they were being tested. Additionally, more than 80% of the men reported none or little knowledge of PSA testing. The findings of Paper II demonstrated that participants found the translation and cultural adaptation of the DA for PSA testing decision to be successful, as they found the DA helpful and comprehensible and almost all participants said they would recommend it to others. The results of Paper III demonstrated that the DA for treatment decision for localized PC was well received by participants. Participants were satisfied with the DA and the realistic information on side effects that was presented. They found the information about the pros and cons of treatment options helpful, and all noted they would recommend the DA to others facing the same decision. Currently, a randomized clinical trial is being conducted to evaluate the effectiveness of the DA for localized PC treatment decision.

The main results from the overall Thesis were that men do not receive adequate information about the pros and cons of PSA testing and that the DAs for PSA testing and localized PC treatment decisions were successfully modified. DAs have been shown to enhance SDM, be cost-effective, and have a minimal burden on the healthcare system. Therefore, the usage of DAs is likely to benefit both patients and healthcare providers of the Icelandic healthcare system.

Keywords: decision aids, shared decision-making, PSA testing, localized prostate cancer, treatment options.

Ágrip

Blöðruhálskirtilskrabbamein (BHKK) er annað algengasta krabbamein meðal karlmanna á heimsvísu og algengasta krabbameinið meðal íslenskra karlmanna. Mikilvægt er að skilja kosti og galla PSA (*prostate-specific antigen*) prófs, sem getur greint BHKK á frumstigi, og einnig kosti og galla mögulegra meðferðarúrræða við staðbundnu BHKK áður en ákvörðun er tekin þar sem ýmsir óvissuþættir fylgja þessum ákvörðunum. Ákvörðunartæki geta stuðlað að sameiginlegri ákvörðunartöku sjúklings og heilbrigðisstarfsfólks en slík ákvörðunartaka hefur jákvæð áhrif á þátttöku sjúklings í ákvörðuninni sem og á samskipti sjúklings og heilbrigðisstarfsfólks. Rannsóknir sýna að íslenska menn sem nýgreindir eru með BHKK, skortir upplýsingar um kosti og galla þeirra meðferðaleiða sem í boði eru. Hinsvegar hefur ekki verið rannsakað hvort íslenskir menn fái nægar upplýsingar um kosti og galla PSA prófs áður en þeir fara í slíkt próf. Hvorki ákvörðunartæki sem aðstoðar menn við að taka ákvörðun varðandi PSA próf né ákvörðunartæki sem aðstoðar menn við að taka ákvörðun um meðferðarleið fyrir BHKK eru í boði á íslensku. Því var markmið þessarar doktorsrannsóknar að 1) sýna fram á að það væri þörf fyrir íslenskt ákvörðunartæki sem aðstoðar menn áður en þeir taka ákvörðun varðandi PSA próf, 2) þýða yfir á íslensku og staðfæra ákvörðunartæki sem aðstoðar við ákvarðanatöku varðandi PSA próf, 3) þróa og staðfæra gagnvirkt ákvörðunartæki til að aðstoða menn, sem hafa greinst með staðbundið BHKK, við að taka ákvörðun um hvaða meðferðarúrræði henti þeim best.

Fyrsta rannsóknin var megindleg rannsókn þar sem kannað var hversu miklar upplýsingar menn fengu um PSA próf áður en þeir fóru í slíkt próf. Þátttakendur voru íslenskir menn, 471 talsins, á aldrinum 51 til 95 ára (*M* = 71.9, *SD* = 7.3) sem höfðu greinst með BHKK á árunum 2015 til 2020. Í næstu rannsókn var ákvörðunartæki, sem aðstoðar menn við ákvörðunartöku varðandi PSA próf, þýtt og staðfært. Síðan var blandaðri aðferð beitt til að kanna notagildi ákvörðunartækisins,

fyrst í eigindlegri rannsókn og síðan megindlegri. Samtals tóku 10 menn á aldrinum 51 til 66 ára (*M* = 59.9, *SD* = 5.6) þátt í eigindlegu rannsókninni þar sem notuð voru hálfstöðluð viðtöl og spurningalistar til að meta upplifun þátttakenda af ákvörðunartækinu. Niðurstöður eigindlegu rannsóknarinnar leiddu til smávægilegra breytinga á ákvörðunartækinu sem síðan var notendaprófað í megindlegri rannsókn meðal 135 manna á aldrinum 50 til 70 ára (M = 59.7, SD = 5.2). Í þriðju rannsókninni var ákvörðunartæki fyrir meðferðarákvörðun fyrir staðbundið BHKK staðfært og umfang þess aukið. Samtals tóku 12 menn á aldrinum 58 til 80 ára (*M* = 70.66, *SD*=6.58) þátt og allir höfðu þeir verið greindir með BHKK. Notendaprófun var gerð með hálfstöðluðum viðtölum og þátttakendur beðnir um að svara kvarða sem metur notandaupplifun. Þemagreining á viðtölunum leiddi í ljós að gera þurfti minniháttar breytingar á ákvörðunartækinu. Lokaútgáfa ákvörðunartækisins var síðan notendaprófuð í megindlegri rannsókn meðal 11 manna á aldrinum 60 til 74 ára (*M* = 66.18, *SD* = 4.79) sem voru nýgreindir með BHKK.

Niðurstöður fyrstu rannsóknarinnar leiddu í ljós að íslenskir menn fá ekki nægar upplýsingar áður en þeir fara í PSA próf og þar af leiðandi er þörf fyrir íslenskt ákvörðunartæki sem aðstoðar menn með ákvörðun varðandi PSA próf. Um helmingur þátttakenda fékk upplýsingar um kosti og galla PSA prófs áður en þeir fóru í prófið, þriðjungur fékk engar upplýsingar og 22.2% þátttakenda vissu ekki fyrirfram að það væri verið að mæla PSA gildin þeirra. Þar að auki greindu 80% þátttakenda frá að þeir hefðu litla eða enga þekkingu haft á kostum og göllum PSA prófs áður PSA gildið þeirra var mælt. Niðurstöður annarar rannsóknarinnar, á ákvörðunartæki fyrir PSA ákvörðun leiddi í ljós að bæði þýðing og staðfærsla ákvörðunartækisins að íslenskum aðstæðum tókst vel. Þátttakendum fannst ákvörðunartækið hjálplegt og auðskiljanlegt og nánast allir þátttakendur sögðust myndu mæla með því við aðra í sömu sporum. Niðurstöður þriðju rannsóknarinnar, á ákvörðunartæki fyrir meðferðarákvörðun fyrir staðbundið BHKK sýndi sömuleiðis fram á að þátttakendur voru ánægðir með tækið og þær upplýsingar sem þar var að fá. Sérstaklega voru þeir ánægðir með þær raunsæju upplýsingar um aukaverkanir sem voru gefnar í tækinu og þeim fannst einnig upplýsingar um kosti og galla hverrar meðferðar gagnlegar. Að auki sögðu allir þátttakendur að þeir

myndu mæla með ákvörðunartækinu við aðra í sömu sporum. Nú fer fram slembiröðuð klínísk rannsókn til að meta virkni ákvörðunartækisins fyrir meðferðarúrræði við staðbundnu BHKK.

Á heildina litið eru niðurstöður doktorsrannsóknarinnar þær að íslenska karlmenn fá ekki nægar upplýsingar áður en þeir fara í PSA próf og að þátttakendur voru ánægðir með bæði ákvörðunartækin. Niðurstöður benda til þess að ákvörðunartækin geti komið að góðum notum fyrir menn sem standa frammi fyrir þessum ákvörðunum. Rannsóknir hafa sýnt að ákvörðunartæki auka þátttöku sjúklinga í ákvörðunartöku, eru hagkvæm og auka ekki álag innan heilbrigðiskerfisins. Ákvörðunartæki ættu því að nýtast vel innan íslenska heilbrigðiskerfisins bæði fyrir sjúklinga og heilbrigðisstarfsfólk en jafnframt fyrir heilbriðiskerfið allt.

Lykilorð: ákvörðunartæki, sameiginleg ákvarðanataka, PSA próf, staðbundið blöðruhálskirtilskrabbamein, meðferðarúrræði.

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List of Studies

This Thesis is based on the following original publications, which are referred to in the text by their Roman numerals (I-III).

I. Eiriksdottir, V.K., Baldursdottir, B. Fridriksson, J.O. & Valdimarsdottir, H.B. (2022). How much Information do Icelandic Men Receive on Pros and Cons of Prostate-specific Antigen Testing Prior to Undergoing Testing? *American Journal of Men's Health, 16*(3). DOI:10.1177/15579883221097805

II. Eiriksdottir, V.K., Baldursdottir, B. Taylor, K. L., Fridriksson, J.O, Einarsdottir, S.E., Palsson, G. & Valdimarsdottir, H.B. Icelandic Translation and Cultural Adaptation of an Interactive Web-based Prostate-specific Antigen (PSA) testing Decision Aid. [*Manuscript submitted for publication].*

III. Eiriksdottir, V.K., Jonsdottir, T. Valdimarsdottir, H.V., Taylor, K. L., Schwartz, M. D., Hilmarsson, R., Gudmundsson, E.O., Fridriksson, J.O. & Baldursdottir, B. (2021). An Adaptation, Extension and Pre-Testing of an Interactive Decision Aid for Men Diagnosed with Localized Prostate Cancer in Iceland: A Mixed-Method Study, *Behavioral Medicine*, *49*(2), 137-150. DOI:10.1080/08964289.2021.2000926.

Declaration of Contribution

The doctoral candidate, Valgerður Kristín Eiríksdóttir (VKE), wrote this doctoral Thesis under the guidance of Heiðdís B. Valdimarsdóttir (HBV) and Birna Baldursdóttir (BB), supervisors, and the Thesis committee, Kathryn L. Taylor (KLT), Laufey Tryggvadóttir (LT) and Bjarki Þór Elvarsson (BÞE). Further collaborators on the manuscripts were Jón Örn Friðriksson (JÖF), Þórdís Jónsdóttir (ÞJ), Marc D. Schwartz (MDS), Rafn Hilmarsson (RH), Eiríkur Orri Guðmundsson (EOG), Sigrún Elva Einarsdóttir (SEE) and Guðmundur Pálsson (GP). The contribution to each study was as follows:

I. VKE designed the research in collaboration with HBV, BB and JÖF. VKE applied for ethical permits and was responsible for the data collection, data analysis and interpretation of results and writing the manuscript with input from HBV, BB and JÖF. HBV, BB and JÖF revised the manuscript. VKE integrated comments and finalized the manuscript. All the authors read and approved the final manuscript.

II. VKE, BB, KLT and HBV designed the research. VKE, BB and SEE translated the DA. VKE, BB, SEE, JÖF and HBV proofread the text of the Decision aid (DA) and modified it. GP oversaw the user interface (UX) design of the DA and led the online publication of the DA. VKE collected qualitative data, oversaw the collection of quantitative data, analyzed the data and drafted the manuscript. BB, KLT, JOF, SEE and HBV revised the manuscript. VKE integrated comments and finalized the manuscript. All the authors read and approved the final manuscript.

III. VKE, ÞJ, HBV, BB, KLT and MDS designed the research in collaboration with RH, EOG and JÖF. VKE applied for ethical permits and collected quantitative data and ÞJ collected qualitative data. VKE was responsible for data collection, data analysis and interpretation of results. VKE wrote the manuscript in collaboration with ÞJ, with input from HBV, BB, KLT, MDS, RH, EOG and JÖF. HBV, BB, KLT, MDS, RH, EOG and JÖF revised the manuscript. VKE integrated comments and finalized the manuscript. All the authors read and approved the final manuscript.

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List of Abbreviations

CT	Computerized tomography
DA	Decision aid
DRE	Digital rectal exam
IPDAS	The International Patient Decision Aid Standards
IPDASi	The IPDAS instrument
MRI	Magnetic resonance imaging
PC	Prostate cancer
PET	Positron emission tomography
PSA	Prostate-specific antigen
RCT	Randomized clinical trials
SDM	Shared decision-making
SUS	System Usability Scale
VCE	Values clarification exercise

1 Introduction

Prostate cancer (PC) is the second most common cancer in men worldwide (Bray et al., 2018). Two unique aspects of PC separate it from many other cancers. First, even though early detection is possible, it is controversial as it can lead to over-diagnosis and over-treatment and does not affect the overall mortality rate (Andriole et al., 2009; Djulbegovic et al., 2010; Fenton et al., 2018; Lin et al., 2008; Pathirana et al., 2019; Regional Cancer Centres, 2022; Schröder et al., 2014; US Preventive Services Task Force et al., 2018; Vickers, 2017). Second, when localized PC has been detected there are several treatment options available, but none is more effective than the others, and all have similar survival rates but differ greatly when it comes to side effects (Donovan et al., 2016; Hamdy et al., 2016, 2023; Lane et al., 2016). Shared decision-making (SDM) is encouraged for both PSA testing decision and PC treatment decision as they involve many uncertainties. Therefore, it is important that patients understand the risk and benefits of all options before making a decision. Decision aids (DAs) can support the process of SDM by providing information about the risks and benefits of all available options and helping patients understand their values and preferences to make a shared decision with their healthcare provider.

1.1 The Prostate

The prostate is an organ that is only found in males and produces one-third of the seminal fluid. The prostate is a part of the male reproductive system and is located below the bladder and in front of the rectum. It is the size of a walnut, or around 20-30 ml, in young men but commonly grows with age and can cause benign conditions like prostatitis (prostate inflammation) and prostatic hyperplasia (prostate enlargement). These conditions do not lead to PC (National comprehensive cancer network, 2020).

1.2 Prostate cancer

PC develops when cells in the prostate gland grow out of control. PC is the second most common cancer in men globally, the fourth most common cancer overall and the sixth leading cause of cancer death among men (Sung et al., 2021). In Iceland, PC is the most common cancer in men, with approximately 24% of all cancers diagnosed yearly as PC (National Cancer Institute, 2011; The Icelandic Cancer Registry, 2021; The Icelandic Cancer Society, 2017). PC can grow at different speed, some develop and grow quickly, although the majority grows slowly. At an early stage, PC can be asymptomatic, requiring minimal or no treatment (Rawla, 2019). More than 80% of men over 80 develop PC, although most are not aware of it and die from health problems unrelated to the PC (Leslie et al., 2020). Well-established risk factors for PC are family history, older age and being of African descent (Cuzick et al., 2014).

