Usability of interactive health technology for kidney living donor assessment: a valuable tool for standardizing the informed consent process

Fernanda Ortiz, Juulia Grasberg, Agneta Ekstrand, Ilkka Helanterä, Guido Giunti

Submitted to: JMIR Formative Research
on: April 01, 2023

Table of Contents

Usability of interactive health technology for kidney living donor assessment: a valuable tool for standardizing the informed consent process

Fernanda Ortiz[1, 2] MD, PhD; Juulia Grasberg[3, 4] MD; Agneta Ekstrand[3, 4] MD, PhD; Ilkka Helanterä[4, 5] MD, PhD; Guido Giunti[6, 7] MD, PhD

[1]Helsinki University Hospital Helsinki FI
[2]Helsinki University Helsinki FI
[3]Helsinki University Hospital Nephrology Helsinki FI
[4]Helsinki University Department of Medicine Helsinki FI
[5]Helsinki University Hospital Transplantation and Liver Surgery Helsinki FI
[6]University of Oulu Oulu FI
[7]Trinity College School of Medicine Dublin IE

Corresponding Author:
Fernanda Ortiz MD, PhD
Helsinki University Hospital
Haartmaninkatu 4
Helsinki
FI

Abstract

Background: Kidney living donation is not a risk-free procedure. Information about the process, risks of nephrectomy, and psychological impact should be given to every candidate, but this practice is not standardized.

Objective: We aimed to evaluate the utility of new interactive health technology as a new tool to improving the informed consent process in kidney living donation.

Methods: This cross-sectional survey study involves all living kidney donor candidates (LD) from Helsinki University Hospital (N=127) from Jan 2019 to Jan 2022. All candidates were invited to use the open institutional portal Health Village-Kidney hub, and the patient-tailored digital care path (LD-dcp), which includes information about the donation process and facilitates communication between clinicians, transplant coordinators, and patients. Participants' eHealth literacy was evaluated with the eHEALS query, usability with the system usability score (SUS), and system utility was assessed with three 5-point Likert scale surveys. Demographics and socioeconomic data were included. An open-ended question was examined with qualitative content analysis.

Results: The Kidney hub was accessed on average by 8000 visitors monthly mostly from a smartphone (60%), 71 % were females, and 25% were aged over 65. Seven out of 127 LD candidates did not use the LD-dcp. Users´ age ranged from 20 to 79 years. Over 3500 messages were exchanged. Fifty-eight percent of all kidney donor candidates consented to participate in the survey. The mean e-HEALS was 3,77. Search on the internet about kidney donation was significantly more common in females than males (84 % vs 55 %, p= 0.038), and was unrelated to education level (0.475), working status (p= 0.325), or income (p= 0.720). The participants' experience with the LD-dcp technical aspect was good (mean SUS 4.4) and they found it useful, but not critical to decide to donate. The main concerns were about both donor and recipient coping after surgery.

Conclusions: LD candidate education about the living donation process was successfully achieved with telemedicine. The LD-dcp is a valuable complementary eHealth tool for clinicians, allowing standardization of steps towards the informed consent process. Clinical Trial: NCT04791670

(JMIR Preprints 01/04/2023:47785)
DOI: https://doi.org/10.2196/preprints.47785

Preprint Settings

1) Would you like to publish your submitted manuscript as preprint?
✓ **Please make my preprint PDF available to anyone at any time (recommended).**

Please make my preprint PDF available only to logged-in users; I understand that my title and abstract will remain visible to all users.
Only make the preprint title and abstract visible.
No, I do not wish to publish my submitted manuscript as a preprint.

2) If accepted for publication in a JMIR journal, would you like the PDF to be visible to the public?
✓ **Yes, please make my accepted manuscript PDF available to anyone at any time (Recommended).**
Yes, but please make my accepted manuscript PDF available only to logged-in users; I understand that the title and abstract will remain v
Yes, but only make the title and abstract visible (see Important note, above). I understand that if I later pay to participate in <a href="http

Original Manuscript

Usability of interactive health technology for kidney living donor assessment: a valuable tool for standardizing the informed consent process

Fernanda Ortiz (1,2), Juulia Grasberg (1,2), Agneta Ekstrand (1,2), Ilkka Helanterä (2,3) and Guido Giunti (4,5)

(1) Helsinki University Hospital- Abdominal center- Nephrology

(2) University of Helsinki, Faculty of Medicine

(3) Helsinki University Hospital- Abdominal center- Transplantation and Liver Surgery

(4) University of Oulu, Faculty of Medicine

(5) Trinity College, School of Medicine, Dublin

Correspondent author
Dr Fernanda Ortiz
Helsinki University Hospital – Haartmaninkatu 4. 00029 HUS Helsinki Finland
Phone number 00358504270795
Fax 0035894711
e-mail fernanda.ortiz@hus.fi

Abstract

Introduction. Kidney living donation carries risks, yet standardized information provision regarding nephrectomy risks and psychological impacts for candidates remains lacking. This study assesses the benefit of interactive health technology in improving the informed consent process for kidney living donation.

Methods: The Kidney Hub institutional open portal offers comprehensive information on kidney disease and donation. Subjects willing to start the kidney living donation process in Helsinki University Hospital (Jan 2019 - Jan 2022) were invited to use the patient-tailored digital care path included in the Kidney Hub. This platform provides detailed donation process information and facilitates communication between healthcare professionals and patients. eHealth literacy was evaluated via eHEALS, usability with the system usability score (SUS), and system utility through 1-5 Likert scale surveys. Qualitative content analysis addressed an open-ended question.

Results. The Kidney Hub portal received over 8000 monthly visits, with sections on donation benefits (1629 views) and impact on donors' lives (4850 views). Of 127 LD candidates, seven did not use the Living-Donor-digital-care-path. Users' ages ranged from 20 to 79 years, exchanging over 3500 messages. Seventy-four living donor candidates participated in the survey. Females more commonly searched the internet about kidney donation (79 females vs 48 males, *P*=.038). Mean eHEALS scores correlated with internet use for health decisions (R 0.45; *P*<.001) and its importance (R 0.40; *P*=.01). Participants found the Living-Donor-digital-care-path technically satisfactory (mean SUS 4.4) and useful but not pivotal in donation decision-making. Concerns focused on post-surgery coping for donors and recipients.

Conclusions. Telemedicine effectively educates living kidney donor candidates on the donation process. The Living-Donor-digital-care-path serves as a valuable eHealth tool, aiding clinicians in standardizing steps toward informed consent. (NCT04791670)

Keywords

eHealth- living kidney donor- informed consent- telemedicine – process standardization

Introduction

The optimal choice for a patient awaiting a kidney transplant is to receive the organ from a living donor. Despite efforts to boost living kidney donation (LD), global rates vary widely [1]. Kidney donation involves risks, making it crucial to ensure donor candidates receive the necessary information to make informed decisions. The process begins with a medical candidacy assessment and comprehensive details about the nephrectomy's process and consequences. Healthcare professionals must confirm that LD candidates comprehend risks, understand potential outcomes for both donor and recipient and can independently decide, leading to an informed consent document.

Informed consent procedures vary across countries, transplant centers, and among healthcare professionals, especially surgeons and nephrologists [2-3]. Standardizing information provided to LD candidates is essential [4]. There is agreement on communicating all potential health, economic, and psychosocial risks to living donors. Various guidelines outline matters to disclose, but their implementation varies by the transplant center. A recent study in The Netherlands found variation in basic procedure knowledge among potential LD candidates despite information following guidelines. A possible cause was donors receiving information in referring hospitals rather than transplant centers [5]. A survey in Europe highlighted gaps in healthcare professionals discussing long-term risks with potential kidney donors [6].

