The role of motivations in patient engagement in research: the case of rheumatoid arthritis (RA) patients participating in RA research on an online crowdsourcing intervention called Share Data Valley

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Abstract

Over the past few decades, patient engagement in research has risen to prominence in healthcare contexts (Harrington et al., 2020; Shippee et al., 2015). One of the challenges of patient engagement in research is drawing patients into research and maintaining consistent patient participation. A concept which plays an important role in drawing in patients into research as well as influencing long-term engagement of patients in research is that of motivation. One of the ways to influence motivations of patients engaging in research is through the design of a website (Bradley et al., 2016; Hemphill et al., 2020; McCarron et al., 2019; Shippee et al., 2015). Knowing the role motivations have in (long-term) engaging patients in research, the goal of this study was to explore the role of motivations in the context of an online crowdsourcing intervention designed to shape a collaborative research project between researchers of TOPFIT Citizenlab and patients with RA. This collaborative research project consists of patients with RA using an online crowdsourcing intervention called Share Data Valley (SDV) for sharing data about fatigue and RA. The data of this collaborative research project can help the participants gain further insight into their own condition (RA), as well as possibly adding to scientific knowledge on RA and fatigue. In this interview study, two aspects of motivation were explored, namely the motivations of participants to use SDV (engage in research), and the opinions of participants about the features and aspects of SDV (knowing that design can influence the motivations of the participants). In exploring these aspects, semi-structured interviews where conducted with participants (patients with RA) of the collaborative research project on RA and fatigue (*n*=10). Whereby the motivations to use SDV were discussed, as well exploring SDV with the participants to gain insights into their opinions the features and aspects of SDV. The results show that the main motivations to use SDV revolve around altruistic/prosocial values and a motivation to learn about their condition (RA), and that the opinions of the participants about the features and aspects of online SDV environment vary widely and are even contradicting at times. From this motivational perspective, this interview study emphasizes the need for researchers of TOPFIT Citizenlab (and researchers organizing other patient engaged research projects) to develop engagement strategies that lend itself to the specific motivations of patients (e.g., emphasizing the benefit of participating for others to draw in altruistically driven patients to engage in research). Furthermore, the varying and contradicting opinions of participants of this interview study, ask for researchers of TOPFIT Citizenlab and other research project to think about design strategies such as applying an adaptive interface to their digital environments to fit with the individual needs and wishes of patients.

Contents

Introduction

Over the past few decades, concepts such as ‘’patient engagement’’, ‘’patient centeredness’’ and ‘’patient and service user engagement (PSUE)’’ have risen to prominence across different healthcare contexts. Rather than only serving as research subjects, patient communities now increasingly have the capacity to partner or lead in research (Harrington et al., 2020; Shippee et al., 2015). In literature, various forms of patient engagement in research have been identified, from self-reporting (e.g., Patient Reported Outcomes) and involvement in shaping research projects to being involved in the development of health technologies. At the extreme end of patient engagement is patient led or patient initiated research (Duffett, 2017; Harrington et al., 2020). Patients Like Me, for example is an online crowdsourcing intervention (=the practice of obtaining needed services, ideas, or content by soliciting contributors from a large group of people, especially through online collaboration and participation), where patients get the opportunity to share their experiences with many chronic illnesses, and input and track their personal health data such as treatments or upload from biometric devices (Bradley et al., 2016; Duffett, 2017; Eitzel et al., 2017).

Involving patients in research is not without challenges, one of these challenges is maintaining consistent and long-term patient participation. In general, studies about patient engagement in research are focused on the effects of the engagement on the research process and outcomes, with less attention paid to the people engaged as research partners (Hemphill et al., 2020; McCarron et al., 2019). An example of an often ignored concept in patient engagement research is that of motivation. Motivation, plays an important role in drawing participants into participating in research as well as influencing the sustainability of long-term research partnerships (Bradley et al., 2016; Hemphill et al., 2020; McCarron et al., 2019; Shippee et al., 2015).

Studies on patient engagement in research in digital environments, such as on online crowdsourcing platforms like Patients Like Me have shown that motivation influences the (long-term) engagement in online crowdsourcing projects. Especially intrinsic motivations have shown to be a determining factor for the amount of persistent (i.e. long-term) effort participants want to put into their crowdsourcing research project (Aitamurto et al., 2017; Eitzel et al., 2017; Soliman et al., 2019; Zhao & Zhu, 2014).

One way to influence (intrinsic) motivations of users in online environments is by focusing on characteristics of digital environments and the influence they can have on patients motivations to use online environments (long-term). As for example has been shown in researchers applying the principles of the Self-determination theory (SDT) from Deci and

Ryan (1985) to technology design, SDT is a motivational framework focusing on the degree to which human behaviour is self-motivated and self-determined (intrinsically motivated) (Ryan & Deci, 2017). Different mini-theories of the SDT revolve around the processes influencing the internalization of behaviour (=the active attempt of transforming extrinsic motives into personally endorsed values).

One of the main mini-theories of the SDT is the basic needs theory (BNT), the main premises of the BNT is that in order for someone's behaviour to be self-determined and self-motivated (intrinsic), the three basic psychological needs of autonomy, competence and relatedness need to be fulfilled (Ryan & Deci, 2017).

In the field of Human Computer Interaction (HCI) it has been shown that BNT is a reliable predictive mediator of sustained engagement, behaviour change and motivation in technology usage, as well being a reliable predictive mediator of motivation, engagement and well-being of users (Peters et al., 2018; Ryan & Deci, 2017; Vansteenkiste & Ryan, 2013).

Current research is still in quest of bridging the gap between these basic needs and the actual design of an online environment in the real world. In the past few years, Peters et al. (2018), Yang and Aurisicchio (2021) and Peters (2021) have made the first attempts to bridge this gap by formulating theoretical frameworks and guidelines which can help support these basic needs in digital environments. Peters (2021) has for instance drawn findings from over 30 years of SDT research on contextual factors that support psychological wellbeing (i.e. basic need satisfaction), to distill a list of 15 heuristics and 30 design strategies that can help with designing for need satisfaction.

The TOPFIT Citizenlab is a consortium adapting principles of citizen science (=the collaboration between researchers and citizens) and crowdsourcing (e.g., Patients Like Me) to find solutions for health problems or to ensure that (chronic) conditions hinder people as little as possible. In findings these solutions, the role of technology is also considered (Eitzel et al., 2017; Topfit, 2021).