1.2.1 Diagnosis of prostate cancer

Detection of PC is possible at an early stage by a blood test that measures a protein called prostate-specific antigen (PSA) and with a digital rectal exam (DRE). A PSA test measures the level of PSA protein produced in the prostate gland. Elevated levels of the PSA protein (> 4 ng/ml) can indicate PC (Cuzick et al., 2014). Although elevation in PSA levels could indicate PC, it can also be caused by benign conditions such as prostatitis (prostate inflammation), prostatic hyperplasia (prostate enlargement) and urinary tract infection (Schröder, 2009). A PSA test, DRE or a combination of both do not give a final diagnosis of PC as further examinations like prostate biopsy and imaging studies are needed to get a definite diagnosis (National comprehensive cancer network, 2020). In a prostate biopsy, a small tissue sample is removed from the prostate with a thin needle to test for cancer. Magnetic resonance imaging (MRI) can be used to scan the prostate or to scan the body as whole, to determine if the cancer has spread. Computerized tomography (CT) scan, positron emission tomography (PET) scan and isotope bone scan are also used to determine if the cancer has spread (National comprehensive cancer network, 2020).

1.2.2 Prostate cancer screening / PSA testing

PSA blood test can detect PC early, however, unlike many other cancers, early detection/screening is controversial. Many guidelines recommend against population-based screening for PC, but the majority of medical organizations encourage men between the ages of 50 and 70 (note that recommendations might vary slightly between medical organizations) to consider the benefits and risks of PSA testing and make a shared decision with their healthcare provider (Djulbegovic et al., 2010; Lin et al., 2008; Regional Cancer Centres, 2022; US Preventive Services Task Force et al., 2018; Vickers, 2017). The clinical guidelines in Iceland for PSA testing follow the Swedish guidelines, where PSA testing for asymptomatic men is neither recommended nor discouraged, but the pros and cons should be considered before making a decision (Fridriksson, J.O., personal communication, February 16, 2023; Regional Cancer Centres, 2022).

Even though PC can be detected at an early stage, large randomized clinical trials (RCT) have reported mixed outcomes on the benefits of PC screening with PSA testing. These RCTs show that PC screening only leads to a small reduction in 10-year disease-specific mortality and does not affect the overall mortality rate (Andriole et al., 2009; Djulbegovic et al., 2010; Hayes & Barry, 2014; Ilic et al., 2018; Lin et al., 2008; Pinsky et al., 2019; Schröder et al., 2014). Additionally, PSA testing does not detect the aggressiveness of a tumour and therefore cannot identify if tumours will become clinically relevant or not. Many PCs develop slowly and do not cause any problems. Hence, PSA testing in asymptomatic men can lead to over-diagnosis, meaning a disease that does not cause symptoms or death is diagnosed. In fact, it is estimated that 20-50% of PC are over-diagnosed (Fenton et al., 2018; Pathirana et al., 2019). Another problem with PSA testing is the specificity of the test, and evidence suggests that PSA tests have low specificity for PC detection (Merriel et al., 2022). For example, around 18% of PSA test results are false positive, that is, a disease is detected when the person does not have the disease (Fenton et al., 2018). False positive results and over-diagnosis require additional tests and medical procedures that can cause the individual physical harm as well as stress and anxiety. They may also lead to excess diagnostic evaluations and over-treatment that can result in lasting side effects such as urinary problems and sexual dysfunction (Djulbegovic et al., 2010; Ilic et al., 2018; Lin et al., 2008; Orom et al., 2015; Vickers, 2017). Because of this, deciding whether to undergo PSA testing can be stressful, and at times, with unnecessary side effects following. Therefore, it is crucial that men understand the benefits and risks of PSA testing before making a decision.

1.2.3 Information received prior to prostate cancer screening / PSA testing

Despite the underscored importance that men understand the pros and cons of PSA testing prior to getting tested, studies have shown that the information that men receive before getting a PSA test is limited (e.g., Cooper et al., 2019; Fridriksson et al., 2012; Han et al., 2013; Hoffman et al., 2009; Lamplugh et al., 2006; Leyva et al., 2016). For example, Lamplugh et al. (2006) reported that 64% of patients that underwent PSA testing reported that they did not have adequate knowledge to make the decision and Fridriksson et al. (2012) showed that 27.1% of men did not receive any information about pros and cons of PSA testing prior to being tested. Similar results were reported in an Icelandic study (Paper I), where 27.9% received no information prior to PSA testing, and over 80% reported low level or no knowledge of the pros and cons of PSA testing (Eiriksdottir et al., 2022).

A systematic review by Hoffman and Del Mar (2015) showed that patients have unrealistic expectations of the benefits and harms of screening as they tend to overestimate the benefits and underestimate the harm. Related to this, a study showed that 67.3% of men reported that they considered it essential to get a PSA test frequently (Martins et al., 2013). Other studies have reported positive attitudes and willingness among men to undergo PC screening (Ojewola et al., 2017; Ugochukwu et al., 2019; Yeboah-Asiamah et al., 2017). This is interesting since PC screening is controversial and does not affect overall mortality (Djulbegovic et al., 2010; Ilic et al., 2018; Lin et al., 2008; Pinsky et al., 2019; Vickers, 2017).

1.2.4 Treatment options for localized prostate cancer

PSA testing and additional tests can result in PC diagnosis with the majority or about 90% of PCs being limited to the prostate gland, referred to as localized PC (American Cancer Society, 2020; Siegel et al., 2020). Several treatment options are available for localized PC, particularly the types of localized PC that have a low or intermediate risk of spreading, but all have their benefits and risks (Donovan et al., 2016; Hamdy et al., 2016; Lane et al., 2016). The treatment options available are either curative treatments or active surveillance of the cancer's progress. The curative treatments’ aim is to cure the cancer and include radical prostatectomy, internal radiation therapy/brachytherapy, and external beam radiation therapy. Radical prostatectomy involves removal of the prostate gland, but external beam radiation therapy and brachytherapy are radiation therapies. In brachytherapy, radioactive seeds are placed within the prostate gland to kill tumour cells, but in external beam radiation therapy, radiation beams are aimed directly at the tumour to kill tumour cells (National comprehensive cancer network, 2020). In active surveillance, the goal is to follow the patient’s condition and possible changes in tumour growth. That includes regular monitoring of the progress of the cancer and cancer symptoms with PSA test, DRE, prostate biopsy, and MRI (National comprehensive cancer network, 2020).

All of those treatment options have similar survival rates and none has been determined more effective than the other (Hamdy et al., 2016, 2023). However, those treatment options differ largely when it comes to severity, frequency and duration of side effects (Chen et al., 2009; Donovan et al., 2016; Hamdy et al., 2016; Lane et al., 2016; National Cancer Institute, 2011). Common side effects of active surveillance are emotional, like cancer worries and distress (Orom et al., 2017) but common side effects of curative treatments are physical, such as urinary incontinence (inability to control urine flow), urinary retention (inability to empty the bladder), and erectile dysfunction (inability to maintain or achieve erection) (Donovan et al., 2016; Hamdy et al., 2016).

The side effects of curative treatments can be temporary or long-term (Chen et al., 2017; Donovan et al., 2016; Lane et al., 2016). For example, erectile dysfunction was reported to affect 78% of those that underwent radiotherapy and up to 88% of those that chose to get radical prostatectomy, six months post-treatment (Donovan et al., 2016). Many that undergo radical prostatectomy report a lack of sexual function as a big or moderate problem, or 54.5%, and only 12% report that it is not a problem. In addition, 20% report dripping or leakage as a big or moderate problem. Similar results are seen for men that undergo radiation therapy, where 44.5% report sexual function as a big or moderate problem and only 15% report that it is not a problem (EUPROMS, 2021; Venderbos et al., 2021).

A year after undergoing curative treatment, 56% of patients reported erectile problems to be worse than they expected, 28% reported worse than expected urinary problems and 17% reported bowel problems that were worse than expected. In addition, 24% reported worse fatigue than expected (Wollersheim et al., 2020). Because these side effects can be long-term and burdensome, some experience regrets after treatment, especially those who undergo radical prostatectomy (Slomski, 2022).

In addition to side effects, some men experience decisional conflict before making a treatment decision (Berry et al., 2013; Ragnarsdóttir et al., 2011; Shirk et al., 2017). Decisional conflict is the perception of uncertainty about which option to choose when the options involve different risks (North American Nursing Diagnosis Association, 2003). Contributing factors to decisional conflict are; being unclear about their own values, feeling uninformed and unsupported in the decision, and having little knowledge about treatment options (Aning et al., 2012; Chien et al., 2014; Christie et al., 2015; Diefenbach & Mohamed, 2007b; Kaplan et al., 2014; Stacey et al., 2008). Those that experience decisional conflict also tend to be more likely to delay decision-making, change their mind and experience decisional regret (Sun, 2005).

1.2.5 Information received prior to prostate cancer treatment decision

Studies have shown that PC patients prefer to be involved in their treatment decision and patients that are involved in the decision-making process report better outcomes (e.g., higher quality of life, higher physical and social functioning, and less fatigue) (Fischer et al., 2006; Hack et al., 2006; Oshima Lee & Emanuel, 2013; Sepucha & Mulley Jr., 2009; Steginga et al., 2002; Stewart, 1995). Despite these findings, PC patients lack information and understanding about treatment options and their side effects (Daum et al., 2017; Fowler et al., 2012; Kaplan et al., 2014; Reykdal et al., 2011; Snow et al., 2007). For example, it has been shown that 80% of newly diagnosed Icelandic men with PC report little knowledge about PC treatment options and related side effects (Reykdal et al., 2011). Another study reported that PC knowledge among newly diagnosed PC patients was low and that more than a third of patients that had a curative treatment did not know about the possible long-term side effects they could entail (Daum et al., 2017). Because of the lack of understanding among PC patients about their disease and treatment options, misapprehension, anxiety, and fear can drive the decision-making process (Gwede et al., 2005; Johansson et al., 2011; Latini et al., 2007; McGregor, 2003). Therefore, many rely on their physician to make the treatment decision. Nevertheless, the goals for PC care often differ between physicians and patients and the speciality of the physician can affect the treatment they recommend. In fact, urologists more often recommend radical prostatectomy and radiation oncologists are more likely to recommend radiation therapy (Davison et al., 2009; Fowler et al., 2000; Sommers et al., 2008). If the treatment decision is made without the patient considering the treatment's side effects, it can later cause decisional regret and less decisional satisfaction (Aning et al., 2012; Diefenbach & Mohamed, 2007b). Furthermore, involving the patient in the decision leads to better treatment outcomes (Fischer et al., 2006; Hack et al., 2006).

1.3 The Icelandic healthcare system

In Iceland the healthcare system is mainly publicly funded state-centred system with universal coverage for all residents. The Parliament is responsible for the regulation, policy, financing and planning of the healthcare system. Most healthcare providers are public but recently there has been an increase in both private non-profit and private for-profit healthcare providers. All hospitals in Iceland are public and provide inpatient and ambulatory care. Outpatient care is provided by private medical specialist (European Observatory on Health Systems and Policies, 2021). Prostate cancer is often diagnosed at primary healthcare centres (publicly operated and funded) as well as at private healthcare providers (privately operated but publicly funded), after which patients are referred to a hospital. If the prostate cancer is localized, patients get a consultation with a urologist and an oncologist to discuss treatment options and following make a shared decision about treatment plan (Guðjónsson, 2021; Ministry of Health, 2016).

1.4 Shared decision-making in healthcare

As stated in section 1.2.5, it is clear that patients lack information in the decision-making process, both prior to PSA testing decision and prior to making a localized PC treatment decision. In this respect, it is important to underline that patients have the right to be informed about their own health, including medical information about their condition and prognosis. They also have the right to be informed of the planned treatment, its risks and benefits, other possible treatments besides the planned treatment and the consequence of no treatment. Healthcare providers are obliged to inform their patients about those issues, but how this should be carried out is not regulated. Therefore, it is entirely under the healthcare providers how they inform their patients (Olejarczyk & Young, 2022).

For the past decades, there has been an increased focus in the healthcare system to move towards patient-centred care and involve patients in their own healthcare decision-making. Patient-centred care is defined by the Institute of Medicine as follows:

> "…care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (Institute of Medicine, 2001).

Before the 1980s, the most common approach to healthcare decision-making was the *paternalistic approach* that involves a healthcare provider individually or in co-operation with other healthcare providers deciding what is the best intervention or treatment for a patient and then informing the patient of the decision and getting the patient to follow that decision. During the 1980s, the paternalistic approach began to be challenged as more and more diseases had no best treatment option and a treatment decision relied largely on trade-offs between risks and benefits, whereafter the patient had to live with the consequences of the decision (Eddy, 1990; Lomas & Lavis, 1996). To address these challenges, the informed and shared decision approaches were developed to compensate for the flaws in the paternalistic approach (Charles et al., 1999). The *informed approach* is the opposite of the paternalistic approach as the patient is informed of all possibilities and it is up to the patient to make the decision. The *shared approach* combines the paternalistic and informed approaches where the healthcare provider shares their expert information with the patient and the patients share their values with the healthcare provider and together they make a shared decision (Charles et al., 1999). The shared decision-making approach and informed decision-making approach, encompass similar elements. Informed decision-making involves providing balanced, understandable and evidence-based information to promote a decision that is not limited to clinical settings (Briss et al., 2004). Shared decision-making (SDM) also involves providing balanced, understandable and evidence-based informations but is more comprehensive and more personalized and includes an interaction between a healthcare provider and a patient, where they exchange information and is limited to clinical settings (Charles et al., 1997, 1999).

SDM is often referred to as the crux of patient-centred care and is becoming the norm in western countries as there is consensus that healthcare should be based on the patient’s needs and that patients have the rights to be involved in their own healthcare decisions (Härter et al., 2017; Stiggelbout et al., 2012). Most people need to make decisions about their own health at some point in their life. Sometimes, the decision is easy because only one option has better outcomes than others, but more often the decision is not that straightforward because no option is best or no option has significantly better outcomes than others. Thus, people have to weigh the risks and benefits of each option and make a decision that fits their values best. In SDM, the healthcare provider shares evidence-based information about the decision and the patient shares their values, preferences and needs regarding the decision. SDM allows discussion and sharing of information so that the patient can understand the pros and cons and outcomes of each option. The healthcare provider and patient mutually decide on a care plan based on the healthcare provider’s expertise, evidence-based information and the patient’s preferences and values (Charles et al., 1997, 1999; Weston, 2001).

With the growing focus on patient-centred care and involving patients in their own healthcare decision-making, increasing trends have been reported among patients preferring SDM when it comes to their own health decisions. Before 1990, only 43% preferred SDM, between 1990 and 2000, 51% preferred SDM and after the year 2000, 71% of patients preferred SDM with the preference being higher among cancer patients or 85% (Chewning et al., 2012). The importance of SDM is reflected in research demonstrating that patients who are involved in their own health decision-making fare better than those who are not and SDM has been linked with better quality of life, better social functioning, less decisional regret, less anxiety about treatment choices and more patient satisfaction (Hack et al., 2006; Oshima Lee & Emanuel, 2013; Sepucha & Mulley Jr., 2009; Stewart, 1995).