Healthcare technology has undergone significant changes, going beyond digitizing health records. Digital transformation implies broad technology use, incorporating electronic health record data and enabling telemedicine. A 2019 US survey on digital services for living donor candidates revealed the potential for mobile health to enhance donor follow-up and aid centers in meeting reporting thresholds. Concerns about cybersecurity, usability, and cost-effectiveness were raised [7]. A 2022 survey in the US supported telemedicine's convenience for improving access and coordination of living donor evaluation. However, participants expressed less confidence in removing regulatory office barriers. Pilot studies focusing on LD candidate education with eHealth tools show promising results [8-10].

Finland's Ministry of Social Affairs and Health partially funded a National Action Plan on Organ Donation and Transplantation to promote online health information and eHealth tools. The establishment of the Virtual Hospital led to 'Health Villages', providing information, patient care, and professional tools. The Health Village, developed by Finnish university hospitals, includes specific hubs like the Kidney hub for individuals with kidney disease [11]. In December 2018, Helsinki University Hospital launched the digital care path for potential living kidney donors (LD-dcp) within the Kidney hub. LD-dcp, exclusively available to those considering kidney donation, aims to increase donors by offering standardized information, secure messaging pathways, and teleconsultation options. Figure 1 illustrates our institution's process for providing digital information to kidney-living donor candidates. The LD-dcp focuses on active use for education initially and continues telemedicine and messaging throughout the kidney donation evaluation process. In Figure 2 the content of the LD-dcp is outlined.

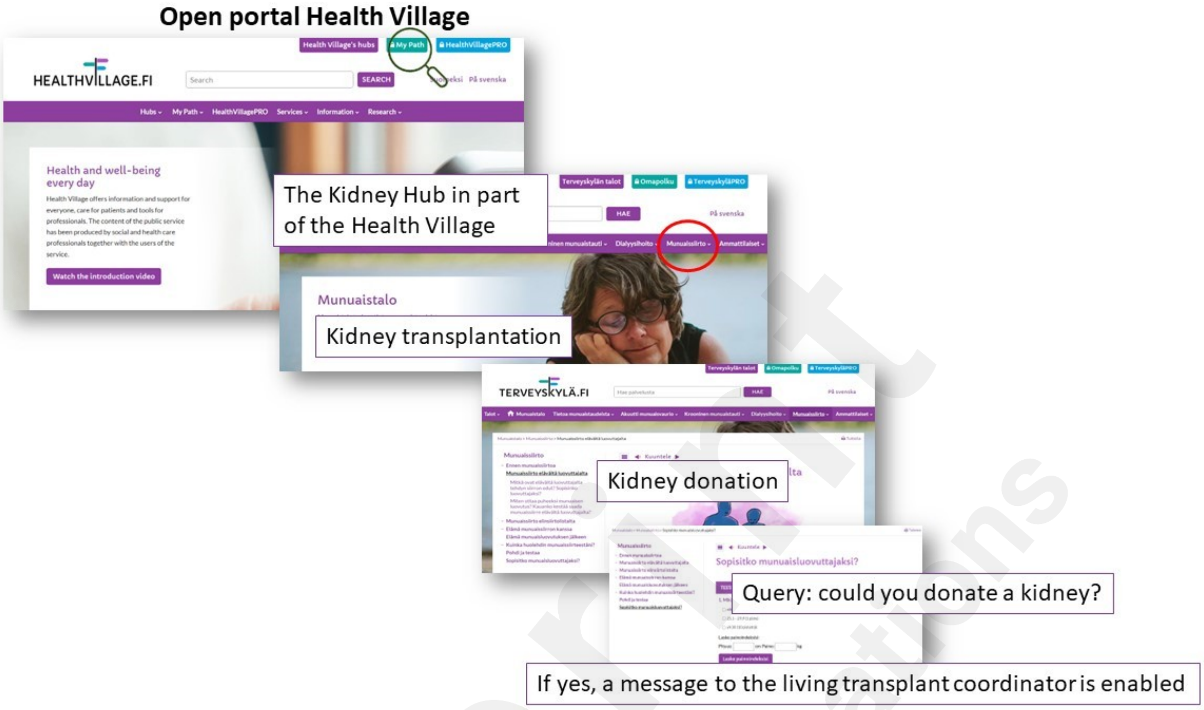


Figure 1. The digital process of the information to kidney donors provided by the hospital web.

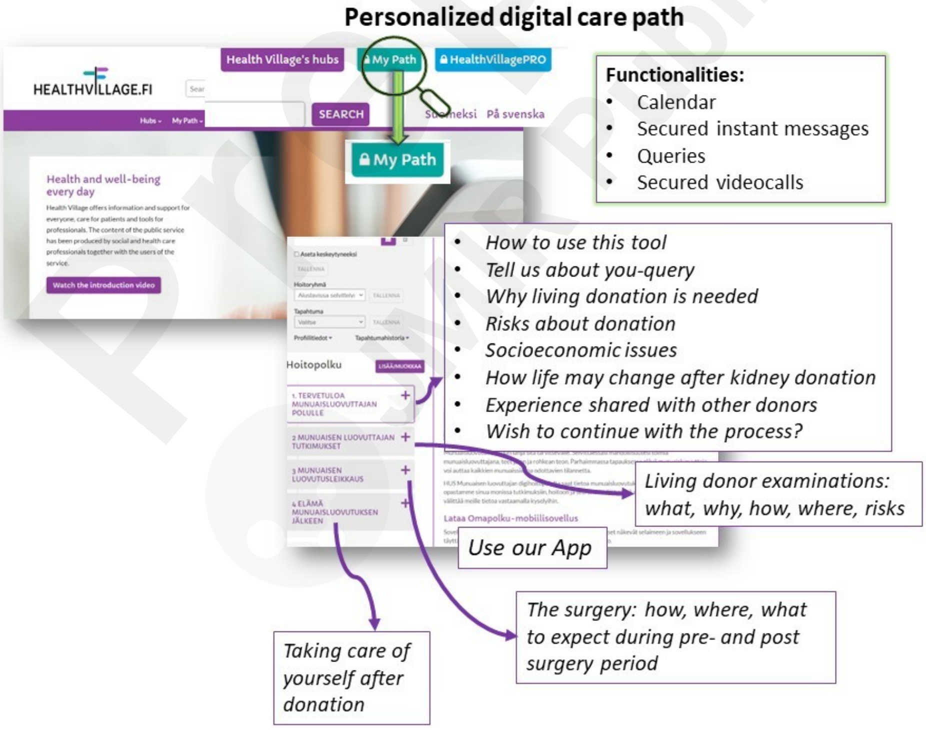


Figure 2. Description of the personalized information steps included in the living-donor digital care path

So far, the performance and usefulness of these eHealth solutions have not been studied. We aimed to examine the benefit and usability of eHealth services designed for kidney donor candidates as a tool for a standardized informed consent process. The secondary aims were to investigate living donor candidates' eHealth literacy and patterns of use of digital health services concerning kidney donation.

Methods

Participants

This was a prospective cross-sectional survey study involving all LD-dcp users (N=127) from Jan 2019 to Dec 2021 evaluated in the Helsinki University Hospital, Department of Nephrology. We approached the participants by phone, text messaging, and/or email, considering the participants' preferences. The consent to participate in this survey was carried on electronically and integrated and secured into the LD-dcp. Detailed information on the study protocol has been previously published. [12] Briefly, we used three questionnaires, and the answers were provided electronically. The first one gathered information about sociodemographic factors, device ownership, and purpose of use. Secondly, eHealth literacy was assessed by the eHEALS survey, an 8-item Likert scale that measures perceived skills at finding, evaluating, and applying electronic health information to health problems (1: strongly disagree to 5: strongly agree). The scale is based on a model that distinguishes between six types of literacy skills: traditional literacy, health literacy, information literacy, scientific literacy, computer literacy, and media literacy. The third questionnaire was intended to assess the Kidney hub and LD-dcp platform's ease of use by applying the System Usability Scale (SUS), and users´ feedback on the LD-dcp was explored with 5-point Likert-scaled questions ((1: strongly disagree to 5: strongly agree)) and one open question for qualitative analysis ("Is there anything you wish kidney donors should be warned about that you were not?"). Written informed consent was obtained electronically within the LD-dcp. See Supplemental material.