One of the projects of TOPFIT Citizenlab involves the collaboration between researchers of TOPFIT Citizenlab and people with rheumatoid arthritis (RA). In the earlier stage of this project, participants of the project (patients with RA) indicated that they preferred to do collaborative research with other people with RA and with the researchers from TOPFIT Citizenlab from the comfort of their own homes, and that a website would be suitable for this purpose. Furthermore, these participants also indicated that the first collaborative research project should be about (chronic) fatigue, which was reported to be one of most burdensome symptoms of RA by these participants (Heesink et al., 2021).

This collaborative research project at TOPFIT Citizenlab is a form of patient initiated research, whereby the participants (patients with RA) were involved in deciding which method (a website) would be used to do research, and which topic should be researched (fatigue). Besides deciding upon the topic and method for this collaborative research project, as well as of course sharing the data for the research, the participants are also involved in interpreting the research data.

For this collaborative research project, an online crowdsourcing intervention will be utilized to collect data about the RA symptom (chronic) fatigue, whereby data from the participants about fatigue-levels and other fatigue related factors (e.g., stress, pain, physical activity) will be collected. The online crowdsourcing intervention which will be used is called Share Data Valley (SDV). This intervention was developed by Dutch universities funded by the Dutch government, originally used for research into sport and exercise[1] (Sport Data Valley, 2021).

For this collaborative research project on SDV, the researchers at TOPFIT Citizenlab hope that the participants will be motivated to engage in the collaborative research project on RA and fatigue in the first place, as well being motivated all the way to the end of the collaborative research project on RA and fatigue. Besides this, knowing that SDV will also be used for other future collaborative research projects on RA, the researchers at TOPFIT Citizenlab also hope that the participants are willing to be (long-term) engaged in future collaborative research projects on SDV.

Knowing that motivation plays an important role in drawing patients (participants in general) into participating into research as well influencing the sustainability of long-term research partnerships, the goal of this interview study is to explore the role of motivations in patient engagement in research in the context of the collaborative research project on SDV.

In reaching this goal, this interview study will focus on two important aspects of motivation in the context of the research project on SDV, namely the motivations to use SDV (why people want participate in this collaborative research project on SDV) and what participants of this interview study think of features and aspects of the online SDV environment. The focus of this part lies on features and aspects of SDV that are of relevance when aiming to design an online environments for basic need satisfaction (which influences intrinsic motivation). To ensure that these features and aspects are taken into account in case of SDV, the SDT based paper of Peters (2021) was used as an inspiration for developing the

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[1] The website is originally called Sport Data Valley, but changed into Share Data Valley because ‘Sport’ is not really fitting with the RA target-group of the research into fatigue and RA.

topic list for the interview questions.

In the broader context of patient engagement in research in online environments, the findings about the motivations of participants for using SDV can possibly provide more insight into what draws patients with RA into participating in research in a digital environment, and how this can possibly translate to other patient-groups. Besides this, the input from the participants about the features and aspects of SDV can possibly provide us with more information about which possible (design) strategies could be applied to address the motivations of the participants (as well as how these design strategies could be applied to address the motivations of other online patient engaged research projects). For this interview study, the following two research questions were used to give direction to this study:

(1) What are motivations of participants (members of TOPFIT Citizenlab with RA) for using SDV?
(2) What are the opinions of the participants about features (e.g., share button on the SDV website) and aspects (e.g., having the opportunity to evaluate the website) of SDV?[2]

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[2] Features is the collective name for parts of SDV like the controls, buttons, analysis graphs, notification (bells), texts, colors, lay-out etc. And aspects is the collective name for things like having the opportunity to evaluate the website or being able to share data on the SDV website. An example of this distinction is that the aspect can be the opportunity to share data, and the data button to share the data is the feature.

Methods

The Share Data Valley website

Share Data Valley is an online crowdsourcing intervention where researchers of TOPFIT Citizenlab and people with RA can be in contact and do research. SDV[3] consists of landingspage, where people can find information about the first collaborative research project, log-in and/or sign-up for SDV (see Figure 1), and the secured SDV website (see Figure 2).

The SDV website will be used to collect data about the RA symptom (chronic) fatigue, whereby data from the participants about fatigue-levels and other fatigue related factors (e.g., stress, pain, physical activity) will be collected. The data will be collected through different questionnaires which are build into the SDV website.

The patients with RA who participate in the first collaborative research project on RA and fatigue, are asked to fill out questionnaires over a three week period of their own choice. At the beginning of the three week period, participants have to fill-out out some one-time questionnaires about personal data (e.g., age, diagnosis, medication intake, location of inflammations), self-efficacy, fatigue-levels, activity-levels, quality of life and their mental health. After filling-out the one-time questionnaires, the participants are asked to fill-out a questionnaire everyday of the three week period. This daily questionnaire asks participants about their fatigue, stress, pain levels and how much time of their day was spend on physical and cognitive activities as well as resting and sleeping. Figure 3 provides examples of the SQUASH-questionnaire (about activity-levels) and the daily RA questionnaire. These questionnaires were also used to test with the participants during the interviews of this study.

The data which will be shared through the questionnaires will be processed and analyzed by the researchers of TOPFIT Citizenlab, and then reported back to the participants at the end of the collaborative research project. The participants of the collaborative research project will also play their part in interpreting the final results. Besides providing insights for the participants themselves, the TOPFIT Citizenlab also hopes that the results of this collaborative research project can add to existing scientific knowledge on fatigue and RA.