Often, patients and healthcare providers have a different focus when it comes to making a treatment decision, and therefore it is important to take both sides into account. For example, patients with breast cancer that were considering their treatment options focused on multiple components in their decision-making like adverse effects and impact on fertility and daily life while physicians focused more on survival (Lee et al., 2010). In addition, when uncertainty is a component in the decision-making process, people are susceptive to bias and sometimes rely on heuristics, which also applies to healthcare providers (Tversky & Kahneman, 1992). Often patients do not have the skills to interpret probabilities and need their physicians to interpret those for them (Woloshin et al., 2001). Therefore, SDM is important in healthcare as a way to combine the values and wishes of the patient with the physician’s specialized advice (Charles et al., 1997). SDM is useful when it comes to medical decisions where there are more than one reasonable option and the decision depends on the preferences, values, and needs of the patient (Charles et al., 1997, 1999; Weston, 2001). Therefore, PSA testing decision and PC treatment decision epitomize SDM, since those decisions have more than one reasonable option and the decision depends on the patient’s preference, values, and needs.

As discussed below, DAs have been developed and tested to enhance SDM. DAs inform patients about their disease and the pros and cons of all possible treatment options and can bridge the gap between the healthcare provider and the patient (Durand et al., 2008; Stacey et al., 2011, 2017; Taylor et al., 2010; Volk et al., 2007).

1.5 Decision aids

With increased focus on SDM and encouraging people to take part in their own health decisions, there is an increased need for resources to support SDM. DAs are evidence-based tools that assist healthcare providers and patients reach a shared health decision. They can assist patients with a wide range of health decisions, like screening decisions, treatment decisions and post-treatment follow-ups (The Ottawa Hospital Research Institute, 2020). DAs can be helpful when there is more than one treatment option, when the options have different pros and cons that can be valued differently between patients and when there is no one option that is better than others when it comes to outcomes, such as mortality (O’Connor, Fiset, et al., 1999; O’Connor, Rostom, et al., 1999; Stacey et al., 2011). The primary goal of a DA is to promote patients' involvement in decision-making, improve patients' knowledge of each option, give more precise expectations of risks and benefits of options, and assist the patient in making a decision with their healthcare provider in accordance with their values and preferences (O'Connor, Rostom, et al., 1999; Stacey et al., 2011). DAs are also intended to provide information about the patient’s options in a balanced and impartial way and help patients think about their options as well as the pros and cons of each option (Knops et al., 2013; O’Connor, Fiset, et al., 1999; O’Connor, Rostom, et al., 1999; Stacey et al., 2011). Thus, DAs facilitate patient participation in making a shared health decision. However, DAs should neither advise one option over another nor replace a consultation with a physician, rather, they should support SDM and improve the quality of a decision (Coulter, 2003).

DAs come in many shapes and sizes, e.g., in the form of a website, brochure, or video. DAs often contain the following: information about the disease and available treatment/screening options, the risk and benefits of each treatment/screening option, uncertainties with each option and a values clarification exercise (VCE). A VCE assists patients in understanding what aspects of treatment options/screening options are important to them and helps them communicate that to their physicians. A VCE is also intended to guide the decision-making to the best outcome for the patient (O'Connor et al., 2005).

Studies have shown that DAs improve patients' knowledge and quality of care, increase decisional satisfaction, decrease distress, decisional regret and decisional conflict and additionally, improve communication with physicians as well as encourage patients to take a more active role in decision-making (Stacey et al., 2011, 2017; Taylor et al., 2010; Volk et al., 2007). Further, research indicates that DAs can reduce cost in the healthcare system by decreasing the number of patients that choose elective surgery and more invasive options when other options are available. When less invasive treatments are chosen, healthcare costs can be reduced in the long term (Oshima Lee & Emanuel, 2013; Stacey et al., 2017). For example, patients that used a DA before hip and knee replacement treatment decision were more likely to choose a less invasive treatment, which resulted in 26% fewer hip replacement surgeries and 38% fewer knee replacement surgeries that further led to 12-20% lower cost over the course of 6 months (Arterburn et al., 2012).

1.5.1 The International Patient Decision Aid Standards

It is important to evaluate the effectiveness and quality of healthcare interventions, such as DAs. Therefore, the International Patient Decision Aid Standards (IPDAS) collaboration was established in 2003. The aim of IPDAS is to increase the effectiveness and quality of DAs for patients by constructing an evidence-informed framework and criteria to support the evaluation, development and implementation of DAs (Elwyn et al., 2006; O'Connor et al., 2005).

The IPDAS instrument (IPDASi) was designed to rate the quality of DAs in a quantitative assessment. The IPDASi measures the quality of the DA using criteria within 12 domains and the results from all domains give an overall quality score of a DA (Elwyn et al., 2009). The domains are the following:

> (1) systematic development process; (2) providing information about options; (3) presenting probabilities; (4) clarifying and expressing

> values; (5) using patient stories; (6) guiding or coaching in deliberation and communication; (7) disclosing conflicts of interest; (8) delivering patient DAs on the internet; (9) balancing the presentation of options; (10) using plain language; (11) basing information on up to date scientific evidence; and (12) establishing effectiveness (Elwyn et al., 2006).

These criteria allow developers and users to assess if DAs include recommended components and if they underwent an evaluation to ensure their quality (Elwyn et al., 2006, 2009). The criteria that the IPDAS collaboration has set forth are considered essential to ensure that DAs are of high quality and minimize the risk of DAs containing harmful bias (Joseph-Williams et al., 2014).

1.5.2 Interactive web-based decision aids

One of the criteria IPDAS recommends is delivering DAs on the internet (Elwyn et al., 2006). Research indicates that web-based programs increase knowledge more efficiently than brochures, video and verbal information (Wantland et al., 2004). They have also been shown to improve preference-sensitive decision-making, mostly because the user has more control over access to the information (Syrowatka et al., 2016). Furthermore, web-based programs are more easily updatable and reachable than, for example, brochures. Interactive technology has been shown to increase interest and help individuals learn more efficiently and easily. It allows for flexible usage, instant feedback and for the user to pursue additional information (Banegas et al., 2013; Bollinger & Kreuter, 2012; Fotheringham et al., 2000).

1.5.3 Values clarification exercises in decision aids

IPDAS also recommends including methods in DAs that assist the user in clarifying and expressing values, such as VCE (Elwyn et al., 2006). VCEs assist people in communicating and forming their relative desirability of decision options. The goal of VCE is to encourage the patient to reflect on which aspects of the available options are most important to them. Thus, making it easier for the healthcare provider to understand the values and preferences of the patient and guide the decision towards the best outcome for the patient built on evidence-based information and the patient’s preferences. VCEs can be either implicit or explicit.

Implicit VCE encourages people to think about their options by learning about the risks and benefits in a non-interactive way, e.g., by using a balance sheet to evaluate each option or listening or watching others give testimonials about their decision (O’Connor et al., 2005). Explicit VCE, on the other hand, requires the patient to engage in an action, for example adding weights to a scale or moving bars. To do this, the patient has to contemplate the impact that each value has on the decision (O’Connor et al., 2005). Research indicates that the use of VCE in DAs leads to patients being better prepared to make a health decision and that patients that used VCE reported less decisional regret compared to those that did not (Feldman-Stewart et al., 2012; O’Connor, Wells, et al., 1999; Peate et al., 2013). Additionally, DAs that include explicit VCE have been shown to lead the patient to a decision that is more congruent with their values than DAs that solely use implicit VCE (O’Connor, Wells, et al., 1999; Peate et al., 2013).

1.5.4 Decision aids for PSA testing decision

As described earlier, many guidelines recommend against population-based screening but encourage SDM when it comes to periodic PSA testing in asymptomatic men between the age of 50 and 70 (Fenton et al., 2018; Mottet et al., 2017). Prior to the shared decision, the patient and healthcare provider should discuss and consider the pros and cons of each option based on comorbidity, family history and race as well as other health needs of the patient and take into the account the patients values and preferences (Carter et al., 2013; Fenton et al., 2018; US Preventive Services Task Force et al., 2018; Wilt et al., 2015). Those that do not express a preference for PSA testing should not be tested (Fenton et al., 2018).

The purpose of DAs for PSA testing is to support the SDM process for asymptomatic men over the age of 50 and under the age of 70 and assist them in making the best decision for them, where their preferences, values, and needs are met. DAs for PSA testing have been tested in RCTs, and have been shown to improve knowledge, increase decisional satisfaction and patient involvement in decision-making as well as reduce decisional conflict (Allen et al., 2010; Baptista et al., 2018; Ivlev et al., 2018; Taylor et al., 2013; Tomko, Davis, Ludin, et al., 2015).

Paper-based and web-based DAs for PSA testing have been shown to increase knowledge and participation in SDM and decrease decisional conflict (Baptista et al., 2018). However, web-based DAs are less costly, more easily modifiable and available for the user (Baptista et al., 2018; Hoffman et al., 2013). Although there are available DAs for men considering PSA testing, most are only available in English, and none are available in Icelandic. It is, however, important to be able to access evidence-based health educational material in your native language before making a health decision. Language can, thus, be a barrier to accessing health educational material since most health educational material is only available in English (Adams & Fleck, 2015).

1.5.5 Decision aids for localized prostate cancer treatment decision

The available treatment options for those that are diagnosed with localized PC, all offer similar survival rates and effectiveness (Albertsen et al., 2005; Hamdy et al., 2016, 2023; Wilt et al., 2012, 2020). However, those treatment options differ largely when it comes to severity, frequency and duration of side effects (Chen et al., 2009; Donovan et al., 2016; Hamdy et al., 2016; Lane et al., 2016; National Cancer Institute, 2011). Since no one treatment option is the optimal treatment for localized PC, it is important that patients understand the risk and benefits of the available options and make a shared decision with their healthcare provider that is based on the patient’s preferences, values, and needs.

Decisional regret often increases the year following a PC treatment and is particularly common among those that undergo a radical prostatectomy. It is common that men make treatment decisions without considering post-treatment quality of life and, therefore, experience decisional regret because of the unexpected side effects that follow treatments (Aning et al., 2012). Making an important medical decision in a state of heightened distress can lead to decisional regret later and more distress among PC patients (Diefenbach & Mohamed, 2007a). However, decisional regret can be reduced by informing patients of the benefits and risks of available treatment options and by providing them with sufficient information before they make a decision. On the contrary, insufficient information and uncertainty can make the decision period distressing (Aning et al., 2012). DAs for localized PC treatment decisions have been developed as brochures, websites, and videos. They have been shown to increase decisional satisfaction and knowledge and reduce the number of patients that choose an invasive option over a conservative one (Stacey et al., 2017; Taylor et al., 2010). Many DAs for men with localized PC have been developed and tested in North America, but they are only available in English (Grüne et al., 2021). Although few DAs are available in Europe, DAs for patients with localized PC are neither available in Iceland nor in the Nordic countries.

1.6 Summary

The decision to undergo PSA testing, and once cancer is detected, to decide on a treatment option for PC cancer is complex and multifactorial. In general, men do not have enough information and knowledge about the pros and cons of PSA testing and different treatment options for localized PC. SDM is very important when making those decisions, as it improves the quality of the decision, risk perception, patient adherence and patient outcomes as well as lowering healthcare cost (Hack et al., 2006; Joosten et al., 2008; Oshima Lee & Emanuel, 2013; Sepucha & Mulley Jr., 2009; Stewart, 1995; Veroff et al., 2013). To enhance SDM, DAs have been developed and tested both for PSA testing decision and PC treatment decisions. These DAs have effectively improved knowledge and patients' involvement in the decision-making process. They have also been shown to increase decisional satisfaction, reduce decisional conflict and also reduce the number of patients that choose invasive options (Allen et al., 2010; Baptista et al., 2018; Ivlev et al., 2018; Stacey et al., 2017; Taylor et al., 2010, 2013; Tomko, Davis, Ludin, et al., 2015).

In Iceland, research on PSA testing and PC treatment decisions is sparse. No study has examined men's knowledge about the pros and cons of PSA testing, while a study has shown that men lack knowledge about the pros and cons of PC treatment options (Reykdal et al., 2011). No DAs exist in Iceland that are designed to promote SDM and assist men with their PSA testing and PC treatment decisions.

2 Aims

2.1 Overall aim

No study in Iceland has examined if men receive information about the pros and cons of PSA testing prior to testing and there are no DAs available for neither PSA testing decision nor PC treatment decision. DAs can facilitate the SDM process when there is more than one possible option, and it is not clear what option is the best option.

Therefore, this Thesis had three specific aims. First, to explore if Icelandic men receive information about PSA testing prior to testing and to establish that there is a need for Icelandic DA that can assist Icelandic men with PSA testing decisions. Second, to translate, culturally adapt and modify a DA for PSA testing decision for Icelandic men and conduct usability testing. Third, to culturally adapt, modify, extend and evaluate the usability of a DA, that assists Icelandic men, newly diagnosed with localized PC to make a treatment decision. An additional aim, not covered in this Thesis, was to evaluate the DA for newly diagnosed men with localized PC in a RCT. This Thesis consists of three papers, each covering the specific aims mentioned above.

2.2 Aim of Paper I

Studies have shown that SDM is lacking in the healthcare system and the information men receive before getting PSA tested is limited (e.g., Cooper et al., 2019; Fridriksson et al., 2012; Han et al., 2013; Hoffman et al., 2009; Lamplugh et al., 2006; Leyva et al., 2016). Although one might expect similar findings to be observed for Icelandic men, no study has examined Icelandic men’s knowledge about the pros and cons of PSA testing. Therefore, the aim of Paper I was to confirm that Icelandic men lack information prior to PSA testing and that there is a need for an Icelandic DA for PSA testing decision. This has not been assessed previously in Iceland. Paper I was a presupposition for Paper II.

2.3 Aim of Paper II

Since the results of Paper I showed that there is a need for an Icelandic DA for PSA testing decision, the aim of Paper II was to translate, culturally adapt and modify a DA that assist men with their PSA testing decision and evaluate its usability. Following a review of the literature, a pre-existing, evidence-based interactive DA that had been tested in a RCT was translated and adapted (Kassan et al., 2012; Taylor et al., 2013; Tomko, Davis, Luta, et al., 2015). The DA has been shown to increase knowledge and decisional satisfaction and reduce decisional regret (Kassan et al., 2012). Cultural adaptation of a DA involves modifying and making it comprehensible and relevant for the targeted population by checking translation and cultural issues (Beaton et al., 2000). To culturally adapt a DA it is not enough to translate it. If it is only translated but not culturally adapted, it cannot be presumed that the translated version of the DA reflects the culture of the targeted population (Albrecht et al., 2011; Berry et al., 2015; European Centre for Disease Prevention and Control., 2016). Therefore, the DA was translated from English to Icelandic and, furthermore, culturally adapted and modified to ensure that only information relevant to Icelandic healthcare services was included. The final aim of Paper II was to explore the usability of the DA, including user satisfaction with the DA, informativeness of the DA and helpfulness of the DA for the user.