The subjects willing to donate a kidney seek information from different sources, one of them being the Kidney Hub. Therefore, access to the Kidney Hub was included in the analysis to serve as a reference for the utilization of this open-access portal in the context of kidney transplantation and living kidney donation.

Statistical analysis.

Webpage demographics and use patterns of the open-portal Kidney Hub were analyzed with Google Analytics and Power BI. The present study is descriptive, and sample size calculation is not needed because the entirety of the LD-dcp users were invited to participate. Descriptive statistics were used to summarize participants' backgrounds and characteristics. Categorical variables were presented as absolute and relative frequencies. Continuous variables were presented as mean and SD or median with the IQR depending on the distribution. A p-value of less than 5% was considered statistically significant. For eHeals and SUS, quantitative analysis followed the instruments' scoring system and the 5-point Likert item response. Cronbach´s alpha correlation was calculated to assert internal consistency. Pearson correlation, Mann-Whitney U, and Chi-square tests were used when appropriate. Qualitative content analysis was used on the open-ended question. We evaluated the presence of words and concepts within the data (meaning units), synthesized them in code units, and made a further analysis by counting the frequencies of the detected categories.

The research protocol has been approved by the Helsinki University Hospital ethical committee (HUS/501/2021) to ensure that the work is done in accordance with the Declaration of Helsinki and the Declaration of Istanbul. This clinical trial has been registered in clinicaltrials.gov, reference NCT04791670.

Results

First, the results of the use of the institutional open portal Kidney Hub are presented. Afterward, the use of the living donor digital care path, and finally the results of the survey of the digital care path users evaluating their experience with the digital services. The digital services user´s flow chart is depicted in Figure 3.

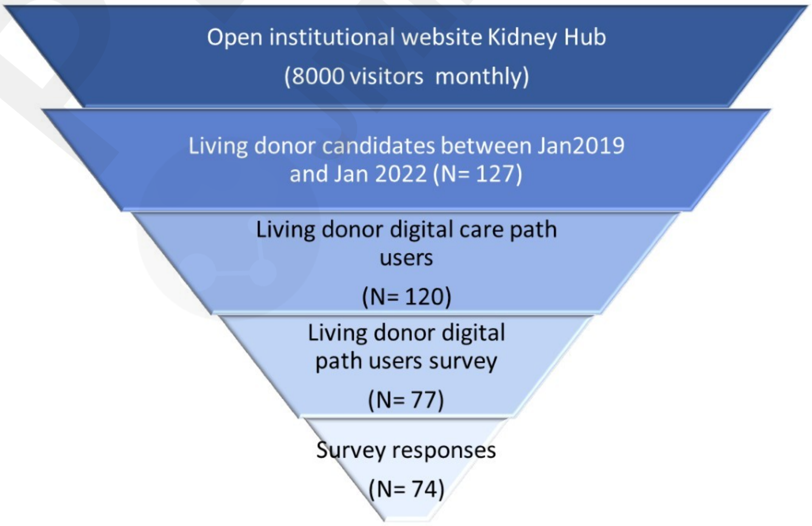


Figure 3. Flow chart of the users of the digital services provided by the Kidney Hub

Utilization of the Kidney Hub open portal

Initially, we analyzed the utilization of the Kidney Hub open portal, considering it would serve as an initial information source for patients needing a kidney transplant and for potential kidney donors. The Kidney Hub was accessed between Jan 2019 and Dec 2021 on average by 8000 visitors per month, of which 71 % were females. Altogether, 4800 out of 8000 of the Kidney Hub visitors (60 %) were from Finland, 2480 (31 %) from Sweden, 480 (6 %) from the USA, and less than 80 (1 %) from Norway, Germany, Spain, the UK, Bulgaria, Russia, and Canada. It was most frequently visited from midday till 10 pm on weekdays. In all, 2000 (25 %) of the 8000 visitors were aged over 65, 1680 (21 %) were 25-34 years old; 1520 (19 %) were 55-64 years old, 1120 (14 %) of the visitors were between 35 and 54 years old, and younger the 25 years old only 640 (8 %) visitors. The website was accessed from a mobile phone by 4800 out of 8000 users (60 %), 2480 (31 %) accessed the website from a desktop, and 640 (8 %) from a tablet.

The Kidney Hub includes tips for patients on how to initiate a conversation about living kidney donation. This page was visited over 2600 times. The general information about the benefits of living kidney donation was visited 1629 times and how living kidney donation impacts the donor ´s life was visited 4850 times.

Utilization of the Living Donor – digital care path

All donor candidates were invited to join the LD-dcp from Jan 2019 onwards. This service is only open to those who expressed their willingness to donate a kidney to the living donor transplant coordinator. This service is free of charge to the living donor candidates and only requires internet access. A reminder is sent to those who did not activate the system within one week. Altogether 127 living donor candidates initiated the evaluation process, of whom 79 (62%) were females. Six donor candidates preferred not to use digital services and one had language barriers. Forty-eight out of 120 LD-dcp users were actively interacting with this system after six months from activation. The age of the LD-dcp users ranged from 20 to 79 years, and 91 (72%) of them were between 40 and 69 years old. In all, 3511 messages were exchanged through the LD-dcp, of which 2247 (64%) were from females. Thirty percent of the participants (N=22) had already donated the kidney when they answered the survey, and some participants did not donate, meaning that they did not experience the entire process. The quality analysis lightened five different topics: unexpected discontinuation of the donor evaluation process due to unknown medical conditions with consequent disappointment, the surprise about the extensive time-consuming medical evaluation and lab tests, practical issues related to the stay on the ward and discharge after surgery, impact of kidney transplantation on both donor and recipients focused on expectations, and finally a positive message to other considering donation (“life doesn’t change that much”).

Survey study participants

Of all 120 LD- dcp users invited to participate in this study by a message through the LD-dcp, 77 agreed. The surveys were answered by 74 participants (response rate of 58 %) and by then, 23% had already donated a kidney. The sociodemographic data of the participants are shown in Table 1.

Age, mean (min-max; IQ range)		50.3 (23–76; 22)
Sex, females in %		60.8
Education, in %	N/A	20.3
	Primary school	4.1
	High school or vocational school	31.1
	Polytechnic or university	41.9
	Other	2.7
	N/A	20.3
Working status, in %	Student	1.4
	Unemployed	1.4
	Employed	60.8
	Retired	2.7
	Other	13.5
Annual income categories, in %	N/A	20.3
	Don´t want to answer	2.7
	Under 20 000 €	5.4
	20 000–40 000 €	28.4
	40 000–60 000 €	24.3
	Over 60 000 €	18.9
Live alone? in %	Yes/No/NA	9.5 /70.3/20.3

Table 1. Sociodemographic data from 74 living-donor digital care path users who responded to the questionnaires. N/A: not available

Living donor candidates’ patterns of use of digital technology

Fifteen out of 74 participants did not respond to this query (response rate 80%). All 59 respondents had a smartphone, 4 participants (5.4 %) did not have a computer and 26 (35 %) did not have a tablet. Fifty-two out of 59 respondents (88 %) used their smartphones for sending messages (including instant messaging), navigating the internet, taking photos or videos, and reading e-mails several days a week or on an everyday basis. Ten out of 59 respondents (17%) percent never watch TV or movies on their smartphone. Social media was used by 42 out of 59 respondents (71 %), health applications by 41 (69 %), and the participants used these services several days a week or every day. Twenty-seven out of 59 respondents (46%) never used their smartphone for gaming.