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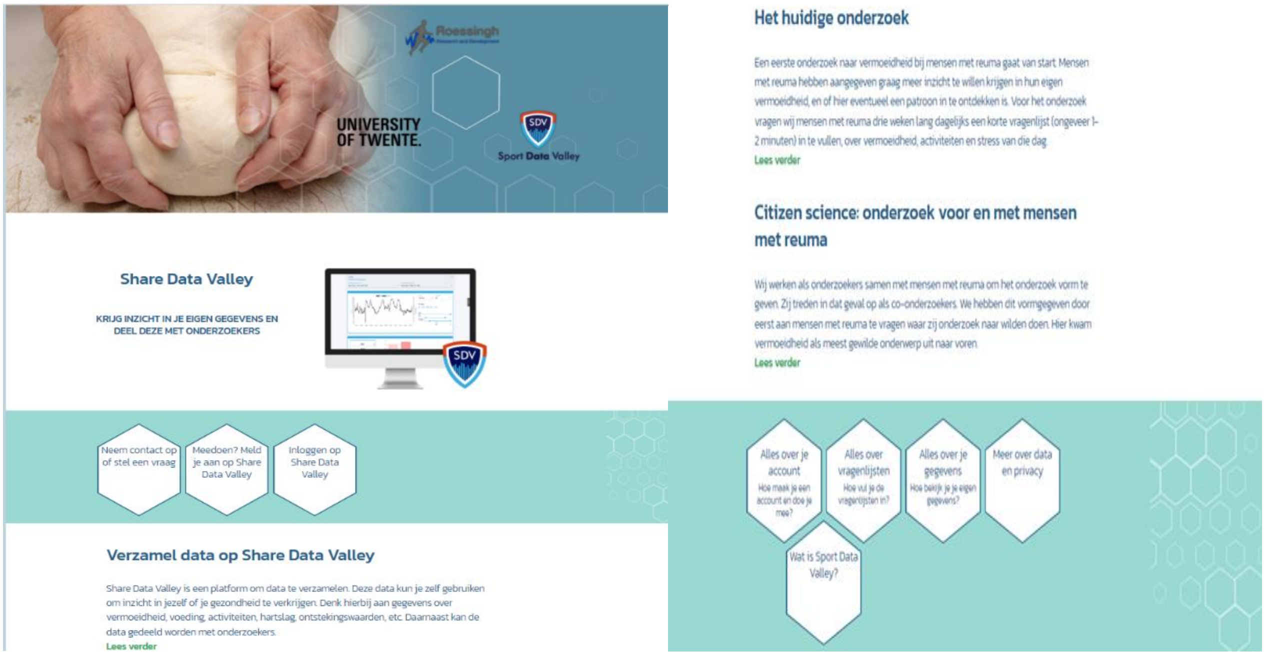
[3] SDV will be used as the collective name for the landingspage, website and questionnaires of SDV. When SDV website is used as a term, it is specifically about the SDV website and not SDV as a whole.

Figure 1.

Landingspage of SDV



Share Data Valley

KRIJG INZICHT IN JE EIGEN GEGEVENS EN DEEL DEZE MET ONDERZOEKERS

Verzamel data op Share Data Valley

Share Data Valley is een platform om data te verzamelen. Deze data kun je zelf gebruiken om inzicht in jezelf of je gezondheid te verkrijgen. Denk hierbij aan gegevens over vermoeidheid, voeding, activiteiten, hartslag, ontstekingswaarden, etc. Daarnaast kan de data gedeeld worden met onderzoekers.
Lees verder

Het huidige onderzoek

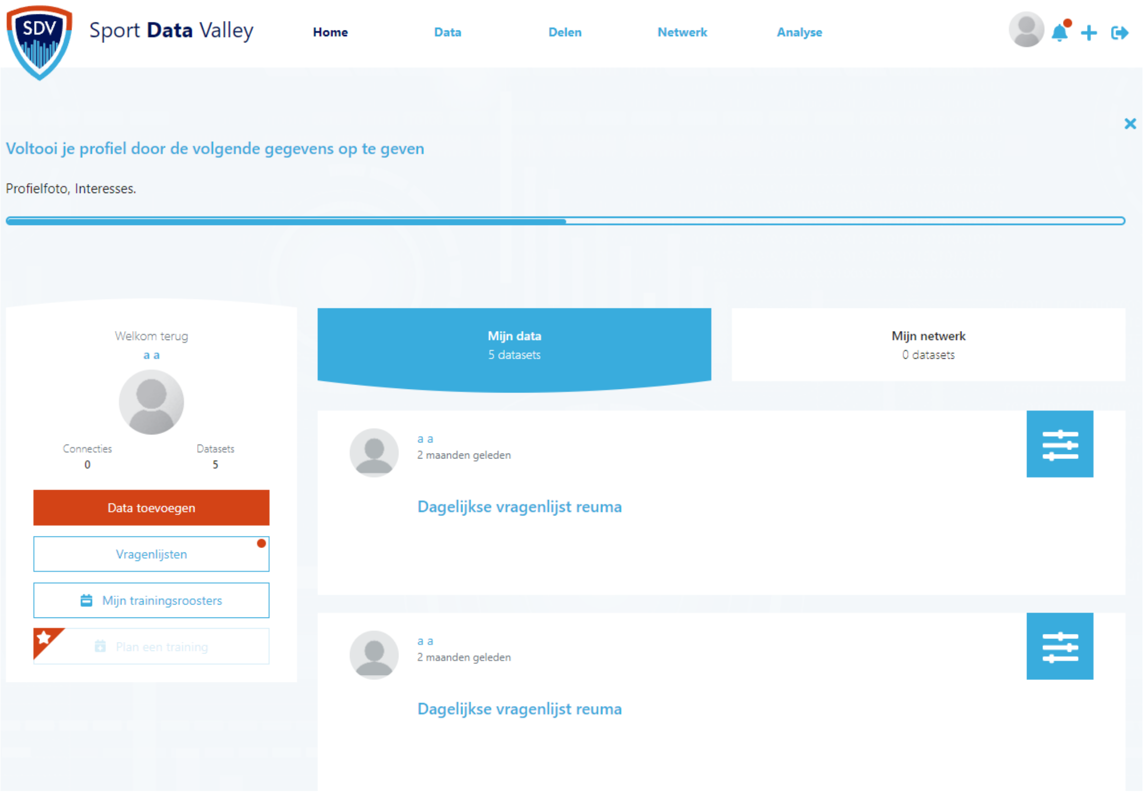
Een eerste onderzoek naar vermoeidheid bij mensen met reuma gaat van start. Mensen met reuma hebben aangegeven graag meer inzicht te willen krijgen in hun eigen vermoeidheid, en of hier eventueel een patroon in te ontdekken is. Voor het onderzoek vragen wij mensen met reuma drie weken lang dagelijks een korte vragenlijst (ongeveer 1-2 minuten) in te vullen, over vermoeidheid, activiteiten en stress van die dag.
Lees verder

Citizen science: onderzoek voor en met mensen met reuma

Wij werken als onderzoekers samen met mensen met reuma om het onderzoek vorm te geven. Zij treden in dat geval op als co-onderzoekers. We hebben dit vormgegeven door eerst aan mensen met reuma te vragen waar zij onderzoek naar wilden doen. Hier kwam vermoeidheid als meest gewilde onderwerp uit naar voren.
Lees verder

Figure 2.