2.4 Aim of Paper III

A previous Icelandic study showed that newly diagnosed PC patients lack knowledge about PC, treatment options and side effects (Reykdal et al., 2011) and experience high decisional conflict, indicating they find it difficult to make a treatment decision (Ragnarsdóttir et al., 2011). Therefore, the first aim of Paper III was to culturally adapt, modify and extend an Icelandic interactive DA, aimed to assist newly diagnosed men with localized PC, with their treatment decision and test its usability. This involved developing an explicit VCE, translating health communication material from various sources to Icelandic as well as culturally adapting and modifying it to ensure that only information relevant to Icelandic healthcare service was included. The second aim of Paper III was to explore the usability of the DA, including user satisfaction with the DA, informativeness of the DA and helpfulness of the DA.

3 Materials and Methods

An overview of the methods used in each of the Thesis's three papers is presented in Table 1.

Paper I is a quantitative study among men diagnosed with cancer that aimed to evaluate how much information about the pros and cons of PSA testing men receive prior to getting a PSA test. Paper II is a mixed-method study using both qualitative and quantitative methodology to evaluate a DA for men considering PSA testing. The qualitative study used semi-structured interviews to examine the usability and receive user feedback about the DA. Minor revisions were made to the DA after the qualitative testing. A quantitative study was then conducted to get user feedback on the final version of the DA. Paper III was also a mixed-methods study that included two studies that tested the usability of a DA for men with localized PC. A qualitative study was conducted to get users' opinions of the contents of the DA and user experience using semi-structured interviews. The results demonstrated that only minor revisions of the DA were needed. A quantitative study was then conducted to examine the usability of the final version of the DA.

Table 1. Overview of methods used in Papers I, II and III.

	Paper I	Paper II	Paper III
Design	Quantitative study	Mixed-methods study consisting of two studies, qualitative and quantitative	Mixed-methods study consisting of two studies, qualitative and quantitative
Participants	Men diagnosed with PC in Iceland from 2015 to 2020. N = 471, Age: 51-95 (*M* = 71.9, *SD* = 7.3)	*Qualitative:* Inclusion criteria: No previous diagnosis of PC. N = 10, Age: 51-66 (*M* = 59.91, *SD* = 5.59) *Quantitative:* Men that used the DA via the Icelandic Cancer Society website from March 2021 to November 2022. N = 135, Age: 50-70, (*M*=59.71, *SD*=5.21)	*Qualitative*: Men diagnosed with localized PC. N = 12, Age: 58-80 (*M* = 70.66, *SD* = 6.58) *Quantitative*: Men newly diagnosed with localized PC. N = 11, Age: 60-74 (M = 66.18, SD = 4.79)
Measures	Sociodemographic variables Questions about PSA testing Year of diagnosis	*Qualitative:* Age Semi-structured interviews User feedback questionnaire *Quantitative*: Age User feedback questionnaire	*Qualitative:* Semi-structured interviews System Usability Scale *Quantitative:* Sociodemographic variables User feedback questionnaire
Procedure	Participants answered a questionnaire, online or paper version.	*Qualitative:* Participants used the DA and then participated in a semi-structured interview and answered a user feedback questionnaire. *Quantitative:* Participants used the DA and then answered a user feedback questionnaire.	*Qualitative:* Participants used the DA and then participated in a semi-structured interview and answered the System Usability Scale. *Quantitative:* Participants used the DA. Two weeks later they answered a user feedback questionnaire.
Data analysis	Descriptive statistics, percentages and frequencies.	*Qualitative:* Identification of repeated patterns and comments in the interviews about improvements of the DA. Descriptive statistics. *Quantitative:* Descriptive statistics, percentages, and frequencies. McNemar analysis and chi-squared analysis.	*Qualitative*: Thematic analysis. *Quantitative*: Descriptive statistics, percentages, and frequencies.

3.1 Participants

3.1.1 Paper I

Participants were Icelandic men diagnosed with PC from 2015 to 2020. A total of 1062 men were diagnosed with PC in this period, and 471 participated in the study.

The age range of participants was 51 to 95 years, with a mean age of 71.9 years (*SD* = 7.3) and the mean age at PC diagnosis being 68.1 years (*SD* = 7.2). The demographics of participants are detailed in Table 2.

Table 2. Demographics of participants (Paper I).

	% (N)
Education	
Primary school or less	14.8% (65)
Vocational education	46.4% (204)
Secondary education	10.4% (46)
University degree	28.4% (125)
Relationship status	
Married/partnered	81.3% (357)
Single/divorced/widowed	18.7% (83)
Employment status	
Full-time work	25.7% (115)
Retired	65.5% (293)
Sick leave/benefits/school	8.8% (39)
Residence	
Capital area	61.1% (272)
Outside capital area	38.9% (173)

3.1.2 Paper II

The qualitative part of the study consisted of 10 participants. Participants were men between the age of 51 to 66 years and the mean age was 59.91 (*SD*=5.59). Participants were male staff members at Reykjavik University, recruited via convenience sample. The inclusion criteria were understanding and reading Icelandic and the exclusion criterion was a PC diagnosis. In total, 12 men contacted the researchers and agreed to participate, but two were excluded since they had previously been diagnosed with PC.

The quantitative part of the study consisted of men that had used the DA, located on the Icelandic Cancer Society website from March 2021 to November 2022. In total, 211 men answered questions before and after using the DA. As the DA was designed for men aged 50 to 70, men outside that range were excluded in the analyses (n=55) and additional 21 men were excluded as they did not report their age. The final sample consisted of 135 men between 50 and 70 years old with a mean age of 59.71 years (*SD*=5.21).

3.1.3 Paper III

The qualitative part of the study included 12 participants diagnosed with localized PC, with mean age of 66 years at diagnosis. Of those, three had chosen active surveillance as a treatment option, three had chosen radical prostatectomy, three had chosen radiation therapy, and three were newly diagnosed and had not undergone treatment yet. The men were between the ages of 58 and 80, and the mean age was 70.66 (*SD*=6.58). Nine men were recruited from support groups hosted at the Icelandic Cancer Society, intended for men with localized PC. A urologist recruited the three men that were newly diagnosed, at the National University Hospital of Iceland. All participants were recruited between March 2nd and April 10th, 2019. See Table 3 for more details on participants' demographics.

The quantitative part of the study consisted of 11 men that were newly diagnosed with localized PC and had not yet made a PC treatment decision. The participants were between 60 and 74 years old with a mean age of 66.18 years (*SD*=4.79). Participants were recruited by urologists at the National University Hospital of Iceland from January 28th to April 14th, 2020. See Table 3 for more details on participants' demographics.

Table 3. Demographics of participants (Paper III).

	Qualitative study % (N)	Quantitative study % (N)
Number of participants	12	11
Education		
Primary school	8.3% (1)	9.0% (1)
Vocational education	8.3% (1)	45.5% (5)
University degree	83.3% (10)	45.5% (5)
Relationship status		
Married/partnered	66.7% (8)	100% (11)
Single/divorced/widowed	33.3% (4)	0% (0)
Employment status		
Full-time/part-time	83.3% (10)	90.9% (9)
Retired	16.7% (2)	18.2% (2)

3.2 Procedure

3.2.1 Paper I

The Icelandic Cancer Registry provided names of 1062 men that were diagnosed with PC in Iceland during the period from 2015 to 2020. An invitation to participate was mailed, via the postal service, to the 1002 individuals that had a registered postal address. The invitation included an information letter describing the study and a link to an online questionnaire. Participants had to provide an informed consent before they could proceed to answer the online questionnaire. Those preferring to answer the questionnaire on paper could contact the researchers and receive the questionnaire by post (N=67). Participants were given two weeks to answer the questionnaire, which resulted in a total of 208 responses within that period. Those that had not responded were contacted via telephone, 438 had registered telephone numbers and answered our calls. Of those, 347 agreed to participate but 82 did not complete the questionnaire. In total, 87 declined participation, two could not participate because of illness and two were deceased. In total, 471 participated and therefore the response rate was 47.0% with a completion rate of 95.1%

3.2.2 Paper II

The DA for PSA testing decision was culturally adapted following a five-step approach to adopting health communication materials developed under the European Centre for Disease Prevention and Control (European Centre for Disease Prevention and Control, 2016). The researchers translated and adapted the DA in collaboration with Icelandic urologists and the Icelandic Cancer Society. The five steps are described below.

Step 1: Selection of DA material

The first step involved selecting a currently available DA for PSA testing. A recent systematic review and meta-analysis by Riikonen and colleagues (2019) identified 19 DAs for PSA testing that fulfilled quality criteria. From those, the *Prostate Cancer Screening: Making the Best Choice* (Kassan et al., 2012; Taylor et al., 2013; Tomko, Davis Ludin, et al., 2015) was selected because of the following three attributes of the DA. Firstly it is web-based, secondly, it includes implicit and explicit VCE and thirdly, it has a high IPDASi score, or 9 out of 10.

Step 2: Early review and design

A urologist and a general practitioner reviewed the DA and ensured that the information was relevant to the Icelandic healthcare service. Some cultural modifications were made following the review; a few concepts were excluded since they are seldom or not used in Icelandic, and a few were tailored to make them more relevant in Icelandic. US screening recommendations and US epidemiology data were replaced with Icelandic ones. Icelandic norms were used for age-adjusted PSA and reviews of RCTs were added, so information on mortality and pros and cons was up to date. This stage also included a redesign of the DA and testing the function of the explicit VCE.

Step 3: Translation of the DA

The DA was forward translated by a psychologist and a public health expert, then reviewed and thereafter a consensus translation was acquired. Minor changes were made after a linguistic expert cross-checked the translations.

Step 4: Qualitative testing

Qualitative testing using in-person semi-structured interviews was conducted from the 17th to the 25th of February 2020 to evaluate the usability of the DA. Participants met up at Reykjavik University and were given a short introduction on the usage of the DA and then asked to use the DA and give comments while going through it. Thereafter, a semi-structured interview was conducted, including questions about the content, design, and usability of the DA. Following the interview, participants answered a user feedback questionnaire (Kassan et al., 2012). Comments from the interviews were evaluated and the most relevant were incorporated into a revised version of the DA and the user feedback questionnaire was examined to get information about how the participants evaluated the DA.

Step 5: Quantitative testing

The final version of the DA was proofread by two native Icelandic speakers, whereafter final modifications were made. A quantitative study was then conducted among a community sample of men to obtain user feedback. The Icelandic Cancer Society hosted the DA and promoted it during a specific PC awareness month (https://akvordunartaeki.karlaklefinn.is/). From March 2021 to November 2022, those that accessed the DA were invited to participate in a survey and answer questions before and after using the DA.

3.2.2.1 Description of the decision aid

The DA includes evidence-based information about PSA testing and its risks and benefits as well as implicit and explicit VCE. The implicit VCE is composed of eight different audio files where men express their different experiences with PSA testing and how it affected their lives. The explicit VCE is in the form of 10 questions throughout the DA, which users are prompted to answer based on their values and preferences. At the end of the DA, the user receives written results from the explicit VCE. The DA is comprised of five chapters that include information about PSA testing, the risks and benefits of testing, the specificity and sensitivity of the PSA test, information about different tests that are used to detect PC and what happens if you are diagnosed with PC. A description of the original DA can be found in Kassan et al. (2012) and Dorfman et al. (2010). In addition, a detailed description of the Icelandic version of the DA is in Appendix A.

3.2.3 Paper III

The cultural adapation, modification and extension of the DA for localized PC treatment decision was based on The Medical Research Council's guidance for the development of complex interventions (Craig et al., 2008), IPDAS (Elwyn et al., 2006, 2009; O'Connor & Elwyn, 2005) and the Ottawa Decision Support Framework (Stacey et al., 2020). In addition to being translated, DAs have to be culturally adapted when used in another country than they were originally designed for (Albrecht et al., 2011; Berry et al., 2015; European Centre for Disease Prevention and Control., 2016). Thus, a five-step approach to adopting health communication materials (European Centre for Disease Prevention and Control., 2016) was followed to culturally adapt the health communication material that was included in the DA. The content was based on: Educational material provided by HealthMark Multimedia, education and decision program for early-stage PC patients by Diefenbach et al. (2012), DA for PC treatment decision by Taylor et al. (2010), peer-reviewed articles about PC survival, studies on outcomes and side effects that are referenced in the DA (Chen et al., 2017; Donovan et al., 2016; Hamdy et al., 2016) and information provided by the Icelandic Cancer Society. The setup of the DA and the explicit VCE was guided by DAs for PC screening and for PC treatment decisions by Taylor et al. (2010, 2013). A clinical psychologist, a urologist and two research assistants translated the material and a specialist in medical text translation proofread the translation. Thereafter, advisory medical doctors reviewed the material to ensure that it was relevant to the Icelandic healthcare service. After the review, incorrect information was deleted and relevant Icelandic data was added. The prototype complied with all IPDASi criteria apart from the evaluation of the DA, which is to be determined in an ongoing RCT.

The DAs usability was tested in two studies, a qualitative and a quantitative study. In the qualitative study, participants were recruited from March 2nd to April 10th, 2019. Emails were sent to members of support groups with information about the research and those interested could contact the researchers if they wanted to participate. A urologist at the National University Hospital of Iceland recruited newly diagnosed men by handing out information letter and interested men could contact the researchers by email. Semi-structured interviews were conducted in person at the Icelandic Cancer Society. Participants provided informed consent before participating in the interviews, which included permission to audiotape the interview. The session started with a brief discussion about the study and instructions about the free-flow procedure, informing the participants that comments were very welcome while using the DA. The interview took place while the participants used the DA, whereafter, they were invited to answer the System Usability Scale (SUS). The qualitative study showed that minor revisions of the prototype were needed. User feedback on the final version of the DA was then evaluated in a quantitative study where newly diagnosed patients were invited to participate. They received a short description of the study from their urologist and an information letter. Those interested signed the information letter indicating they would like to get more information about the study and mailed it by post to the researchers. Interested participants were contacted via telephone and informed in more detail about the study. If they agreed to participate, a link was sent to them via email, including an informed consent form and a questionnaire. After completing the questionnaire, participants received another email containing access to the DA. Both verbal and written instructions about the usage of the DA were provided before they were given access to the DA. Participants could contact the research team at any time by telephone or email if they needed assistance while using the DA. Two weeks later, a user feedback questionnaire about the DA was sent to participants.

3.2.3.1 Description of the decision aid

The DA was created in a collaboration between the research team, advisory medical doctors at the National University Hospital of Iceland, patients with localized PC and web designers and programmers. The DA includes information about PC, an overview of treatment options, the pros and cons of each treatment option and an explicit VCE to assist users in weighing the risks and benefits of each treatment option. The explicit VCE consists of 18 questions that are presented throughout the DA and belong to two different components. The first component determines whether the user leans towards curative treatment, active surveillance, or is undecided. If the user leans towards curative treatment, another result page is presented that is composed of the second component which determines if the user leans towards radical prostatectomy, radiotherapy or is undecided. The results of the explicit VCE are presented visually on a gauge on a result page, and the user is informed if he leans towards a curative treatment or active surveillance. If he leans towards curative treatment, he is represented with another gauge that indicates if he leans towards radical prostatectomy or radiation therapy. See a detailed description of the DA in Appendix B.