Use of the internet for searching for information about health

Over 86 % of the respondents (64 out of 74 participants) agree or strongly agree with the importance and helpfulness of the internet to find out about health issues. Almost 80 % of the participants (59 out of 74) knew what, where, and how to find health resources on the internet. However, fewer participants felt they had the skills to evaluate the quality of the information they found, and only 30 out of 74 (40%) felt confident in using this information to make decisions about their health. The detailed results of the eHEALS survey are displayed in Figure 4. The Cronbach's alpha was 0.86, indicating good internal consistency. The mean eHEALS was 3.77 (IQR 3.5-4.0). Cut points have not been validated for the eHEALS, and scores cannot be categorized reliably. There was no significant correlation between eHEALS and age [R -.127 *P*=.301]. Mean eHeals was not statistically different across educational levels (*P*=.249), working statuses [*P*=.164], or income levels (*P*= .289). Mean eHEALS was similar between males and females [*P*=.338] and positively correlated with using the internet for decision-making [R 0.45; *P*<.001) about health issues and the importance of using the internet for health-related issues [R 0.40; *P*=.01].

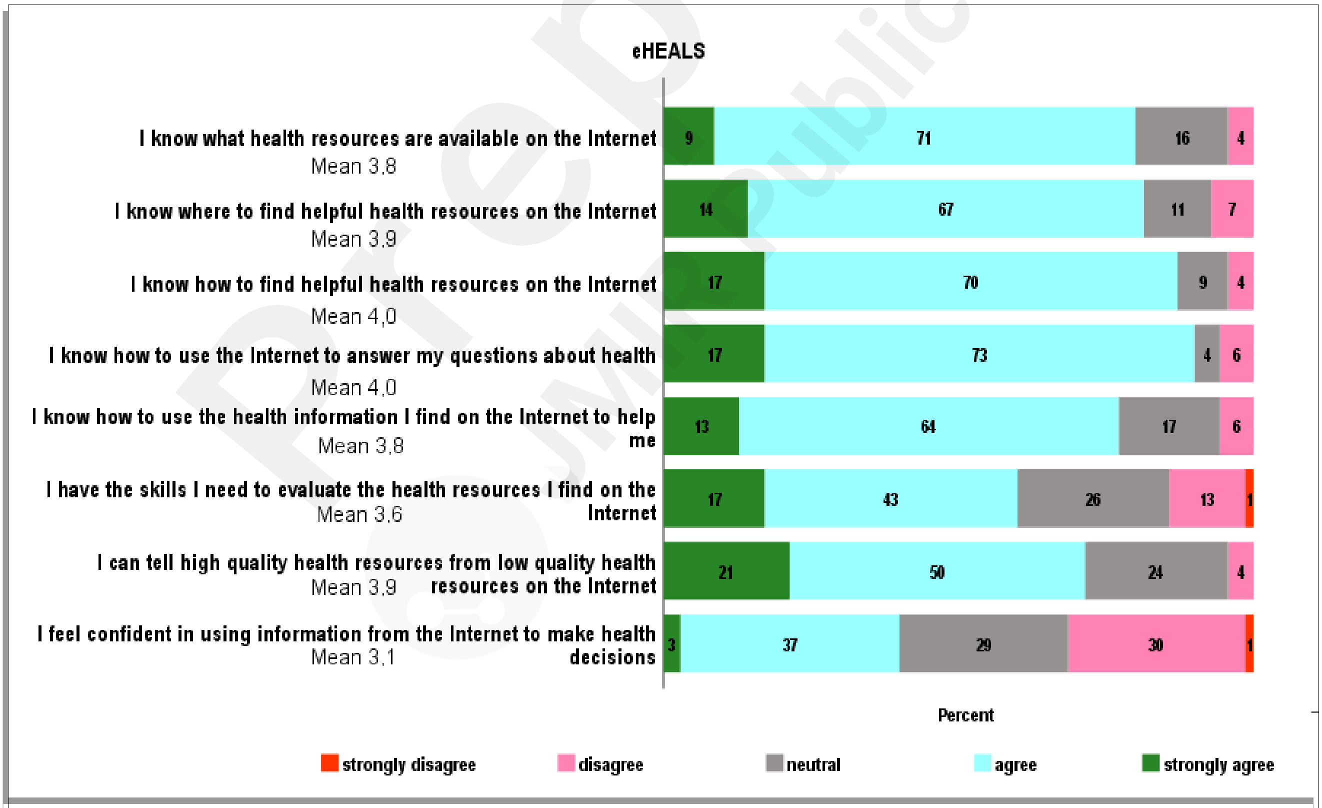


Figure 4. eHEALS (eHealth Literacy Scale) The frequency of responses is expressed in percentage in each bar (N=74=

Usefulness and satisfaction with the LD-dcp

Fifty-four out of 74 participants (73%) had searched the internet for information about living kidney donation before contacting the transplant coordinator. Search on the internet about kidney donation was significantly more common in females (46 females and 28 males out of 74 participants, 84 % vs 55 %, p= 0.038). Search on the internet about kidney donation was not related to their education level (100% of primary education, 68% of high school, and 81% of university education; P=.475), working status (100% of students, 79% of employed, and 100 % of retired; *P*= .325), or income (67% of income below 40000€/year, 75% of income between 40000 and 6000€/year and 86% of income over 60000€/year; p= .720). The source of information about living kidney donation were the hospital website & the Kidney Hub (24 out of 74, 33 %), patient associations (30 out of 74, 40 %), general search engines (ie. google, Wikipedia, social media (17 out of 74, 23 %), and other donors (4 out of 74, 5 %). Sixty-six out of 74 participants (90%) considered that the information about living kidney donation available in the Kidney hub open portal was useful.

The results of the System Usability Score and Utility queries are shown in Figure 5. The Cronbach’s alpha of the System Usability Scale was 0.89 implying good reliability and the Cronbach’s alpha of the Utility Scale was 0.73, indicating that the reliability is acceptable. We were unable to detect any gender differences in the SUS-mean score (mean score in males 4.2 vs females 4.3, *P*=.345) or the Utility mean score (mean score in males 4.1 vs females 4.1, *P*=.953). Neither score correlated with age (R -0.127; *P*=.913 and R 0.016 *P*=.958 respectively). The participants agreed that the information about kidney donation available in the Kidney Hub is useful (mean 4.44).