Homepage of Share Data Valley



Voltooi je profiel door de volgende gegevens op te geven

Profielfoto, Interesses.

Welkom terug
a a

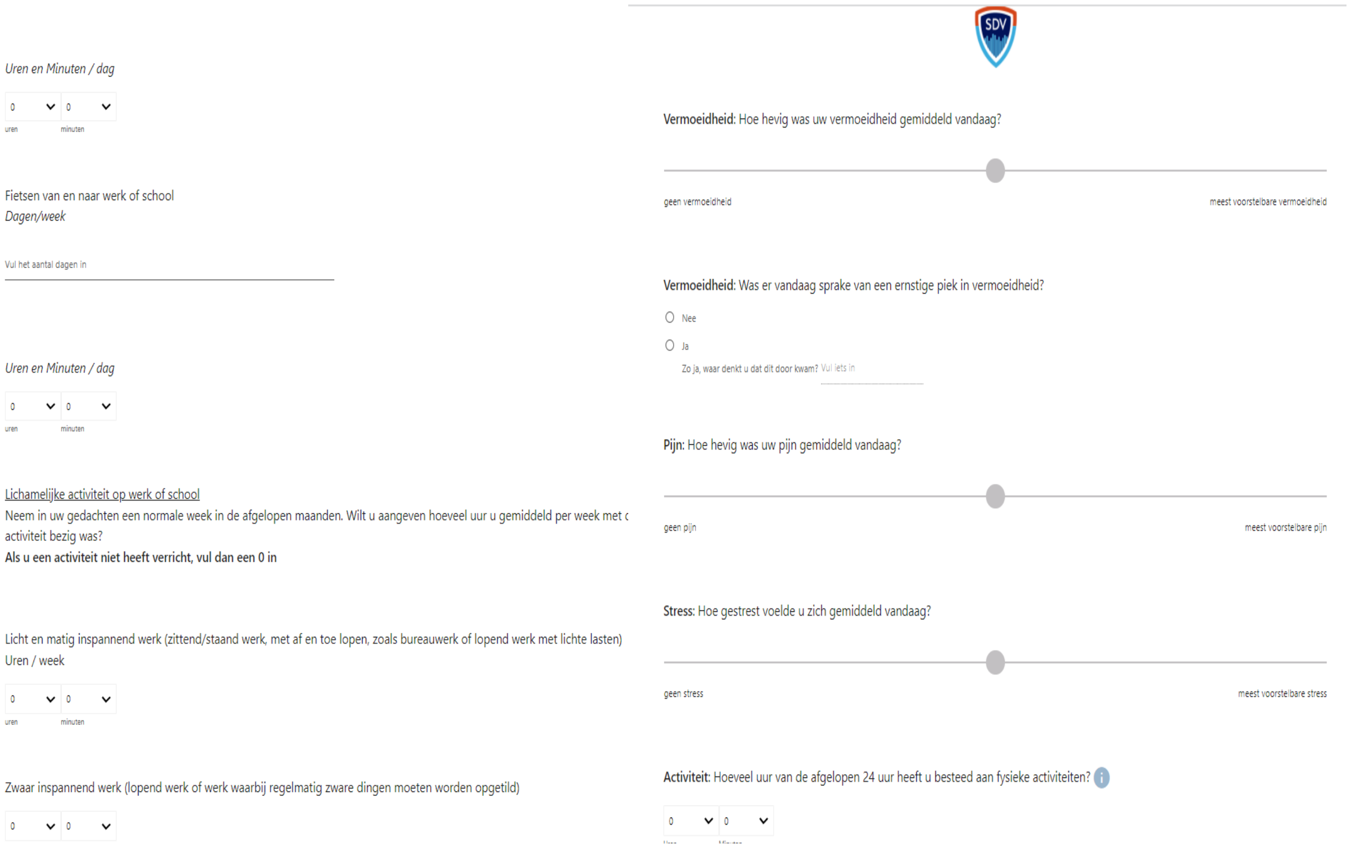
Connecties 0
Datasets 5

a a
2 maanden geleden
Dagelijkse vragenlijst reuma

a a
2 maanden geleden
Dagelijkse vragenlijst reuma

Figure 3.

Parts of the SQUASH-questionnaire (left) and daily RA questionnaire (right)



Uren en Minuten / dag

0 0

Fietsen van en naar werk of school
Dagen/week

Vul het aantal dagen in

Uren en Minuten / dag

0 0

Lichamelijke activiteit op werk of school
Neem in uw gedachten een normale week in de afgelopen maanden. Wilt u aangeven hoeveel uur u gemiddeld per week met
activiteit bezig was?
Als u een activiteit niet heeft verricht, vul dan een 0 in

Licht en matig inspannend werk (zittend/staand werk, met af en toe lopen, zoals bureauwerk of lopend werk met lichte lasten)
Uren / week

0 0

Zwaar inspannend werk (lopend werk of werk waarbij regelmatig zware dingen moeten worden opgetild)

0 0

Vermoeidheid: Hoe hevig was uw vermoeidheid gemiddeld vandaag?

Vermoeidheid: Was er vandaag sprake van een ernstige piek in vermoeidheid?

○ Nee

○ Ja

Zo ja, waar denkt u dat dit door kwam? Vul iets in

Pijn: Hoe hevig was uw pijn gemiddeld vandaag?

Stress: Hoe gestrest voelde u zich gemiddeld vandaag?

Activiteit: Hoeveel uur van de afgelopen 24 uur heeft u besteed aan fysieke activiteiten?

0 0

Study design

For this study a qualitative research design was used to identify the motivations of participants for using SDV, as well as gaining insight about the opinions of the participants about the features and aspects of SDV. To gather the data, semi-structured interviews using the video-conferencing software Zoom were conducted in a 1 month period between the 17th of December 2021 and the 20th of January 2022.