3.3 Measures

3.3.1 Paper I

Participants' year of PC diagnosis was provided by the Icelandic cancer registry. Other information was obtained through a questionnaire. The questionnaire included *standard sociodemographic variables*, such as age, employment status, relationship status and residency.

Questions about PSA testing were based on a questionnaire by Fridriksson et al. (2012) with the following three questions: a) "What was the reason for your first PSA test?" (e.g., I had voiding symptoms, I was worried about having prostate cancer, my doctor recommended it), b) "Did you receive any information about the pros and cons of PSA testing prior to testing?" (i.e., verbal, written, verbal and written, none or was not aware that PSA level had been tested) and c) "How did you receive the results from the PSA testing?" (i.e., at an appointment with your doctor, via telephone, via email).

The above-described questions were translated into Icelandic by Dr Heiddis B. Valdimarsdottir, Dr Birna Baldursdottir and Valgerdur Kristin Eiriksdottir with permission from the author, Dr Jon Orn Fridriksson.

Additionally, participants were asked how they would *rate their knowledge of PSA testing* prior to being tested on a 5-point Likert scale, possible answers ranged from "no knowledge" to "very much knowledge". Lastly, they were asked if they *had symptoms of PC prior to getting a PSA* test with possible answers being, "no, I did not have symptoms”, “yes, I had voiding symptoms”, “yes, I had other symptoms from the urine or genital organs”, and “yes, I had other symptoms”. The responses were grouped into “yes” or “no” for statistical analysis.

3.3.2 Paper II

The qualitative study included *semi-structured interviews* with open-ended questions about the user’s experience of the DA, its format, design, content, text flow and usability. Following are examples of the questions included in the in-person interview: “How was your overall experience of the DA?”, “Were there any concepts that needed more explanations?”, “How did you like the layout of the DA?” and “Do you have any suggestions or comments regarding the DA?”.

In the quantitative study, participants were asked about their *intention to undergo PSA testing* in the next 12 months, both before and after using the DA, with possible answer options “I am getting tested”, “I’m not getting tested”, or “I am undecided”.

A *user feedback questionnaire* was used in both the qualitative and the quantitative study to assess satisfaction with the amount and quality of the information included in the DA, the helpfulness of the DA, as well as the clarity of the DA. The user feedback questionnaire is an 8-item questionnaire based on Kassan et al. (2012). The questions were translated into Icelandic by Dr Heiddis B. Valdimarsdottir, Dr Birna Baldursdottir and Valgerdur Kristin Eiriksdottir with permission from Dr Kathryn L. Taylor.

3.3.3 Paper III

The qualitative study included semi-structured interviews with open-ended questions about the user’s experience of the DA to identify possible issues with design, content, and usability. Following are examples of the questions included in the interview: “Were there any concepts that needed more explanations?”, “How did you like the layout of the DA?” and “Do you have any suggestions or comments regarding the DA?”.

To get an overall rating of the usability of the DA in the qualitative study, the System Usability Scale (SUS) was used (Brooke, 1996). The SUS is a simple scale that can be used to assess the usability of a product or service, like websites and applications. It is a 10-items scale, and response options range from “Strongly agree” to “Strongly disagree” on a 5-point Likert scale. The SUS is well-established and has been shown to be a robust tool to assess usability (Brooke, 2013). The SUS yields a score on a scale from 0-100, where 100 is the best possible score that indicates the overall usability of the DA with a score of 68 as the benchmark for acceptability (Brooke, 1996).

In both the qualitative and quantitative study, basic sociodemographic variables were collected, i.e., age, education, relationship status and employment status. In the quantitative study, user feedback on the DA was collected using the same user feedback questionnaire as in Paper II.

3.4 Statistical analysis

3.4.1 Paper I

Descriptive statistics were used to examine sociodemographic variables. Mean and standard deviations were calculated for participants’ current age as well as for participants’ age at the time of diagnosis. To analyse questionnaire data on PSA testing, PSA testing knowledge and if participants had symptoms prior to PSA testing, descriptive statistics were used, i.e., frequency and percentage.

3.4.2 Paper II

Mean and standard deviations were calculated for participants’ age in both parts of the study. The qualitative data analysis included identifying patterns in answers and comments about how the DA could be modified to be more comprehensible and cater better to Icelandic culture. Descriptive statistics were used to analyse data from user feedback questionnaire in both the qualitative and the quantitative study. The analysis included frequency and percentages in each sample. To examine whether there were changes in intention towards PSA testing from before to after using the DA, two groups were compared, a decided group and an undecided group.

Those that had decided to either undergo or not undergo PSA testing, before using the DA were combined into one group. Those that had made a PSA decision after using the DA were also combined into one group. A McNemar analysis was then used to explore if the decided and undecided groups differed. A chi-squared analysis was used to determine if men interpreted the overall message of the DA differently based on their intentions towards PSA testing before using the DA.

3.4.3 Paper III

Descriptive statistics, including frequency and percentage, were used to examine sociodemographic variables in both studies. Mean and standard deviations were calculated for participants' age in both studies. Thematic analysis was used to analyse the qualitative data. Themes were systematically and objectively qualified using both inductive and deductive coding. The thematic analysis involved six steps (1) getting familiarized with the data, (2) making initial codes, (3) searching for themes, (4) reviewing themes, (5) defining the themes and (6) writing up the results (Braun & Clarke, 2006). Percentages were used to calculate the frequency of participants endorsing each sub-theme. Descriptive statistics, i.e., percentages and frequency were used to analyse user feedback questionnaire data from the quantitative study.

3.5 Ethical considerations

3.5.1 Paper I

The study received ethical approval from the National Bioethics Committee (Reference number: VSN-21-050) and the Icelandic Cancer Registry. Informed consent was obtained from all participants after they had received verbal information about the study and were informed that they could quit the study at any time without consequences.

3.5.2 Paper II

The National Bioethics Committee deemed that the study did not require their permission since no personal identification was collected and all study material was anonymous. The study followed the rules of the Helsinki Declaration on medical ethics. All participants in the qualitative study were informed verbally about the study and its purpose and that they could quit the study at any stage without consequences. All participants in the quantitative study received written information explaining that the study was anonymous and answers could not be traced back to individual participants. In addition, it was explained that they did not need to participate and could quit their participation at any stage in the study.

3.5.3 Paper III

The study received ethical approval from the National Bioethics Committee (Reference number: VSN-18-127) and the chief medical officer at the National University Hospital of Iceland. In the qualitative study, informed consent was obtained in person from participants after they had been informed about the study, including that they could quit the study at any stage without any complications and that the informed consent involved giving permission for the researcher to audiotape the session. In the quantitative study, informed consent was obtained online from participants after they had gotten verbal information via telephone about the study, explaining that they could quit the study at any stage without consequences.

4 Results

This section presents the main results from the three papers on which this Thesis is based. A more detailed description of the results of each paper is presented in the individual papers at the end of the Thesis.

4.1 Paper I

Most of the participants, or 63.3%, were asymptomatic prior to undergoing PSA testing. In total, 49.8% did receive information about PSA testing prior to testing, either verbal, written or both. Thereof, 40.7% received only verbal information. However, 27.9% did not receive any information prior to PSA testing and 22.2% did not even know that their PSA level had been tested. Figure 1 shows that asymptomatic and symptomatic men received similar information prior to PSA testing.

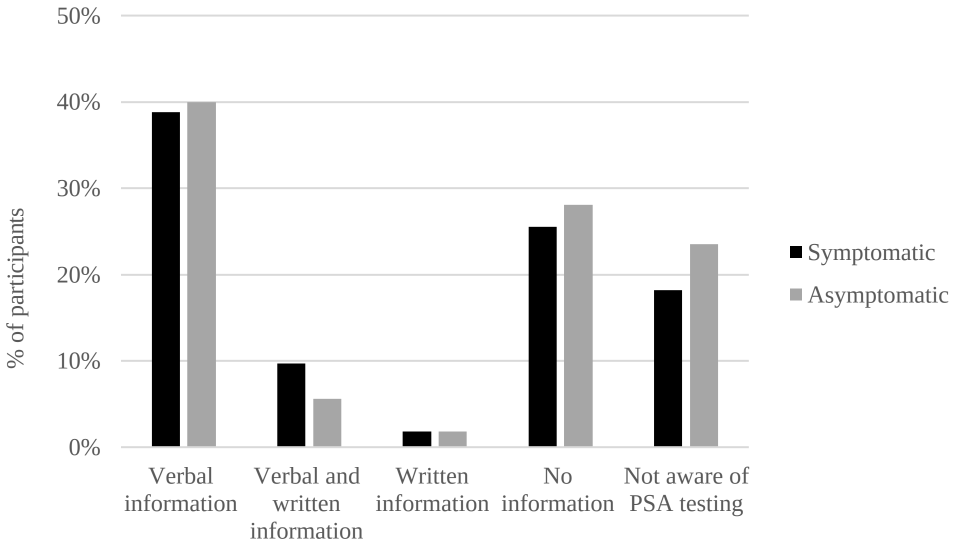

Figure 1. Comparison of information symptomatic and asymptomatic men received prior to PSA testing (Paper I).

Majority of participants or 81.8%, reported no knowledge, very little or little knowledge of the pros and cons of PSA testing prior to testing. In fact, 49.8% reported no knowledge of the pros and cons of PSA testing prior to undergoing a

PSA test. A total of 8.9% of participants reported that they had neither little nor much knowledge and 6.4% of participants reported that they had much or very much knowledge.

The PSA test results were most often (70.4% of cases) presented to the patient by their physician when they came for an in-person appointment. However, 25.3% of patients did receive their PSA results from their physician via telephone call and 3.1% received their results by letter or email. Of those that received their results via telephone, 55.7% resided in the capital area.

4.2 Paper II

4.2.1 The qualitative study

A prototype of the DA was evaluated by in-person usability and comprehension testing using semi-structured interviews.

4.2.1.1 Comments and user feedback

Participants in the semi-structured in-person interviews mainly commented on the translation and wording of the DA. Therefore, only minor modifications to the DA were made after the interviews. Participants also reported that the DA was helpful and informative, for example, participant no 8 reported, "I found it very informative, I needed to know more about this topic because some say you should get tested while others say it is unnecessary". A few participants reported that the DA was too long but often added that it was a complicated decision, and all of the information was very relevant and important to include. For example, participant no 10 reported, "it is long, however, this is not an easy subject to decide on and it includes matters that have to be scrutinized". Some participants commented that the DA needed more appropriate illustrations, for example, that the DA should mostly contain pictures of men aged 50 to 70 years old because that is the target age for the DA. Subsequently, those pictures were updated.

In the user feedback questionnaire, all 10 participants reported that the DA was helpful and comprehensible and that they would recommend it to others. The majority rated that the overall message of the DA as neutral. However, most reported that they found the DA too long or much too long. Despite that, the length of the DA was not changed, considering that most participants that commented that the DA was too long also added that they found the information relevant to this complicated decision.

4.2.2 The quantitative study

A revised version of the DA, based on comments and user feedback from the qualitative study, was evaluated in a quantitative study with a community sample of men.

4.2.2.1 Descriptive statistics from user feedback evaluation

All participants disclosed that the DA was helpful when it came to understanding the risks and benefits of PSA testing, and in fact, 65.2% found it very helpful. Most participants, or 96.3%, reported that they did not have any trouble or just very little trouble reading and understanding the DA and 61.5% reported that the DA was exactly the right length. When the participants were asked about what they thought the overall message of the DA suggested, 54.1% indicated that the overall message was neutral, but 37.0% reported that they thought the DA indicated that men should get a PSA test and 8.9% that men should not get a PSA test. In total, 61.5% reported that the DA made them think of new questions to ask their physician and 82.2% reported that the DA did not make them fearful about PSA testing. Finally, 97.8% said they would recommend the DA to others facing the same decision.

4.2.2.2 The decision aid and PSA testing intentions

Those that were decided (either intended to undergo or not undergo PSA testing) before using the DA, tended to stick with their decision after using the DA. More specifically, 81.3% of the participants that intended to get a PSA test prior to using the DA, maintained their decision post-using the DA and 71.4% of those that did not intend to get a PSA test before using the DA maintained their intention after using the DA. About 40% of those that were undecided before going through the DA, decided to either undergo a PSA test (29.0%) or not (12.9%) after using the DA (see Table 4).

Table 4. Intentions towards PSA at baseline and after using the DA (Paper II).

	Intentions towards PSA testing after using DA		
Intentions towards PSA testing at baseline	Getting a PSA test	Not getting a PSA test	Undecided
Getting a PSA test	81.3% (52) §	3.1% (2)	15.6% (10)
Not getting a PSA test	0.0% (0)	71.4% (5) §	28.6% (2)
Undecided	29.0% (18)	12.9% (8)	58.1% (36) §

§ Participants whose intention towards PSA testing remained unaltered (70.2% (n=93))

To further explore the effects of the DA on PSA intention, we combined the two groups that had made a PSA decision (to get a PSA test and not get a PSA test) before using the DA. The groups that had made a PSA decision post using the DA were also combined. The difference between the decided and the undecided groups were analyzed using a McNemar analysis. A significant difference, $p<0.05$, was observed with the McNemar analysis between the groups as 83.6% of those that had made a decision prior to using the DA remained decided after using the DA, but 16.4% went from being decided prior to using the DA to being undecided after using the DA. However, 58.1% of those that were undecided prior to using the DA remained undecided post-using the DA while 41.9% had made a decision.

4.2.2.3 PSA intentions and perception of the overall message of the decision aid

A chi-square analysis that compared the interpretation of the overall message of the DA (men should get a PSA test, men should not get a PSA test or neutral) to intentions regarding PSA testing before using the DA showed that PSA testing intentions on baseline affected how the overall message of the DA was interpreted, χ^2 (4, N = 135) = 18.372, $p < 0.001$ (see Table 5). Those that intended to get a PSA test were more likely to interpret the message of the DA as men should get a PSA test or 54.5%. Those that did not intend to get a PSA test or were undecided were more likely to interpret the overall message of the DA as neutral or 85.7% and

66.1%, respectively (see Table 5).

Table 5. Men's interpretations of the overall message of the DA by their intentions towards PSA testing at baseline (Paper II).

Intentions towards PSA testing at baseline	Interpretations of overall message of the DA		
	Men should get a PSA test	Men should not get a PSA test	Neither
Getting a PSA test	54.5% (36)	6.1% (4)	39.4% (26)
Not getting a PSA test	0.0% (0)	14.3% (1)	85.7% (6)
Undecided	22.6% (14)	11.3% (7)	66.1% (41)

4.3 Paper III

4.3.1 The qualitative study

Participants in the semi-structured interviews expressed their satisfaction with the DA and the realistic and extensive information about the side effects of curative treatments. They also found the explicit VCE useful. Most comments about improvements of the DA concerned the text flow and length. The thematic analysis identified four key themes, 1) usability and design, 2) content and knowledge, 3) deciding factors of decision-making and 4) social support (see Figure 2).