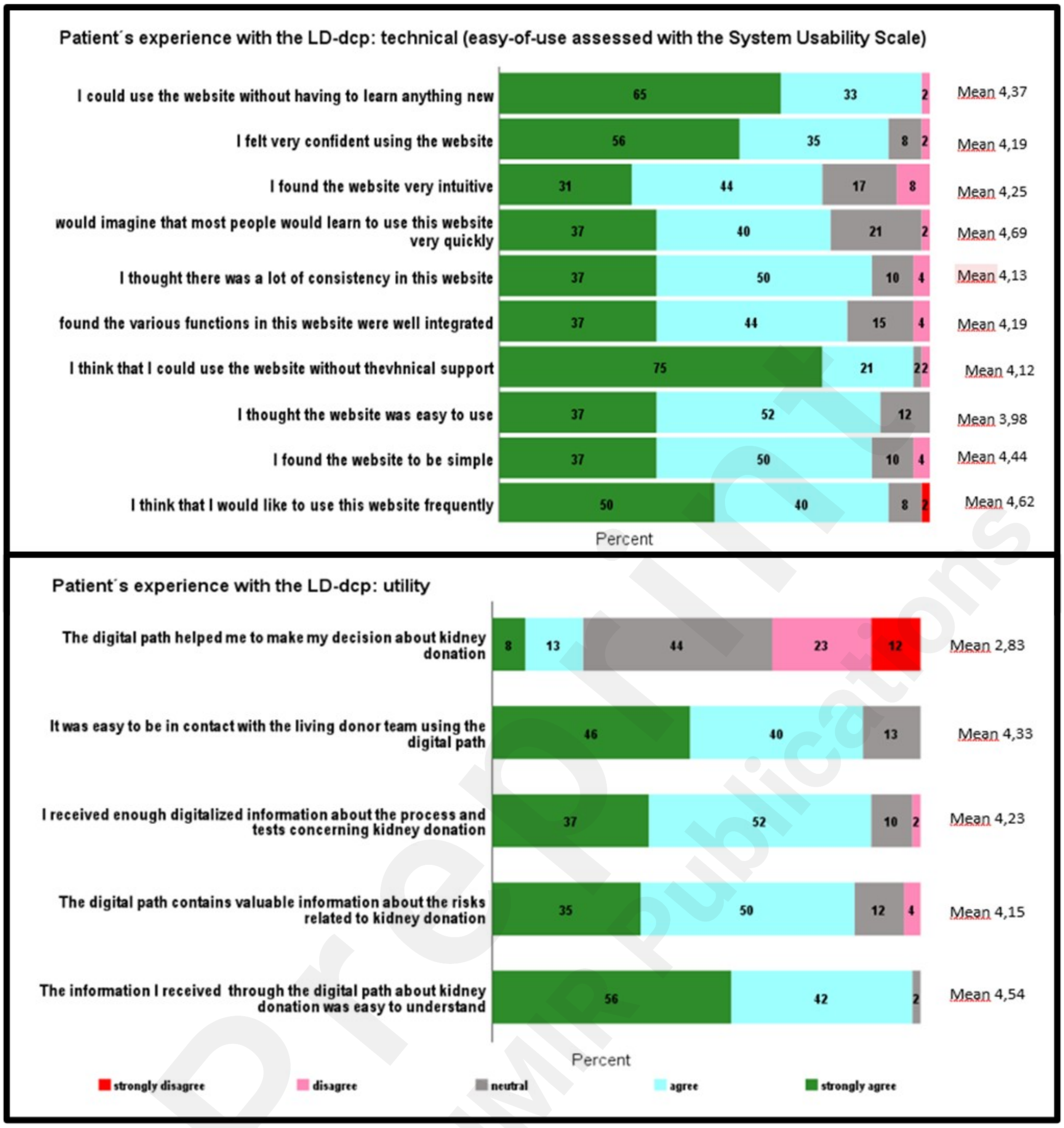


Figure 5. Patients’ experience with the LD-dcp. (N=74) The upper panel shows technical usability; the lower panel shows the utility of the content. The mean value was calculated with the answers to the 1 to 5 Likert scale (1: strongly disagree to 5: strongly agree)

The last question in the survey allowed the participants to provide free feedback about any missing advice during the kidney donation process (“Is there anything you wish kidney donors should be warned about that you were not?”). The most common issues of concern are detailed in Table 2.

Content	Description	Quotes
More information	Detailed information about the evaluation process itself	“It would have been good to know early during the process what tests will be done, and for what reason.” “The number of blood tests was surprisingly

		high.”
Own health	Health status during the evaluation process	“I thought I was healthy before starting the process, but some risks came up. It was anyway good to know.”
Surgery	Practical issues about post-op recovery	“It´s needed to organize beforehand how are you going to manage your daily life after discharge from surgery, particularly when both donor and recipient live under the same roof.” “I would advise others about everything happening in the ward after the surgery, to prepare yourself.”
Expectations	The kidney recipient’s well-being after surgery	“Kidney recipient might recover slowly and have complications from his own disease or cannot tolerate well immunosuppression. This is a burden for both the donor and recipient.”
Long term effects	About coping after donation	“Make clear to others that life doesn´t change much after donation.”

Table 2. Quality analysis of the answers to the open question “Is there anything you wish kidney donors should be warned about that you were not?”

Discussion

We found that Finnish LD candidates actively used the internet for health-related issues and felt confident about the acquired information. Females were more engaged in this activity, and the dedicated open portal section regarding the impact of living kidney donation on the donor's life was highly visited. Interestingly, almost half of male donor candidates did not initiate an internet search before commencing the organ donation process. Contrary to the general internet usage in Finnish society, where men are more active and only 67 % of those over 65 use it monthly [13], there is concern about almost 30% of individuals over 65 not receiving kidney donation information. Therefore, alternative formats like TV, magazines, or personal interactions are necessary for this age group. Active internet searches by LD candidates explained why the LD-dcp did not influence decision-making. The primary information source was the web portal from the patients' association, emphasizing coordinated efforts. Utilizing written information and checklists could standardize the process, as suggested by a survey from the European Renal Association and the European Society of Organ Transplantation [6].

Technological advancements, especially during the COVID-19 pandemic, saw increased reliance on telemedicine and web-based information by LD candidates. However, a Dutch study revealed that delivery modes mostly focused on individual and passive learning, lacking group learning or active knowledge construction [14]. Educational platforms like the iChoose Kidney Aid eHealth portal showed significant knowledge improvement but didn't increase access to transplantation

[15]. Although LD candidates found information from the Kidney hub useful, the impact on long-term outcomes remains uncertain [16].

Interactive platforms like 'The Talking About Live Kidney Donation Social Worker Intervention' and the 'Living Organ Video Educated Donors (LOVED)' program showed promise but faced implementation challenges due to technology concerns [9-10]. In the liver donation process, the Evaluation of Donor Informed Consent Tool (EDICT) displayed initial positive outcomes [17]. Digital technologies offer opportunities to enhance consenting processes. For instance, our research obtained electronic consent through the LD-dcp, similarly explored in cancer research, although met with some resistance [18].

Our survey's open question allowed LD-dcp users to share their experiences, although the tool's short usage period limited long-term effect assessments and excluded many participants without kidney donation experience. A larger study indicated LD concerns about surgery, kidney health, lifestyle changes, psychosocial impacts, and positive effects on donor-recipient relationships [19]. Evaluation experiences highlighted LD candidates investing emotions and time, potentially facing disappointment if contraindications for donation arise. This underscores the necessity for pre-surgery preparation, anxiety reduction, and support during evaluation, minimizing unnecessary delays [20].

Limitations include LD-dcp availability only in Finnish, potential bias towards positive eHealth experiences due to non-participation, and limited scope to Helsinki. Nonetheless, our findings showcase LD candidates benefiting from the LD-dcp, receiving standardized donation process information, and embracing digital services positively. However, its contribution to decision-making was limited, possibly due to prior active internet searches. Future eHealth services should integrate therapeutic education, self-management promotion, and seamless integration into electronic health records. Our future focus involves updating LD-dcp based on this study's insights and expanding its nationwide use.

Acknowledgments

We want to express our thanks to specialized nurse Johanna Takala and national living donor coordinator Jenni Kippola for their invaluable contributions to developing the LD-dcp.