Participants

The participants for this study were recruited via email, a population of 35 patients with RA was approached for this study. The population approached for this study had participated before in the project of TOPFIT Citizenlab focusing on RA research. Inclusion criteria were: being 16 years or older and having a diagnosis of RA.

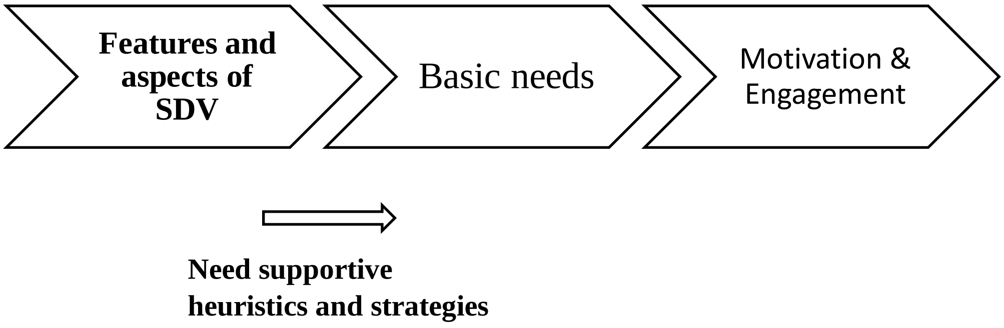
From the 35 patients which were approached for this study, 15 were willing to participate. Reasons for the people in the population of 35 persons to not participate in this interview study were unknown. From the 15 participants willing to participate, 4 participants were not interviewed due to time constraints (the results of the interviews needed to be released in March 2022) as well as 1 participant not being able to participate due to illness. Leaving this study with a sample of 10 participants (*n*=10, *M* age=55.3, *SD* age=12.1, 90%=Female, *M* years since diagnosis RA=11.3 , *SD* years since diagnosis RA=10.70).

Utilization need supportive heuristics and strategies of Peters (2021)

Before going into the detailed procedures of the semi-structured interviews, it is of importance to clarify to how the need supportive heuristics (and strategies) of Peters (2021) were utilized in this study. The heuristics and strategies formulated by Peters (2021) are guidelines for designing a website for basic need satisfaction. These guidelines were utilized in this interview study to formulate the topic list and interview questions of this study. So these heuristics (and strategies) were utilized so that the opinions of the participants were about those aspects and features of SDV that could possibly influence basic need satisfaction. Which as can be seen in Figure 4, serves as a mediator for influencing (intrinsic) motivation and (long-term) engagement in digital environments.

Figure 4.

Conceptual model for research question 2



Thus, in this interview study the focus lies on exploring only the characteristics (design features and aspects) of the SDV environment that influence the basic needs. Important to emphasize is that features and aspects discussed with the participants are the existing features and aspects of the SDV, as well as some features (e.g., a social feature) and aspects (e.g., having the opportunity to evaluate the online SDV environment) that are planned to be added to SDV or those that can be added and for which the researchers wanted the gather the opinions of the participants as well.

So the features and aspects of SDV that were explored, were the translation of some of the need supportive heuristics (and strategies) into the context of SDV. Meaning topics, methods and interview questions for this interview study were developed based of these heuristics. For example, the heuristics ***apply best practices for accessibility*** *(supporting autonomy)* and ***apply best practices for usability*** *(supporting competence)* were used as the main inspiration to decide that a flexible think-aloud method was going to be used to gain insight in the opinions of the participants about the user-friendliness and accessibility of SDV (Fonteyn et al., 1993).

Furthermore, for developing the open-ended questions about the features and/or aspects of the SDV website, landingspage and questionnaires for part three of the interview, the need supportive heuristics (and strategies) were used as an inspiration for shaping a topic list from which the open-ended interview questions were derived. The translation of the heuristics (and strategies) into the topic list and open-ended interview questions was done in consultation with the researchers of TOPFIT Citizenlab of the RA project.

The steps for translating the heuristics into the context of SDV worked as follows: first, the researchers made an assessment of which of the heuristics fitted with one of the feature(s) (e.g., share button on the SDV website) and/or aspect(s) (e.g., having a RA collaborative research project community) of SDV.

Second, the fitting heuristic for the particular feature and/or aspect were then chosen, whereby sometimes the suggested strategies which support the heuristic were used as an inspiration to form a topic. From the topic found, an open-ended interview question was formulated. An example of this process is the question in the interview whereby participants were asked about whether they felt it was necessary to evaluate (provide feedback) about the SDV website after (or during) the collaborative research project on RA and fatigue.

First, the idea for this question came from the heuristic ***Empathize with your user's frame of reference*** *(supporting autonomy),* which states that you can support users goals and values if you know what they are. One of the strategies that can be employed to empathize with the user's frame of reference is by ***Provide ongoing opportunities for user feedback and input.*** Knowing that in this project at TOPFIT Citizenlab, having evaluative focus-group sessions with the participants with RA is a staple in this project, it was decided to ask the participants what they thought about having the opportunity to evaluate the SDV website (or give general feedback about the project) after or during the collaborative research project. Sometimes participants were also asked whether they would like to evaluate SDV in future collaborative research projects. From this the topic *Evaluation* was formed, from which the following research question was derived: *Do you need to be able to evaluate the website after February/March/April (start of the research)? If yes/no, why/why not? How often would you like to do this and how would you like to evaluate the website? Would you like to do that for future research projects on SDV as well?* An overview of the different heuristics and strategies used as an inspiration for part three of interview can be found in Appendix A.

Procedures

When approached for this study, participants received a mail consisting of an explanation of the research and an informational letter including further detailed information about the study, participation, data privacy and informed consent. When participants volunteered to take part in the study, the participants received an invite for the interview including a Zoom meeting-link with the agreed time and date for the interview. The semi-structured interviews were conducted in a two-on-one format, meaning two researchers and one participant. In this case, the main researcher focused on asking the questions, and the other researcher mainly focused on keeping an eye on the time and sharing the screen with the participant. This format was chosen because it allowed for the main researcher to just focus on asking the questions and giving the participant instructions.