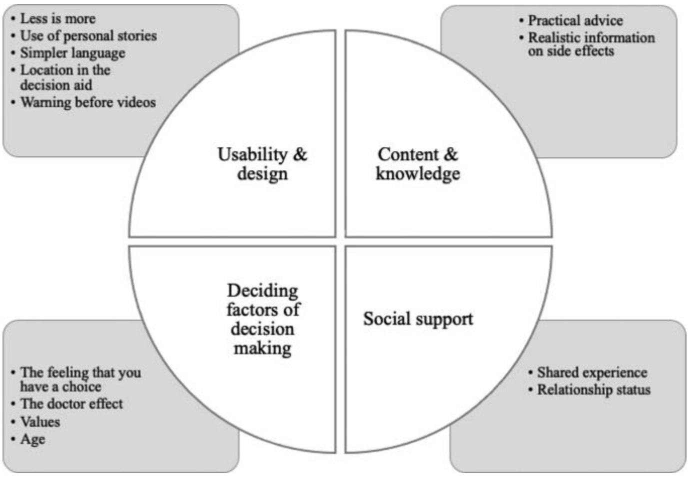

Figure 2. Themes and sub-themes in the qualitative study (Paper III).

The theme usability and design included the following sub-themes:

- Less is more. Some participants reported that the text should be shorter.
- Use of personal stories. Some participants reported that stories about men facing treatment decisions for localized PC would be a helpful addition to the DA.
- Simpler language. Some participants reported that the language should be simpler.
- Location in the DA. Some participants reported that it would be helpful to see where they are in the DA to know how much is left.
- Warnings before videos. A few participants did not want to watch the video about radical prostatectomy and commented that there should be a warning before the video started.

The theme content and knowledge included the following sub-themes:

- Practical advice. Many participants discussed practical advice, like the importance of pelvic muscle exercise and the use of pads for urinary problems.
- Realistic information about side effects. Some participants commented on their satisfaction with the detailed information about the side effects of treatments.

The theme deciding factors of decision-making included the following sub-themes:

- The feeling that you have a choice. Many participants that had undergone curative treatment commented that they felt they never had a choice and that the cancer just had to be removed.
- The doctor’s effect. Most participants were informed that they had localized PC following a routine check at their general health practitioner. As a result, most of them were referred to a urologist, and some mentioned that it might have influenced their treatment decision.
- Values. Many participants noted values concerning choosing life or choosing quality of life.
- Age. Some participants reported that age was an important factor in decision-making regarding erectile dysfunction.

The theme social support included the following sub-themes:

- Shared experience. All participants commented on the importance of meeting and sharing experiences with others that had gone through the same thing.
- Relationship status. Most participants were married and emphasized the importance of discussing possible side effects with their partner.

4.3.2 The quantitative study

Following the qualitative study, a revised version of the DA was constructed based on comments and concerns from the qualitative study. The revised version was evaluated in a quantitative study. All participants in the quantitative study reported that they found the DA helpful in terms of understanding the pros and cons of treatment options. Also, all participants reported having very little or no trouble reading and understanding the DA. A majority reported that the DA was just the right length or 81.8%. A total of 45.5% rated the overall message as neutral, 27.3% rated that the overall message was that men should choose curative treatments and 27.3% that men should choose active surveillance. Most, or 72.7%, reported that the DA made them think of new questions to ask their physician and all participants reported that they would recommend the DA to others facing the same decision.

5 Discussion

The aims of this Thesis were threefold; 1) to evaluate the need in Iceland for a DA that assists men with their PSA testing decision, 2) to translate, culturally adapt and modify a DA for PSA testing and evaluate its usability and 3) to culturally adapt, modify and extend an interactive DA that assists men that are newly diagnosed with localized PC with their treatment decision and evaluate its usability.

The main findings of this Thesis indicate that there is indeed a need for an Icelandic PSA testing DA (Paper I). Also, the culturally adapted and modified DA for PSA testing decision (Paper II) as well as the culturally adapted, modified and extended DA for treatment decision for localized PC (Paper III) were both well received and evaluated positively. Participants found both DAs helpful and comprehensible and also reported that they elicited questions to bring to their healthcare provider and that they would recommend the DAs to others facing the same decision. These results present evidence for the acceptability of the DAs and suggest that they could be helpful in assisting men with these decisions and moreover, promote SDM.

The aim of Paper I was to evaluate the need for a DA for a PSA testing decision by examining how much information Icelandic men receive prior to undergoing a PSA test and how much knowledge they have on the pros and cons of PSA testing. The results showed that Icelandic men lack information prior to PSA testing with approximately half of the participants receiving information about the pros and cons of PSA testing and a third reporting that they did not receive any information. Alarmingly, 22.2% of participants were unaware that they were being tested. These findings are consistent with results from earlier research that have shown that men lack information prior to making a decision about PSA testing and men are often unaware that they are being tested (Federman et al., 1999; Fridriksson et al., 2012; Han et al., 2013; Hoffman et al., 2009; Volk et al., 2013). The results also showed that even though approximately half of the participants had received information prior to PSA testing, 80% reported that they had little or no knowledge about the pros and cons of PSA testing. This aligns with previous studies showing that knowledge about the pros and cons of PSA testing is, in general, low (Hoffman et al., 2009; Lamplugh et al., 2006). As previous research was conducted over a decade ago, the present findings suggest that, since then, there have not been improvements in providing men with information about the pros and cons of PSA testing.

The above findings are of concern, as PSA testing to detect PC in asymptomatic men is controversial since it can lead to over-diagnosis and overtreatment of PC (Fenton et al., 2018; Pathirana et al., 2019) with accompanying side effects that can have adverse effects on quality of life. It is therefore critical that men understand the risks and benefits of undergoing PSA testing. However, it is clear that Icelandic men are not receiving enough information about the pros and cons of PSA testing and that they are not taking part in shared PSA testing decision-making with their healthcare providers. This is thought-provoking, as there has been an increasing emphasis on involving patients in their health decisions (Carter et al., 2013; US Preventive Services Task Force et al., 2018). The results from Paper I, thus, strongly indicated that there is a need for an Icelandic DA for PSA testing decision.

The importance of DAs, in general, has been confirmed and research indicates that DAs facilitate SDM, for example by improving communications with healthcare providers and encouraging patients to take a more active role in decision-making. They also improve patients' knowledge, quality of care, increase decisional satisfaction and decrease distress, decisional regret and decisional conflict (Stacey et al., 2011, 2017; Taylor et al., 2010; Volk et al., 2007). Even though DAs for PSA testing are available and have been found to be effective (Baptista et al., 2018; Taylor et al., 2013) no DAs for PSA testing decision are available in Iceland. Therefore, the aim of Paper II was to translate and culturally modify the first Icelandic interactive web-based PSA testing DA. To make a PSA testing decision, men need to be able to access evidence-based information in their native language (Adams & Fleck, 2015). Towards that end, a pre-existing DA was translated and culturally modified to an Icelandic context (Kassan et al., 2012; Taylor et al., 2013;

Tomko, Davis, Luta, et al., 2015). User feedback was evaluated twice, first in a qualitative study and then with a community sample in a quantitative study. Both user feedback evaluations demonstrated that the participants were pleased with the helpfulness of the DA, most reported it to be comprehensible and that it made them think of new questions to ask their physician. The majority reported that they would recommend it to others facing the same decision. This suggests that the DA was successfully translated and culturally adapted.

Additional analysis of the data from Paper II showed that the intention to undergo PSA testing among those that had made a decision to either undergo or not undergo PSA testing prior to using the DA did not change after reviewing the DA. The DA did, however, affect PSA intention among those that were undecided prior to going through the DA, with 41.9% having made a decision after using the DA to either undergo a PSA test (29%) or not (12.9%). This is consistent with findings from a systematic review (Stacey et al. 2017) where the usage of DAs was shown to lower the number of undecided patients. This finding is also consistent with Schwartz et al. (2009), that reported that DAs affected treatment decisions among undecided patients but not among those that had made a decision before using the DA (Schwartz et al., 2009).

The DA is designed to give balanced information on the pros and cons of each option, however, in the present study, only about half of the participants thought the overall message of the DA was neutral. The rest thought the overall message was either that men should get a PSA test (37.0%) or should not (8.9%). Additional analysis revealed that those who had decided to get a PSA test prior to going through the DA were more likely to perceive that the overall message as men should get a PSA test, thus, supporting their decision. On the other hand, those that were undecided or intended not to undergo a PSA test were more likely to perceive the overall message as neutral. Previous studies have reported similar results that even though efforts are made to give balanced information, the user experiences that the information favours one side (Dorfman et al., 2010; Griffith et al., 2008; Mathieu et al., 2010; Smith et al., 2010).

As explained in the introduction, a PSA test can lead to a PC diagnosis, with localized PC being the most common diagnosis, as approximately 90% of those that are diagnosed with PC have localized PC (American Cancer Society, 2020; Siegel et al., 2020). When diagnosed with localized PC, men face a difficult treatment decision since different treatments are available, all with similar survival rates but the side effects differ greatly (Donovan et al., 2016; Hamdy et al., 2016, 2023; Wilt, 2008). The need for an Icelandic DA to assist newly diagnosed men with localized PC with treatment decision had been underscored in previous Icelandic studies. It is reported that PC knowledge is low among newly diagnosed Icelandic men, where 80% revealed that they had little knowledge of PC and its treatment options and side effects (Reykdal et al., 2011). In addition, Icelandic men experienced high decisional conflict before making a treatment decision (Ragnarsdóttir et al., 2011). Thus, the aim of Paper III was to modify, extend and evaluate the first DA for Icelandic men newly diagnosed with PC. A prototype was developed and evaluated, first in a qualitative study using semi-structured interviews and then following, a revised version was evaluated in a quantitative study. Participants in the qualitative study reported that the DA was easy to use, comprehensible and helpful. They were satisfied with the immense and realistic information about the side effect of curative treatments and the balanced information on treatment options. They noted though, that the DA should contain less amount of text and simpler text with the option to view more information if desired. The text of the DA was revised accordingly and an option to view more information was added. The prototype of the DA was rated high on the System Usability Scale or 85.43 out of 100 with the benchmark for acceptability being 68 (Brooke, 1996). A revised and final version of the DA was then usability tested in a quantitative study. Participants reported that the final version was comprehensible, helpful and suitable length. All reported that they would recommend the DA to others facing the same decision. Importantly, a little over 70% reported that the DA had made them think about new questions to ask their physician. These findings suggest that newly diagnosed Icelandic men might benefit from using the DA to support SDM regarding their treatment decision. The participants‘ positive attitude towards the DA is consistent with findings from other studies that have reported DAs for localized PC decision to be well accepted and feasible (Diefenbach et al., 2012; Feldman-Stewart et al., 2012).

Although healthcare providers may provide patients with the pros and cons of each treatment, the information can be difficult to process when presented verbally during a stressful time or following a PC diagnosis. Therefore, using a DA that can be viewed when desired and gives access to evidence-based information about the pros and cons of each treatment option, gives the patient the option to contemplate which treatment decision is most in line with own values and preferences in a less stressful situation, which also improves the retention of information.

5.1 Methodological limitations and strengths

5.1.1 Paper I

There are several limitations that need to be considered in Paper I. All participants were men that had been diagnosed with PC, which limits the generalizability of the results. For example, the results might not generalize to the population of men that have undergone PSA testing but have not been diagnosed with PC. Another limitation is that the information participants received was not evaluated and therefore, we do not know what type or how much information was provided. Also, SDM was not assessed, but the findings demonstrate that the majority of those that reported they had received information about the pros and cons of testing, reported that they had little knowledge about PSA testing, suggesting that participants and their healthcare providers did not make a shared decision. In addition, the response rate was relatively low, or 47.0%, which can lead to nonresponse bias and limit generalizability. However, a low response rate has been reported in surveys that rely on answers from older populations, such as our study, where the mean age was relatively high or 71.9 years (Edelman et al., 2013; Gregson et al., 1997). The data is also subjected to recall bias as participants were asked retrospectively to recall events and symptoms that happened one to six years ago. Memory can be a limiting factor in retrospective self-reports and may affect the accuracy of answers and cause biases (Schacter, 1999; Van den Bergh & Walentynowicz, 2016). The major strength of the study is, however, that it was conducted with a large sample of men diagnosed with PC, in fact, the sample included all men that were diagnosed with PC in Iceland in a six-year period. In addition, this is the first study that assesses information that Icelandic men receive prior to PSA testing and thus, addresses the existing knowledge gap in the field and underscores a need for Icelandic PSA testing DA.

5.1.2 Paper II

Several limitations need to be recognized in Paper II, including a possible lack of generalizability since both the qualitative study and the quantitative study consisted of convenience samples. Additionally, the qualitative study was homogenous since all participants were members of staff at Reykjavik University and might have more education than the general population. The participants in the quantitative study accessed the DA via the Icelandic Cancer Society's website, but those that seek information there might not represent the general population. However, promoting the DA via the Cancer Society's website could also be a strength since our targeted audience are likely to navigate this website. In the quantitative study, the group that had decided to not get a PSA test both before and after using the DA was relatively smaller than the group that had decided to get a PSA test and the undecided group. That might affect the results.

Furthermore, there are still some important questions that need to be evaluated, such as, does the DA increase PSA knowledge about the pros and cons of testing and decrease decisional conflict and decisional regret? These measures are important to address when evaluating DAs (Stacey et al., 2017). Moreover, actual behaviour regarding PSA testing was not evaluated, only intentions. Additionally, we did not collect information about how the participants navigated the DA (e.g., the amount of time spent in each section of the DA). To maximize participation, it was considered important to keep the questionnaire short, but future studies could incorporate the above-mentioned questions as well as more extensive sociodemographic data.

Prior to this doctoral research, no DAs for PSA testing decision were available in Icelandic. As most health educational information is only available in English and language can hinder access to quality health information, it is vital that patients can access information to facilitate SDM, in their native language (Adams & Fleck, 2015). Thus, the main strength of Paper II is the translation and modification, to Icelandic context, of a pre-existing, validated and evidence-based DA that has been shown to reduce decisional regret and increase decisional satisfaction and knowledge (Kassan et al., 2012; Taylor et al., 2013; Tomko, Davis, Ludin, et al., 2015; Tomko, Davis, Luta, et al., 2015).

5.1.3 Paper III

Some limitations are worth mentioning in Paper III. Participants in the qualitative study were homogenous as they were recruited from support groups which might limit the generalizability of the results. Additionally, when the participants were recruited, they were undecided on a treatment option, but at the time of the interview, they were all leaning towards radical prostatectomy. On the other hand, the quantitative study only included undecided newly diagnosed men with localized PC. The main strength of Paper III is that the DA was designed to cater to those with low health literacy and lower education by using simple language and short sentences (readability was equivalent to 8th grade level). In addition, pictures and videos were used to explain complex terms (Eiriksdottir et al., 2021). The length of the DA is, however, a limitation. It was considered important to include information that are relevant to the decision which meant that the DA was lengthy and because of its length it might not cater to those with lower health literacy and those less educated.