Conflict of Interest Statement

The authors have no competing interests to declare that are relevant to the content of this article and do not have any commercial activity related to the Health Village services.Funding

The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors

Multimedia Appendix 1: [Queries]

References

1. Global observatory on donation and transplantation: Search fields: kidney from living donors by geographic area all from 2000 to 2022 https://www.transplant-observatory.org/data-charts-and-tables/chart/ [Accessed on February 26th, 2023]
2. Kortram K, Ijzermans JN, Dor FJ. Towards a standardized informed consent procedure for live donor nephrectomy: What do surgeons tell their donors? Int J Surg 2016; 32:83-8. DOI: 10.1016/j.ijsu.2016.05.063
3. Parekh AM, Gordon EJ, Garg AX , Waterman A, Kulkarni S, Parikh C. Living kidney donor informed consent practices vary between US and non-US centers. Nephrol Dial Transplant 2008;23(10):3316-24. DOI: 10.1093/ndt/gfn295

4. Kortram K, Lafranca JA, IJzermans JNM and Dor F. The need for a standardized informed consent procedure in live donor nephrectomy: a systematic review. Transplantation. 2014;98(11):1134–1143. DOI: 10.1097/TP.0000000000000518
5. Spoon EQW, Kortram K, Ismail SY, Nieboer D, d'Ancona FCH, Christiaans MHL, Dam RE, Hofker HS, Hoksbergen AWJ, van der Pant KA, et al. Living Kidney Donor Knowledge of Provided Information and Informed Consent: The PRINCE Study. Journal of Clinical Medicine. 2022; 11(3):698. https://doi.org/10.3390/jcm11030698
6. Mjøen G, Maggiore U, Kessaris N, Kimenai D, Watschinger B, Mariat C, Sukru Sever M, Crespo M, Peruzzi L, Spasovski G, Sørensen S, Heemann U, Pascual J, Viklicky O, Courtney A, Hadaya K, Wagner L, Nistor I, Hadjianastassiou V, Durlik M, Helanterä I, Oberbauer R, Oniscu G, Hilbrands L, Abramowicz D. Long-term risks after kidney donation: how do we inform potential donors? A survey from DESCARTES and EKITA transplantation working groups. Nephrol Dial Transplant 2021;36(9):1742-1753. DOI: 10.1093/ndt/gfab035
7. Eno AK, Ruck JM, Van Pilsum Rasmussen SE, et al. Perspectives on implementing mobile health technology for living kidney donor follow-up: In-depth interviews with transplant providers. Clin Transplant 2019; 33(8):e13637 https://doi.org/10.1111/ctr.13637
8. Al Ammary F, Motter JD, Sung HC, et al. Telemedicine services for living kidney donation: A US survey of multidisciplinary providers.. J Am J Transplant 2022; 22(8):2041-2051. doi: 10.1111/ajt.17093
9. Cabacungan AN, Diamantidis CJ, St Clair Russell J, Strigo TS, Pounds I, Alkon A, Riley JA, Falkovic M, Pendergast JF, Davenport CA, Ellis MJ, Sudan DL, Hill-Briggs F, Browne T, Ephraim PL, Boulware LE.

Development of a Telehealth Intervention to Improve Access to Live Donor Kidney TransplantationTransplant Proc 2019; 51:665–75 DOI: 10.1016/j.transproceed.2018.12.032

10. Sieverdes JC, Nemeth LS, Mueller M, Rohan V, Baliga PK, Treiber F. Acceptability of a Mobile-Health Living Kidney Donor Advocacy Program for Black Wait-Listed Patients. IJERPH 2021; 18(16) DOI: 10.3390/ijerph18168239
11. Helsinki University Hospital. Digital health village https://www.digitalhealthvillage.com/en/about-us [Accessed on Feb 23rd, 2023]

12. Ortiz F, Giunti G. Usability assessment of an interactive health technology for kidney living donors: protocol for a prospective cross-sectional survey. BMJ Open 2022; 12:e051166. https://doi.org/10.1136/bmjopen-2021-051166
13. Centre for Economic Development, Transport and the Environment: digitalization as a work tool (In Finnish) https://sotenavigaattori.fi/digitalisaatio-tyon-tukena/ [Accessed on Feb 23rd, 2023]
14. van Klaveren Ch, de Jong P, Hendriks R, Luk F, de Vries APJ, van der Boog PJM, Reinders MEJ. Topics, Delivery Modes, and Social-Epistemological Dimensions of Web-Based Information for Patients Undergoing Renal Transplant and Living Donors During the COVID-19 Pandemic: Content Analysis. J Med Internet Res 2020;22(10):e22068. doi: 10.2196/22068
15. Patzer RE, McPherson L, Basu M, Mohan S, Wolf M, Chiles M, Russell A, Gander J, Friedewald J, Ladner D, Larsen C, Pearson T, Pastan S. Effect of the iChoose Kidney decision aid in improving knowledge about treatment options among transplant candidates: A randomized controlled trial. Am J Transplant 2018;18(8):1954-1965. doi: 10.1111/ajt.14693
16. Tang J, James L, Howell M, Tong A, Wong G. eHealth interventions for solid organ transplant recipients: a systematic review and meta-analysis of randomized controlled trials. Transplantation 2020; 104:e224–35 DOI: 10.1097/TP.0000000000003294
17. Gordon E, Mullee J, Butt Z, Kang J, Baker T. Optimizing informed consent in living liver donors: Evaluation of a comprehension assessment tool. Liver transplant 2015; 21:1270–1279 DOI: 10.1002/lt.24175
18. Chimonas S, Lipitz-Snyderman A, Gaffney K, and Kuperman GJ. Electronic Consent at US Cancer Centers: A Survey of Practices, Challenges, and Opportunities. JCO Clin Cancer Inform. 7:e2200122, 2023 01. DOI: 10.1200/CCI.22.00122
19. Hanson CS, Chapman JR, Gill JS, Kanellis, J, Wong,G, Craig, J, Teixeira-Pinto, A, Chadban, S, Garg, A Ralph, A, Pinter, J, Lewis, J, Tong, A. Identifying Outcomes that Are Important to Living Kidney Donors: A Nominal Group Technique Study. Clin J Am Soc Nephrol 2018;13(6):916-926. doi: 10.2215/CJN.13441217
20. Hanson C, Ralph A, Manera K, Gill JS, Kanellis, J, Wong,G, Craig, J, Chapman J, Tong Al. The