Before the first official interviews were conducted, a pilot of an interview was conducted with a volunteer outside of the project population of TOPFIT Citizenlab. The pilot was done to test which of the questions from the script designed for the interview (see materials section) worked, as well as to see whether technical issues (if any) would come up during the pilot-interview. Possible issues that came up during the pilot-interview were discussed with the other researchers and questions were adapted where necessary.

The interviews started with providing the participants with some general background information about the TOPFIT Citizenlab, the collaborative research project on fatigue and RA and SDV. After this, the participants were asked for their consent and when they consented, the recording of the interviews were started.

The interviews were divided in three parts. In part one, the topic motivation was discussed with the participants. Whereby the following question was asked to gain insight into the motives of the participants to use the SDV (and thus participate in the collaborative research project on fatigue and RA): *What is/are your motivation/motivations for using the Share Data Valley website (called citizen science website in the interviews)?*

In part two, the usability and accessibility of the SDV website, landingspage and questionnaires was explored with the participants using a flexible think-aloud method. In this case the think-aloud method was called flexible, because during the data collection process it was noticed that a stringent application of the think-aloud method was not fitting with this specific target-group (people with RA). And therefore the think-aloud method was applied less rigidly, whereby participants were not forced to think-aloud constantly and were also allowed to ask questions during the process. In the second part, the second interviewer had a web browser opened with two different tabs: one of the landingspage of SDV and one consisting of a fictional outlook mailbox made by the researchers with email containing a link to the test-questionnaire. On the day before the interviews, the main researcher made sure that the test-questionnaire was send to the outlook mailbox created for this interview.

During the think-aloud part, the second interviewer shared this screen with the participants and also gave the controls of the screen over to the participants. When the participants got control over the screen, they were given different tasks to perform on SDV, such as: *log-in into SDV* and *explore the landingspage and the website*. The participants started on the landingspage and then went to a test-questionnaire, which after it was filled out landed the participants automatically on the actual SDV website.

When the second part was finished, the controls over the screen were given back to the researcher. The participants were then asked whether they would want to leave the screen open, if case they wanted to illustrate an answer to a question from part three by pointing at a feature or aspect of the SDV website, landingspage or questionnaire.

In part three, open-ended questions about the features and aspects of SDV were discussed with the participants. After the first three parts of the interviews were finished, the participants were asked whether they wanted to receive a summary of the results of the interviews as well as asking them how they experienced the interview itself. During the process of the data collection, a few adaptations were made to the script and technicalities of the interviews, these adaptations are described in Appendix B. Finally, to minimize any kind of burden for the participants of the study, the maximum time of the interviews was limited to 90 minutes. This limit was exceeded once with consent of the participant.

Materials

For conducting the semi-structured interviews a script was used, including the topics and questions which were discussed during the interviews. This script consisted of a detailed description of information that would be shared with the participant during the interview and am estimation of the time that would be necessary for every part of the interview (see Appendix A).

Data-analysis

The audio-recording of the interviews were transcribed using Amber script. For the analysis of the data, the qualitative data-analysis software Atlas.ti 22 was used. The method used for analyzing the data was a thematic analysis, with a mixed-approach of deductive and inductive coding to identify themes and codes (Braun & Clarke, 2006). To structure the data-analysis the six steps of the thematic analysis from Braun and Clarke (2006) were used.

For research question 1, the answers about the different motivations for using SDV were inductively coded. For research question 2, the heuristics and strategies from the paper of Peters (2021) were used as a deductive coding framework. In this case, to structure the data-analysis, the topics for the interviews inspired by the paper of Peters (2021) were used. For instance, the code *Evaluation* was formed based on the autonomy supportive heuristic *Empathize with your user's frame of reference* and the fitting strategy *Provide ongoing opportunities for user feedback and input*. Answers about the possible evaluation of SDV were then fitted under the code evaluation, which was then part of the theme called *autonomy supportive heuristics*.

To help this coding process for research question 2, a coding scheme was used (see Table B1). To give structure to the results section, the answers of the participants to the different interview questions were fitted under either autonomy supportive heuristics, competence supportive heuristics or relatedness supportive heuristics (e.g., answers about accessibility SDV, theme: autonomy supportive topic, code: accessibility).

For this data-analysis process, only the main researcher was involved in the actual coding process. However, members from the TOPFIT Citizenlab (some outside of this research project and some inside) were involved in reading the transcripts, evaluating the data-analysis plan, evaluating the data collection process (e.g., attending interviews) and providing feedback on the interpretations and the data-analysis process.

Furthermore, some of the inside members were also involved in checking-up on the reporting of the results and interpretations of the findings. Also, to further improve the credibility of the data-analysis, the participants of the interviews got a summary send of the main findings of this interview study, giving them the opportunity to provide feedback on the interpretation of the results. Besides this, the bias of the interpretation of the results was attempted to be reduced by keeping a self-critical account of the research process (see Table B2).

Ethical considerations

The data collection process was approved by the ethical committee of the faculty of Behavioural Management and Social Sciences (BMS) of the University of Twente (ethical application number: 210019). The informed consent for this study was given orally before the interview and as a formality and the beginning of each interview. Before the recording started, the participant was also asked to give the oral informed consent again when the recording started. Lastly, participants of this study received a 10 euro bol.com gift card for their participation.

Results

Motivations for using the SDV

To identify the motivations for using the SDV website (also called citizen science website/platform in the interviews), the participants were asked the following question: *What is/are your motivation/motivations for using the citizen science website?* Answers to this question were inductively coded. In the end, four main themes were derived from the data-analysis. Table 1 provides an overview of the four main themes and codes with example quotes.

Table 1.