The results from the quantitative study suggest the acceptability of the DA among newly diagnosed men, as the participants found it helpful and comprehensible and reported that they would recommend the DA to others facing the same decision. The men also reported that the DA had raised questions that they would like to bring to their physician, suggesting that the DA could facilitate SDM in the treatment decision-making process. The DA is currently being tested in a RCT to explore the effectiveness of the DA compared to usual care. The main strength of Paper III is the modification and extension of the first DA for newly diagnosed

Icelandic men with localized PC that assists with their treatment decision.

5.2 Future directions

Findings from Paper I suggest that at least half of the participants did not make a shared decision prior to undergoing PSA testing, and even though the majority of physicians prefer SDM (75%), previous studies have indicated that the use of SDM prior to PSA testing is low (Han et al., 2013; Murray et al., 2007). One way to support SDM is by using DAs; however, the use of DAs have been reported to vary considerably among specialist that treat patients with PC and the usage has been reported from low to moderate, or 34% to 54% (Graham et al., 2007; Wang et al., 2015). It seems, despite the established knowledge that DAs benefit PC patients (e.g., Stacey et al., 2017; Taylor et al., 2010), enhance SDM, are cost-effective and have a little burden on the healthcare system (Arterburn et al., 2012; Stacey et al., 2014), they are not widely implemented into the healthcare system. To our best knowledge, no DAs are currently being used in the Icelandic healthcare system. The study reported in *Paper I* was retrospective but to get answers that are less likely to be subject to biases, prospective studies are needed to examine how much information about the pros and cons men receive prior to making a PSA testing decision. Additionally, our study did not assess the quality of information that Icelandic men received prior to PSA testing. As it is important that men receive balanced information about the pros and cons of PSA testing, future studies should assess the information quality and content. If men do not receive balanced information, then the decision does not qualify as a shared decision (Hoffman et al., 2009). It has been reported that only 8% of those that had a discussion about PSA testing with their physician prior to testing, did receive balanced or full SDM that involved a discussion of both pros and cons of PSA testing as well as a discussion of the uncertainty of PSA testing (Han et al., 2013). Thus, it would be of interest to evaluate the frequency of balanced SDM prior to PSA testing among Icelandic men.

DAs for PSA testing decision (Paper II) and PC treatment decision (Paper III) were modified and evaluated. Although participants were satisfied with the DAs and would recommend them to others facing the same decision, their effectiveness needs to be tested in a RCT before the benefit of their usage can be determined. In addition, it should be assessed if the DAs enhance SDM both from the patient's and the healthcare providers' perspective, for example, by improving patient-healthcare provider communication, promoting active involvement of the patient in the decision and by improving the quality of the decision. Furthermore, it would be of interest to examine potential moderators or for whom the DAa are effective, as well as potential mediators or through what mechanism the DAs might improve knowledge, decrease decisional regret, and increase decisional satisfaction. Currently, a RCT is being conducted to evaluate the DA for treatment decisions for localized PC. The effectiveness of the English version of the DA for PSA testing decision has been evaluated in a RCT but a RCT to evaluate the effectiveness of the Icelandic version of the PSA testing DA is to be determined. If results from RCTs show that the DAs benefit the users and are more effective than usual care, then the next step would be to implement the DAs in the healthcare system in Iceland and make them available for those that are facing those decisions. A part of implementing the DAs could be integrating them into workflow and guidelines of Icelandic healthcare facilities.

6 Conclusions

Consistent with previous studies, our findings revealed that Icelandic men lack information and knowledge about PSA testing and they also lack information about the pros and cons of different treatment options for localized PC. These findings indicated that there was a pressing need for Icelandic DAs for these decisions, as DAs increase knowledge and facilitate SDM. Hence, DAs for PSA testing decision and localized PC treatment decision were modified and extended for Icelandic men. Our results revealed that both DAs were successfully modified, well received, initiated questions and participants indicated that they would recommend the DAs to others facing the same decision.

The DAs are the first available in Icelandic for those health decisions and to our best knowledge, the first interactive web-based DAs available in Icelandic overall. As such, they could facilitate further research and development of Icelandic DAs and increase the use of DAs in the Icelandic healthcare system. DAs have been shown to be cost-effective, have a minimal burden on the healthcare system and enhance SDM.

The findings suggest that the usage of DAs in the Icelandic healthcare system could have a beneficial impact, on patients and healthcare providers as well as the healthcare system, by reducing cost and providing more efficient SDM.

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Original Publications

I. Eiriksdottir, V.K., Baldursdottir, B. Fridriksson, J.O. & Valdimarsdottir, H.B. (2022). How much Information do Icelandic Men Receive on Pros and Cons of Prostate-specific Antigen Testing Prior to Undergoing Testing? *American Journal of Men's Health, 16*(3). DOI: 10.1177/15579883221097805

II. Eiriksdottir, V.K., Baldursdottir, B. Taylor, K. L., Fridriksson, J.O, Einarsdottir, S.E., Palsson, G. & Valdimarsdottir, H.B. Icelandic Translation and Cultural Adaptation of an Interactive Web-based Prostate-Specific Antigen (PSA) testing Decision Aid. [*Manuscript submitted for publication].*

III. Eiriksdottir, V.K., Jonsdottir, T. Valdimarsdottir, H.V., Taylor, K. L., Schwartz, M. D., Hilmarsson, R., Gudmundsson, E.O., Fridriksson, J.O. & Baldursdottir, B. (2021). An Adaptation, Extension and Pre-Testing of an Interactive Decision Aid for Men Diagnosed with Localized Prostate Cancer in Iceland: A Mixed-Method Study, *Behavioral Medicine*, *49*(2), 137-150. DOI: 10.1080/08964289.2021.2000926.

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Paper I

Paper II

Paper III

Appendix A

Description of the Decision aid for PSA testing decision

The decision aid (DA) includes evidence-based information about PSA testing and its risks and benefits as well as implicit and explicit values clarification exercises (VCE). The DA is divided into five chapters that include the following topics:

a) Chapter one consists of an introduction to PSA testing and why deciding to get a PSA test is a complex decision. The chapter additionally includes basic information about the prostate gland and prostate cancer (PC).

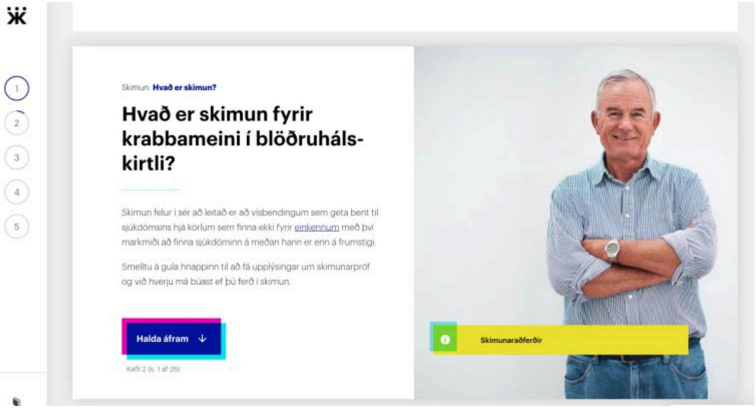
b) Chapter two includes information about the risks and benefits of PSA testing, the specificity and sensitivity of the PSA test and information about various tests that are used to detect PC and their possible results. Additionally, there is information about shared decision-making (SDM) and its importance.

c) Chapter three focuses on what happens after a PSA test detects a possible PC. This includes treatment options for PC and the risks and benefits of available treatments.

d) Chapter four includes information about the symptoms of PC and risk factors for PC.

e) Chapter five gives the user results from the explicit VCE and provides questions for the user that might be relevant for them to ask their physician.

Figure 1 shows the layout of the DA. Some pages include yellow banners that can be opened for more details about the page’s topic. Each page contains a short headline and underneath a text about the topic of the headline. To the left, the user can see which chapter he is viewing and approximately how much is left of the chapter, by following how much of the circle around the chapter number is filled.



Skimun: Hvað er skimun?

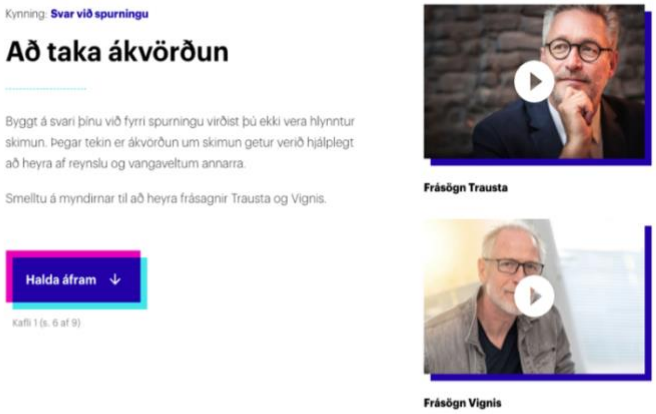
Hvað er skimun fyrir krabbameini í blöðruhálskirtli?

Skimun felur í sér að leitað er að vísbendingum sem geta bent til sjúkdómsins hjá körlum sem finna ekki fyrir einkennum með því markmiði að finna sjúkdóminn á meðan hann er enn á frumstigi.

Smelltu á gula hnappinn til að fá upplýsingar um skimunarpróf og við hverju má búast ef þú ferð í skimun.

Figure 1. The layout of the DA.

The implicit VCE was composed of eight audio files where men expressed their different experiences with PSA testing and how it had affected their lives. Figure 2 shows an example the implicit VCE.



Kynning: Svar við spurningu

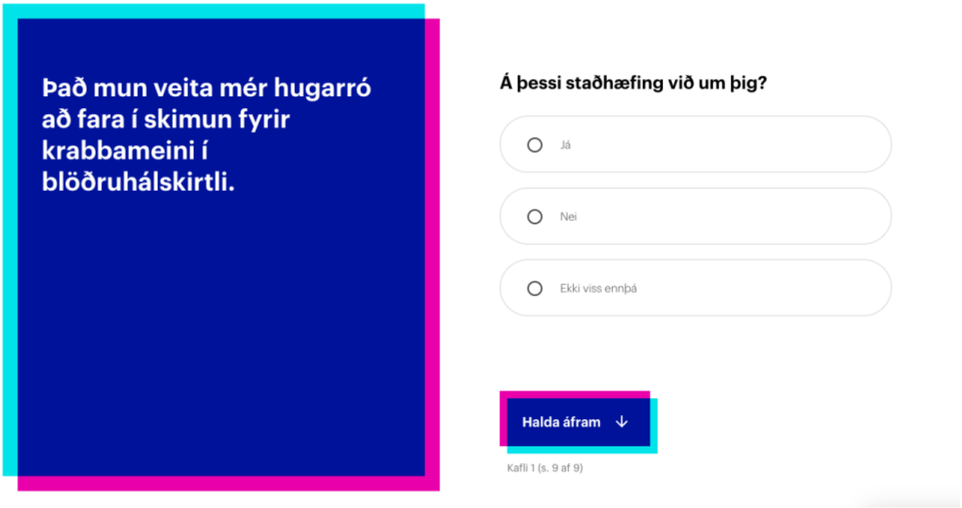
Að taka ákvörðun

Byggt á svari þínu við fyrri spurningu virðist þú ekki vera hlynntur skimun. Þegar tekin er ákvörðun um skimun getur verið hjálplegt að heyra af reynslu og vangaveltum annarra.

Smelltu á myndirnar til að heyra frásagnir Trausta og Vignis.

Figure 2. An example of the implicit VCE.

The explicit VCE was in the form of 10 questions situated throughout the DA and which users were prompted to answer based on their values and preferences. Each question is a statement, and users are prompted to answer if they agree with the statement with *yes, no,* or *not sure yet*. Questions include “PSA testing will give me peace of mind” and “even though PC treatment might elongate my life, it is not worth it because of possible side effects”. Figure 3 shows an example of the questions that comprise the explicit VCE.



Það mun veita mér hugarró að fara í skimun fyrir krabbameini í blöðruhálskirtli.

Á þessi staðhæfing við um þig?

○ Já

○ Nei

○ Ekki viss ennþá

Figure 3. An example of the explicit VCE.

Skipped questions were automatically marked as *not sure yet*. A summary score from all questions was generated by classifying answers as pro or con PSA testing. Responses that were con PSA testing were ranked as -1 and responses that were pro PSA testing were ranked as 1 and neutral responses were ranked as 0. The total score ranges from -10 to 10. A positive score ranging from 6 to 10 indicates that the user leans towards PSA testing and a negative score ranging from -6 to -10 indicates that the user leans away from PSA testing. Scores that fall between -5 and 5 indicate undecidedness.

The user receives written results from the explicit VCE at the end of the DA in concordance with their answers as described above. Figure 4 shows the result page of a user that leans towards PSA testing.

Niðurstaða: **Staðreyndir um meðferð**

Þú virðist hallast að því að láta rannsaka blöðruhálskirtilinn

Ef þessi samantekt er ekki í samræmi við það sem þú bjóst við að sjá þá getur verið að svör þín við spurningunum séu að gefa þér nýtt sjónarhorn á skoðanir þínar. Einnig getur verið að þú hafir ekki svarað sumum spurninganna eins og þú ætlaðir þér.

Figure 4. The results page.

A description of the original DA can be found in Kassan et al. (2012) and Dorfman et al. (2010).

Appendix B

Description of the Decision aid for newly diagnosed men with localized PC

The DA includes the following topics:

a) Information about PC.

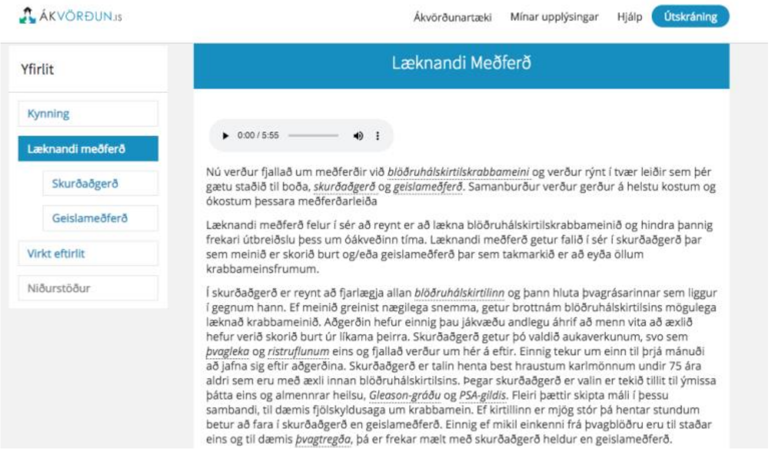
b) Overview of available treatment options, i.e., active surveillance, radical prostatectomy, and radiation therapy.

c) Risks and benefits of each treatment option.

d) Explicit VCE to assist users in weighing the risks and benefits of each treatment option.