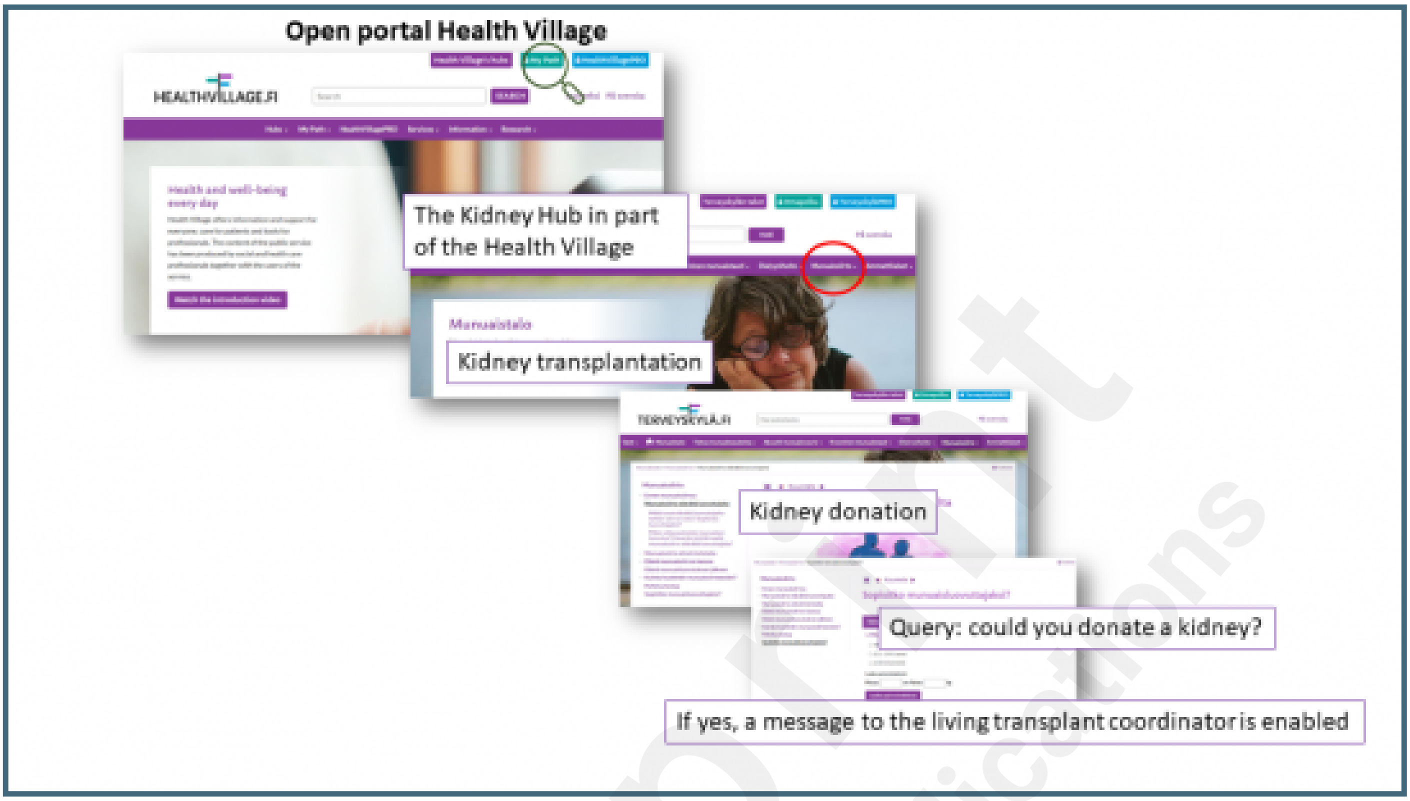
Lived Experience of “Being Evaluated” for Organ Donation. Clin J Am Soc Nephrol. 2017; 12(11): 1852–1861 DOI: 10.2215/CJN.03550417

Supplementary Files

Untitled.
URL: http://asset.jmir.pub/assets/62a8790e23c4ec13720e4fd6ac4a65e1.pdf

Figures

The digital process of the information to kidney donors provided by the hospital web.



Open portal Health Village

The Kidney Hub in part of the Health Village

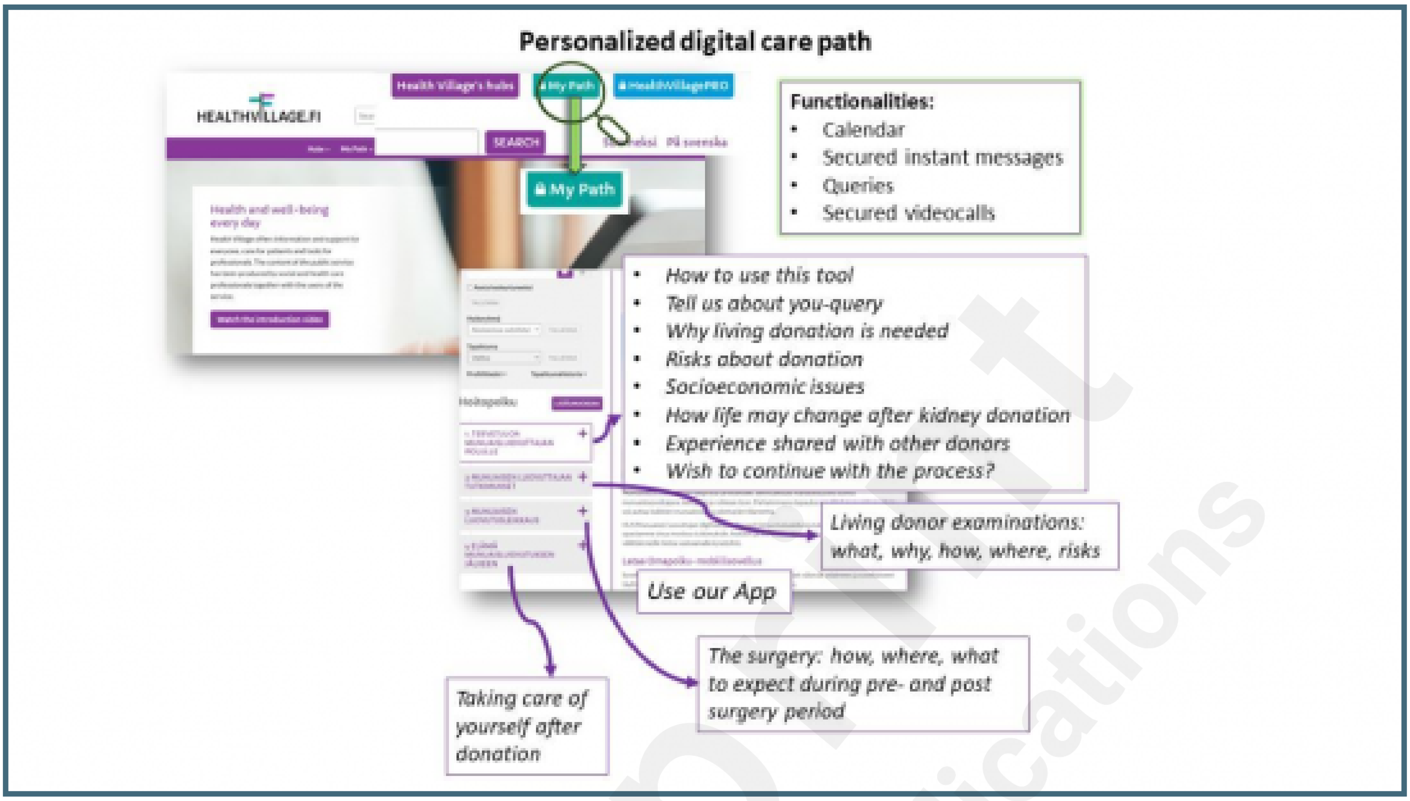
Kidney transplantation

Kidney donation

Query: could you donate a kidney?

If yes, a message to the living transplant coordinator is enabled

Description of the personalized information steps included in the living-donor digital care path.



Personalized digital care path

Functionalities:

- Calendar
- Secured instant messages
- Queries
- Secured videocalls

- *How to use this tool*
- *Tell us about you-query*
- *Why living donation is needed*
- *Risks about donation*
- *Socioeconomic issues*
- *How life may change after kidney donation*
- *Experience shared with other donors*
- *Wish to continue with the process?*