Motivations for using SDV

Theme	N_{Theme}	Codes	N_{Code}	Example quote code
Prosocial motive	9	Helping the researchers	14	*Because I have experience myself with designing websites and what all of that comprises of as a visitor of a website with this condition [RA]and my limitations, so that is actually the reason why I am willing to participate in this research (Participant 1).*
		Helping others with the condition	6	*I mean in our family it is a little bit more common yes, for all we know my children will also get it or my grandchildren or my great-grandchildren later on. Well, then it might be of some use to them. (Participant 9).*

Gaining insight	7	Gaining insight into the condition	13	*Well yes, indeed look into where does the fatigue come from and what can you do about it? Maybe that you can receive tips or that you find something about your own patterns. Like, you could do this different, that you can maybe improve things (Participant 4).*
		Gather data to share with medical experts	3	*Yes, maybe, because then I can always take [the gathered data] with me when going to the rheumatologists, like: that is the way I experience it (Participant 7).*
Research on RA	5	Bringing attention to research on RA	8	*Yes, you slowly but surely find out that patients indicate that fatigue is [symptom] number one and is barely considered. And then I am like, yes, how is that possible? So I support everything that takes the patients into consideration (Participant 5).*
		Research on fatigue	4	*[...] [The findings of this collaborative research study] should not collide [with the results of the research on fatigue at Reuma The Netherlands], that you are thinking like: I am reading the same things for both research iniatives [...] (Participant 10)*
Interest	2	Curiosity	8	*Yes, yes, a bit like what don't I know and what else do I want to know? Is there something else coming? Yes, curiosity, wanting to be informed about what is going on around my disease, that is definitely something that comes into play here (Participant 1).*

Note. This table provides of the main themes and codes identified relating to the motivations of participants to use the SDV. N_{Theme} gives an indication of in how many of the 10 interviews this theme was mentioned[4]. N_{Code} gives an indication of how many times the specific code was mentioned in the interviews.

Prosocial motive

Prosocial motives were identified in participants descriptions of being willing to help or support other people, such as sharing their experiences with website-design with the researchers to support them in fitting SDV to the user-group or supporting other people with RA in dealing with their condition through sharing their data on SDV. Within this theme, two different codes were distinguished, namely, *helping the researchers* and *helping others with the condition (RA).*

Helping the researchers. Some of the participants were motivated to use the SDV, because they wanted to help the researchers with their research project. Some of these

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[4] This is a better representation of the importance of the theme than mentioning the amount of times the specific theme was mentioned across all interviews. Because it for example could have been that one participant mentioned one theme several times in one interview, which not necessarily means it is a theme that is important for all the participants of this study.

participants just stated that they wanted to help without giving any further specification on why they wanted to help the researchers. However, there were also two participants expressing specific reasons on why they wanted to help the researchers. Participant 5 stated for example that she wanted to help the researchers, because she liked the way the research was set-up (actively involving people with RA in research). And the other participant felt that her knowledge about building a website for this specific user-group would be useful for helping the researchers, and therefore wanted to help the researchers (see Table 1).

Helping others with the condition (RA). There were also participants that were motivated to use the SDV, because they wanted to help other people with RA through sharing their data and/or experiences with RA on the SDV website. Findings from this shared data may then be used to help people who just go diagnosed, people who will be diagnosed in the future (e.g., future generations, such as great-grandchildren), and people who do not have that much knowledge (yet) on dealing with their condition. It was noteworthy that most of these participants stated that they still wanted to learn something from the research themselves, but that this was subordinate to helping others with the condition.

Gaining insight

This theme reflects the participants being motivated to use the website, because gathering data on their condition can help them gather insight into their symptoms, learn about patterns, supporting them in decision-making, as well as being able to share their gathered data with medical experts. Two codes fitting with this theme were found namely, *gaining insight into the condition (RA)* and *gather data to share with medical experts.*

Gaining insight in the condition (RA). A part of the participants wanted to use the SDV, so they could gather insight in their condition. Most of the participants mentioned that they wanted to gain insight in their symptoms and discover patterns relating to their condition (RA). Which could for instance support them in dealing with their condition and/or improving their condition (see Table 1).

Gather data to share with medical experts. Some of the participants were motivated to use SDV, because the website would allow them to take their health data (gathered on SDV) to a medical expert, like a rheumatologist (see Table 1).

Research on RA

This theme was identified in participants description of being motivated to participate in this collaborative research project because they feel like it brings more attention to research on RA, and also to check whether this collaborative research project on RA and fatigue is different from other RA and fatigue research projects. Within this theme, Two codes were identified, namely *bringing attention to research on RA* and *research on fatigue.*

Bringing attention to research on RA. Bringing more attention to research on RA was mentioned by a few participants to be a motivation to use SDV. Most of the participants talking about this topic, were motivated to use SDV because it brings more attention to research on fatigue and RA. These participants indicated that research on RA and fatigue is an under-exposed topic, and were therefore motivated by the fact that this research project is bringing more attention to this topic (see Table 1).

Research on fatigue. Another motivation mentioned by participants, was participating in this research project to check whether the research on fatigue (on SDV) is different from other arthritis initiatives (one of which one of the participants was a part of) researching RA and fatigue. One of the participants discussing this, stated that she was afraid that other initiatives researching RA and fatigue would be researching the exact same thing. Which would be a waste of time and resources (see Table 1).

Interest

This theme reflects participants willingness to use the SDV out of curiosity and being interested in the information that will come from participating in the research. One code was found to be fitting with this theme, namely *curiosity.*

Curiosity. Some of the participants mentioned to be motivated purely out of curiosity, and being interested in the data they will collect on SDV, as well as the being interested in the end-results of the study.

Opinions of participants about current and possible new aspects and features of SDV

The heuristics and strategies of the paper of Peters (2021) were used to deductively form the main themes and codes of this paragraph. To structure this paragraph, the different codes were fitted under three main themes called: *autonomy supportive heuristics, competence supportive heuristics and relatedness supportive heuristics.* The codes were named after the topic names which were used to formulate the interview questions of part two and three of the interview. For example, the heuristic *apply best practices for accessibility* was used to come to the topic *accessibility,* which was also used as the name for the code. The answers of the participants relating to the accessibility of SDV were then coded with *accessibility*. An overview of the most important findings relating to the 3 overarching themes and the 12 codes are given in Table 2 below.

Table 2.