The content of the DA was designed to fit users with low health literacy by using simple language, short sentences and defining complex terms (McCaffery et al., 2013).

The first time the DA is used, the user is asked to answer two questions, i.e., if they have first-degree relatives that have been diagnosed with PC and if they have first-degree relatives that have been diagnosed with breast cancer. If the user answers yes to either of those, they are informed that they should discuss this further with their physician as active surveillance might not be an option for them. Randomization process is integrated into the DA, and thus, each user is randomized to either start at the chapter about curative treatments (i.e., radical prostatectomy and radiotherapy) or at the chapter about active surveillance. Figure 5 shows the layout of the DA. To the left is a navigation banner that shows in which chapter the user is located and how many chapters are left. A voice record was made for all information in the DA and thus, users can listen to the text by playing an audio file located at the top of the page.



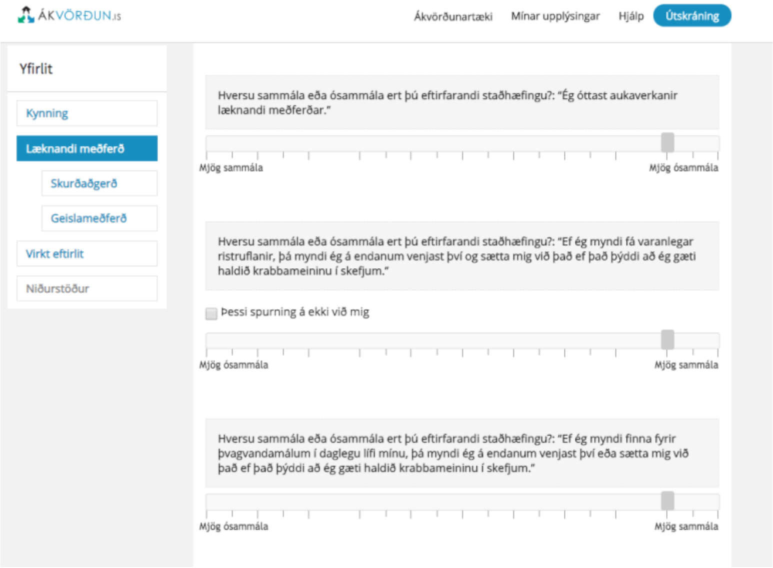
Nú verður fjallað um meðferðir við *blöðruhálskirtilskrabbameini* og verður rýnt í tvær leiðir sem þér gætu staðið til boða, *skurðaðgerð* og *geislameðferð*. Samanburður verður gerður á helstu kostum og ókostum þessara meðferðarleiða

Læknandi meðferð felur í sér að reynt er að lækna blöðruhálskirtilskrabbameinið og hindra þannig frekari útbreiðslu þess um óákveðinn tíma. Læknandi meðferð getur falið í sér í skurðaðgerð þar sem meinið er skorið burt og/eða geislameðferð þar sem takmarkið er að eyða öllum krabbameinsfrumum.

Í skurðaðgerð er reynt að fjarlægja allan *blöðruhálskirtilinn* og þann hluta þvagrásarinnar sem liggur í gegnum hann. Ef meinið greinist nægilega snemma, getur brottnám blöðruhálskirtilsins mögulega læknað krabbameinið. Aðgerðin hefur einnig þau jákvæðu andlegu áhrif að menn vita að æxlið hefur verið skorið burt úr líkama þeirra. Skurðaðgerð getur þó valdið aukaverkunum, svo sem *þvagleka* og *ristruflunum* eins og fjallað verður um hér á eftir. Einnig tekur um einn til þrjá mánuði að jafna sig eftir aðgerðina. Skurðaðgerð er talin henta best hraustum karlmönnum undir 75 ára aldri sem eru með æxli innan blöðruhálskirtilsins. Þegar skurðaðgerð er valin er tekið tillit til ýmissa þátta eins og almennrar heilsu, *Gleason-gráðu* og *PSA-gildis*. Fleiri þættir skipta máli í þessu sambandi, til dæmis fjölskyldusaga um krabbamein. Ef kirtillinn er mjög stór þá hentar stundum betur að fara í skurðaðgerð en geislameðferð. Einnig ef mikil einkenni frá þvagblöðru eru til staðar eins og til dæmis *þvagtregða*, þá er frekar mælt með skurðaðgerð heldur en geislameðferð.

Figure 5. The layout of the DA.

When the user goes through the DA for the first time, they need to proceed through each section of the DA and answer the questions to receive results from the explicit VCE. An example of questions of the explicit VCE is shown in Figure 6.



Hversu sammála eða ósammála ert þú eftirfarandi staðhæfingu?: "Ég óttast aukaverkanir læknandi meðferðar."

Mjög sammála — Mjög ósammála

Hversu sammála eða ósammála ert þú eftirfarandi staðhæfingu?: "Ef ég myndi fá varanlegar ristruflanir, þá myndi ég á endanum venjast því og sætta mig við það ef það þýddi að ég gæti haldið krabbameininu í skefjum."

☐ Þessi spurning á ekki við mig

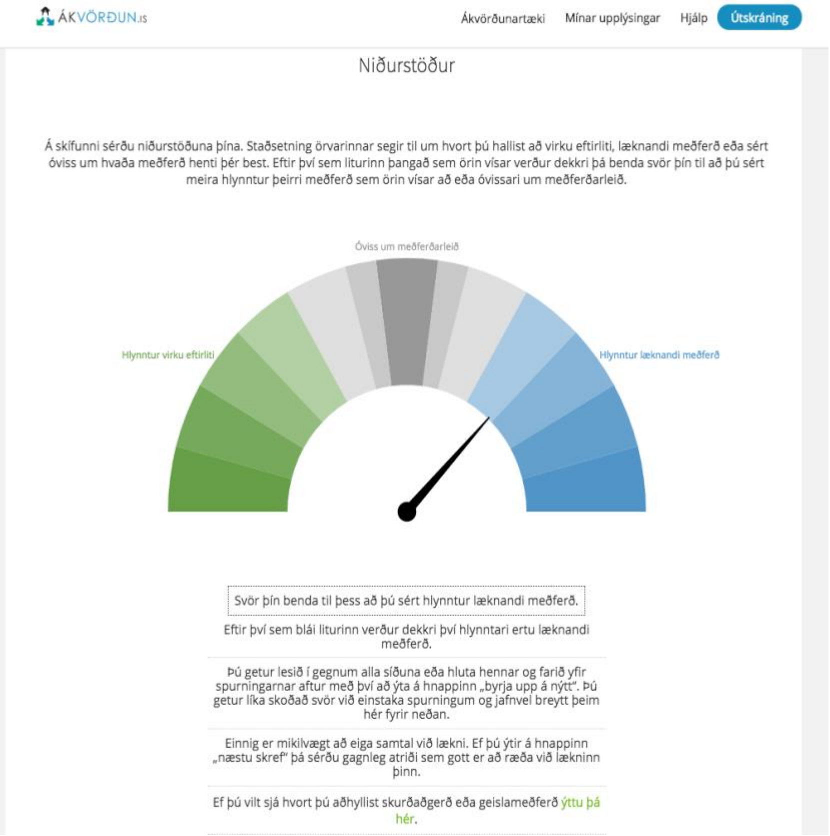
Mjög ósammála — Mjög sammála

Hversu sammála eða ósammála ert þú eftirfarandi staðhæfingu?: "Ef ég myndi finna fyrir þvagvandamálum í daglegu lífi mínu, þá myndi ég á endanum venjast því eða sætta mig við það ef það þýddi að ég gæti haldið krabbameininu í skefjum."

Mjög ósammála — Mjög sammála

Figure 6. An example of questions in the explicit VCE.

The explicit VCE consists of 18 questions that are presented throughout the DA and belong to two different components. The first component is composed of 12 questions, and those determine if the user leans towards curative treatment, active surveillance or is undecided. If the user leans towards curative treatment, another result page is presented that is composed of the second component which includes six questions that determine if the user leans towards radical prostatectomy or radiotherapy or is undecided. Each question of each component is rated on a scale from -10 to 10. The user places the bar on the scale that best represents his answer. In the first component, positive answers favour curative treatment, and negative ones favour active surveillance. A summary score ranges from -120 to 120. Then the summary score is transformed into an absolute score by adding 120 to the summary score. Thus, the final summary score only includes positive numbers ranging from 0 to 240. This makes it possible to divide the scale into percentages. The lowest 33.3% leans towards active surveillance, i.e., a score under 80. The highest 33.3% lean towards curative treatment, i.e., a score over 160. Scores in between those indicate that the user is undecided. In the second component, positive answers favour radical prostatectomy and negative favour radiation therapy. A summary score ranges from -60 to 60. The summary score is then transformed into an absolute score by adding 60 to the summary score. Therefore, the final summary score only includes positive numbers ranging from 0 to 120. The lowest 33.3% leans towards radiation therapy, i.e., a score under 40, and the highest 33.3% leans towards radical prostatectomy, i.e., a score over 80. Scores in between those indicate that the user is undecided. The results of the explicit VCE are presented visually on a gauge on a results page where the user is informed if he leans towards a curative treatment or active surveillance. An example of a results page for a user that leans towards curative treatments is shown in Figure 7.



Niðurstöður

Á skífunni sérðu niðurstöðuna þína. Staðsetning örvarinnar segir til um hvort þú hallist að virku eftirliti, læknandi meðferð eða sért óviss um hvaða meðferð henti þér best. Eftir því sem liturinn þangað sem örin vísar verður dekkri þá benda svör þín til að þú sért meira hlynntur þeirri meðferð sem örin vísar að eða óvissari um meðferðarleið.

Svör þín benda til þess að þú sért hlynntur læknandi meðferð.

Eftir því sem blái liturinn verður dekkri því hlynntari ertu læknandi meðferð.

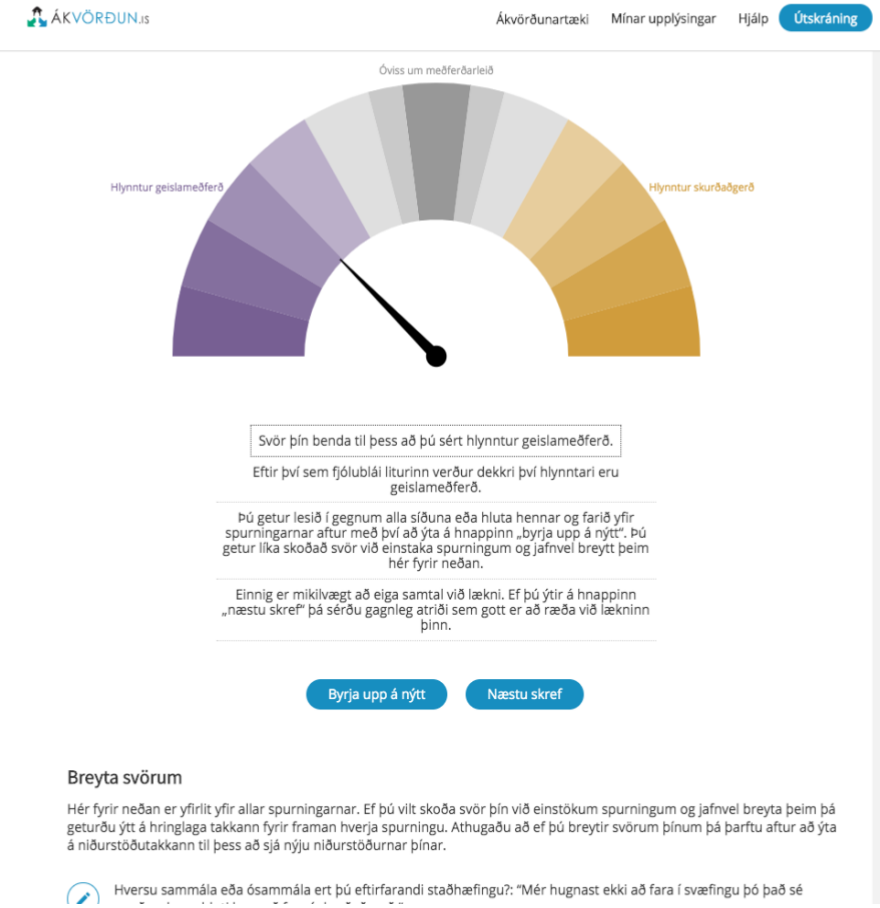
Þú getur lesið í gegnum alla síðuna eða hluta hennar og farið yfir spurningarnar aftur með því að ýta á hnappinn „byrja upp á nýtt“. Þú getur líka skoðað svör við einstaka spurningum og jafnvel breytt þeim hér fyrir neðan.

Einnig er mikilvægt að eiga samtal við lækni. Ef þú ýtir á hnappinn „næstu skref“ þá sérðu gagnleg atriði sem gott er að ræða við lækninn þinn.

Ef þú vilt sjá hvort þú aðhyllist skurðaðgerð eða geislameðferð ýttu þá hér.

Figure 7. Results for a user that leans towards curative treatment.

If the user leans towards curative treatment and not active surveillance, he is represented with another gauge that indicates if he leans towards radical prostatectomy or radiation therapy. In Figure 8 a results page for a user that leans towards radiation therapy is presented.



Svör þín benda til þess að þú sért hlynntur geislameðferð.

Eftir því sem fjólubláí liturinn verður dekkri því hlynntari eru geislameðferð.

Þú getur lesið í gegnum alla síðuna eða hluta hennar og farið yfir spurningarnar aftur með því að ýta á hnappinn „byrja upp á nýtt". Þú getur líka skoðað svör við einstaka spurningum og jafnvel breytt þeim hér fyrir neðan.

Einnig er mikilvægt að eiga samtal við lækni. Ef þú ýtir á hnappinn „næstu skref" þá sérðu gagnleg atriði sem gott er að ræða við lækninn þinn.

Breyta svörum

Hér fyrir neðan er yfirlit yfir allar spurningarnar. Ef þú vilt skoða svör þín við einstökum spurningum og jafnvel breyta þeim þá geturðu ýtt á hringlaga takkann fyrir framan hverja spurningu. Athugaðu að ef þú breytir svörum þínum þá þarftu aftur að ýta á niðurstöðutakkann til þess að sjá nýju niðurstöðurnar þínar.

Hversu sammála eða ósammála ert þú eftirfarandi staðhæfingu?: "Mér hugnast ekki að fara í svæfingu þó það sé

Figure 8. Results page for a user that leans towards radiation therapy.

When users have been presented with the results page, they can view any section of the DA again, in no specific order and change their responses to the questions, whereafter they get a new results page. The results page can be printed, and it also provides an option to print a list of questions that can be helpful for users to discuss with their physicians as well as a space to add their own questions. Users are encouraged to show their physician their results to assist with the SDM process and discuss possible questions and concerns.