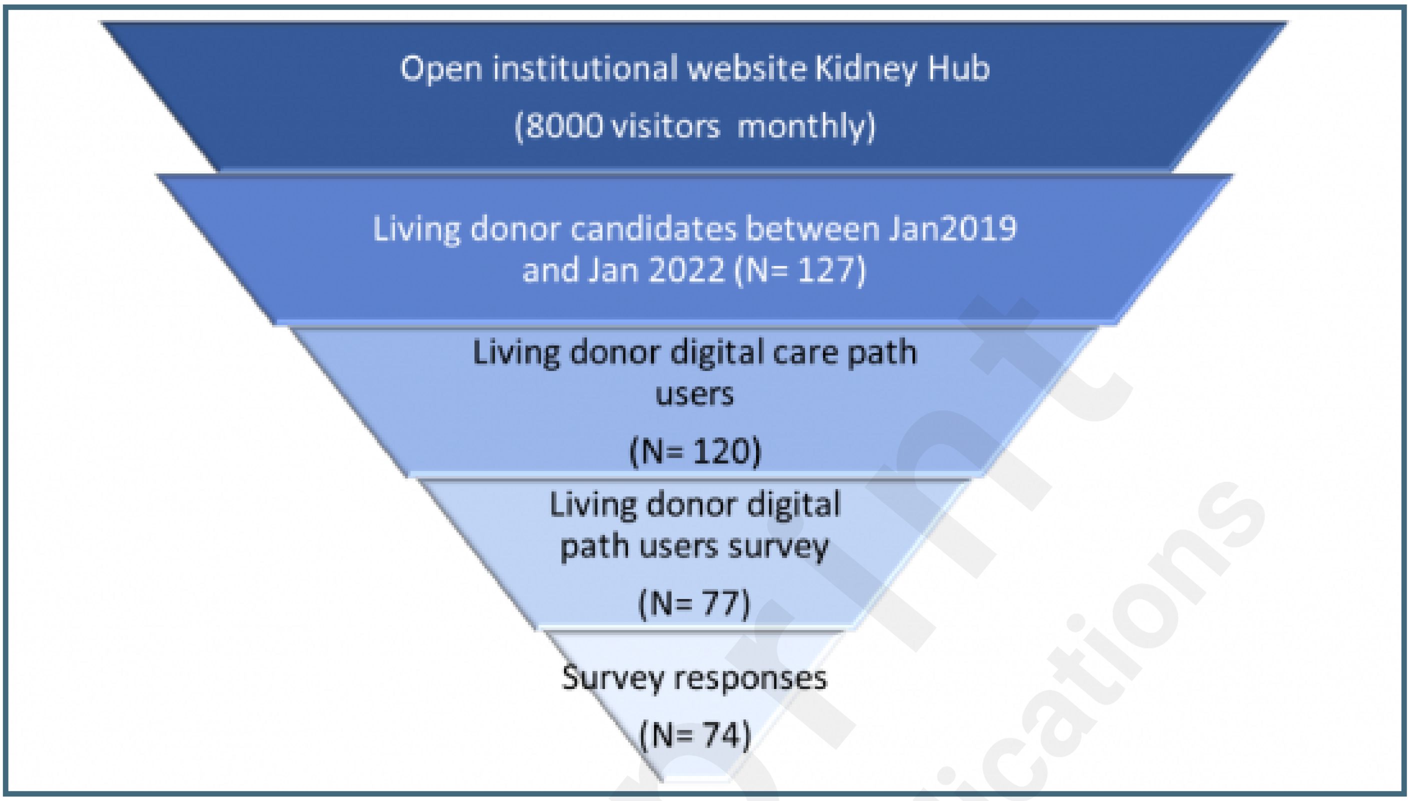
Living donor examinations: what, why, how, where, risks

Use our App

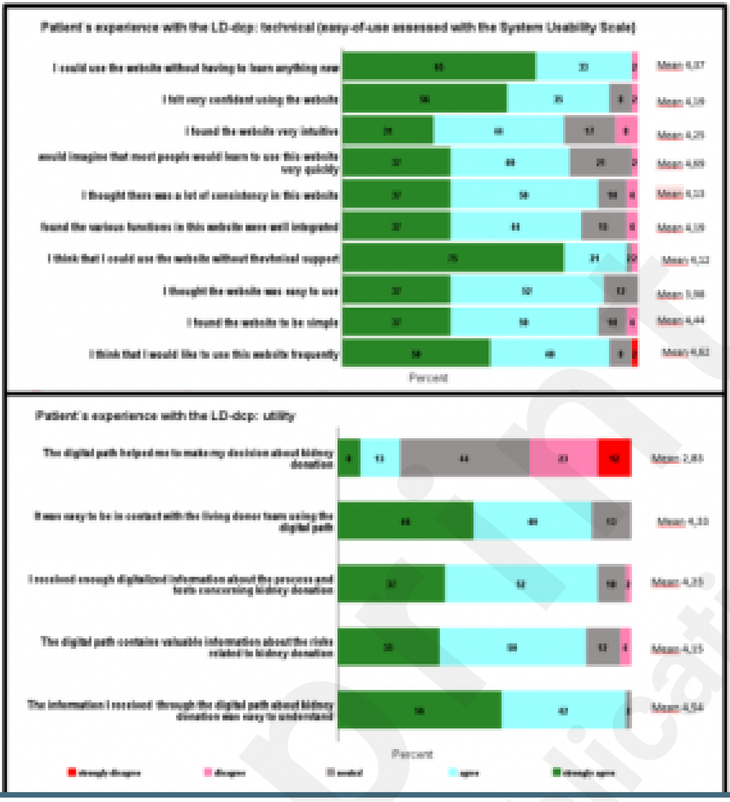
The surgery: how, where, what to expect during pre- and post surgery period

Taking care of yourself after donation

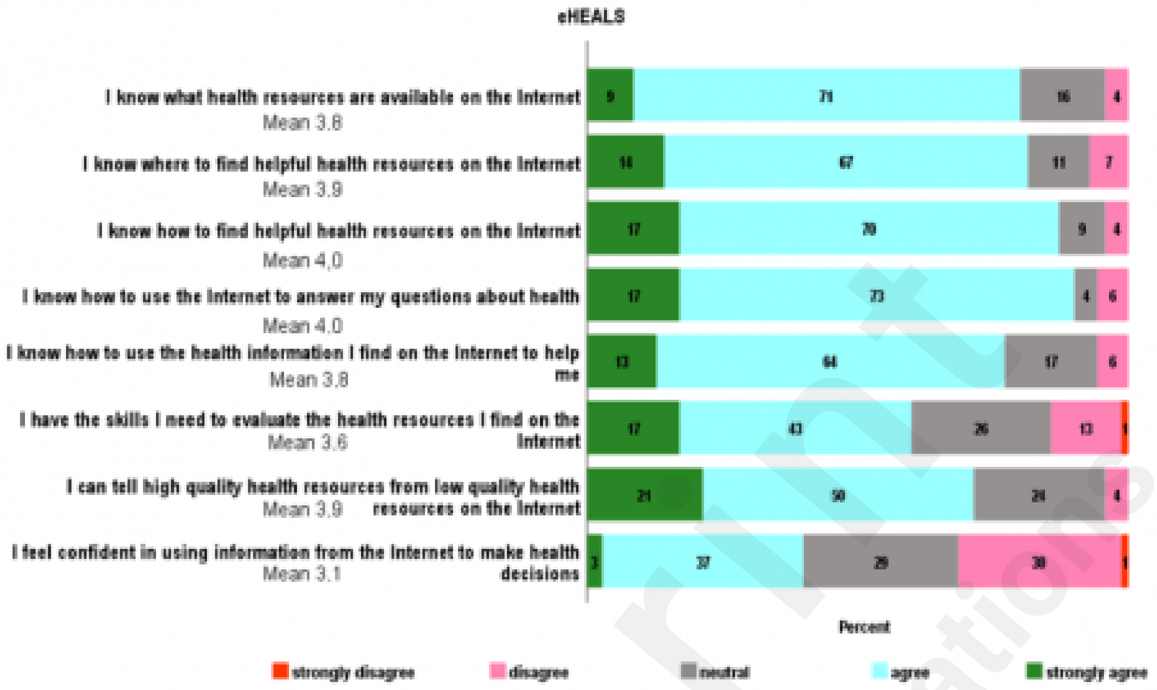
Flow chart of the users of the digital services provided by the Kidney Hub.



Patients’ experience with the LD-dcp. The upper panel shows technical usability; the lower panel shows the utility of the content.



eHEALS (eHealth Literacy Scale) The frequency of responses is expressed in percentage in each bar.



Multimedia Appendixes

Queries.
URL: http://asset.jmir.pub/assets/0a823a02daa21d193acb6f8ab0bd6b29.pdf