Overview of results interview

Need supportive heuristic (and theme)	Translation to the context of SDV	Attitudes of the participants towards these features and/or aspects SDV (and code)
Comply with web-accessibility standards, such as ensure that pages are clear and simple and provide context and orientation information. Technology can be accessed by all intended users. **Theme: Autonomy supportive heuristics**	The colors, clarity, font size, contextual information on the landings page, website and in the questionnaires can influence the accessibility of SDV. SDV fits with the needs and wishes of the participants, as well as being easily accessible.	Mixed findings: some of the participants found the lay-out, format, structure and overview of the landingspage to be easily accessible and fitting with the user-group, while others indicated that the colors and font size used on the landingspage were difficult to read. Mixed findings: some of the participants found the website to be easy and clear to understand, while others found the website to be overloaded with information and the letters on the website to be a bit light and thus hard to read. Website could be more accessible if users would have the opportunity to change the brightness used on the website (and landingspage). Mobile-friendliness SDV makes it more accessible overall. Some participants felt like SDV is not completely accessible for every person with RA, since in general the older age-group with RA is less digitally able. **Code: Accessibility**

Empathize with the user’s frame of reference by providing ongoing opportunities for user-feedback and input. **Theme: Autonomy supportive heuristics**	To provide ongoing opportunities for user-feedback and input, I could be possible to add a feature or aspect to SDV, whereby participants get the option to evaluate SDV and/or give feedback about the proceedings of the collaborative research project.	Participants generally had a positive attitude towards having the opportunity to provide the researchers with feedback about SDV and the three week collaborative research project on RA and fatigue, as well as for future research projects on SDV. Overall, participants wanted to evaluate after the three weeks, mostly important to give users a choice if they want to evaluate, as well as when and how they want to evaluate the website (e.g., email, online group-meetings). **Code: Evaluation**
Providing a meaningful rationale by providing clear and sufficient information to give users the feelings that their actions (when using a technology) are autonomous are self-endorsed. **Theme: Autonomy supportive heuristics**	Features on SDV, such as the little i (see Figure 5) and information that helps users understand why they would use a certain button or feature.	Mixed findings: for some of the participants, the information provided on the landingspage helped them understand the website and the collaborative research project. While others felt like the landingspage should provide more information on why someone would want to participate and what the research project is about. Also providing more information about privacy and data sharing was seen as a necessity. Also useful to add more little i’s icons (see Figure 5) to the website and questionnaires, seeing that they were seen as useful in the questionnaires. **Code: Information and explanation**
Ensure that people that when users are rewarded in an autonomy supportive way for their efforts put into for instance an online research project (e.g., reward people for their efforts put in and not for reaching the	Current features and aspects of SDV that could already help participants in using SDV consistently. Or possibly adding features or aspects to SDV that can ensure consistent use of SDV in three week period as well as for future projects.	Existing features such as daily notification to fill-out questionnaire supports participants in using SDV consistently. Mobile-friendliness of SDV also makes consistent usage. Update on progress of research and update of other participants experiences could support consistent participation in three week period as well as long-term participation in other research projects **Code: Consistent use**

goal of filling out a questionnaire everyday). **Theme: Autonomy supportive heuristics**		
Communicate in autonomy supportive ways by making sure that notifications are not distracting and pushy, as well as giving users choices with regards to notification settings. **Theme: Autonomy supportive heuristics**	Notification system SDV for this collaborative research project supports participants in filling-out questionnaires daily. Participants receive notification between 7 and 8 PM. Also gives users the option to choose on how to receive the notification (SMS or email).	Participants found it of importance that they can have a choice in setting when to receive notification in time-window, and that it would be useful to offer a broader time-window for receiving notifications (between 6 PM and 10 PM instead of between 7 and 8 PM). **Code: Notifications**
Communicating in autonomy-supportive ways by avoiding controlling and directive language. **Theme: Autonomy supportive heuristics**	The language and tone used on SDV can influence autonomy. Therefore the participants were asked what they thought about the language and tone used on SDV, as well as how they would wanted the language and tone of SDV to be.	In general, participants felt like using an open and informal tone supported their feelings of autonomy, because it made them feel like they are doing the research together with the researchers. Participants stated that is important to avoid using jargon and using different for one thing (e.g., is a citizen the same as a practical expert?). **Code: Language and tone**
Support mindful attention, ensure that using a technology does not cost a lot of energy. **Theme: Autonomy supportive heuristic**	Asking the participants about how much energy using SDV costed, and what influences this according to the participants.	In general, the participants expressed that the website did not cost them a lot of energy and did not have a big cognitive load. SDV was reported to have a calm appearance, require little thinking and being easy to use daily. Important to make sure that website has colors and text which is easy to read, as well as requiring not to much clicking. **Code: Energy**

Ensure functionality and ease-of-use of the technology. **Theme: Competence supportive heuristics**	One of the foundational heuristics for supporting competence in a digital environment, is to ensure functionality and ease-of-use of the digital environment Therefore the user-friendliness of SDV was explored.	Mixed findings: some participants found the website and landingspage to be well-organized and easy-to-use, while others found that using the website and landingspage required to much clicking and that is important to notify users of where to scroll on the website and landingspage. Questionnaire had easy to use controls according to some of the participants (see Figure 3 for example), also participants who felt that filling-out the questionnaire required too much clicking and dragging. **Code: user-friendliness**
Giving users the opportunity to learn. **Theme: Competence supportive heuristics**	Features and aspects of SDV that give participants the opportunity to gain insight or learn something from using SDV.	Participants stated that the analysis feature of SDV (see Figure 6) is a possible useful feature to learn something about their condition. There were also some participants felt that gaining insights in the data was mostly for the researchers to do. The interpretation from the researchers could then later on be used to learn from. **Code: Gaining insight(s)**
Ensure caring for others (other users), this can for instance be done by providing opportunities to contribute or share (data/information) with others when using the specific technology **Theme: Relatedness supportive heuristics**	Knowing that there is a share data features, participants were asked whether they valued it to being able to share and compare data from SDV with other participants of SDV (and if so, how they would want to do this).	In general, most of the participants valued the opportunity to share data with other participants. Participants expressing this positive attitude, wanted to share data with other users to help them deal with their condition on a daily bases. With regards to comparing data with other participants of SDV (and how they would want this comparing), there we mixed views on whether comparing data with others users would be advantageous. Could be most advantageous when participants can compare their data with the data of others on a group-level. Being able to compare oneself with another person with RA can also have negative consequences (e.g., competitiveness). **Code: Sharing and comparing data**
Support a sense of community/belongingness, by for instance making the community salient. **Theme: relatedness supportive heuristics**	Participants were asked about their opinions about whether they valued having that community-feel (a sense of belonging) when using SDV and how this sense of community then could be created on SDV (if they valued this).	Nearly all of the participants had a negative association with creating a sense of a community in digital environments. Most of them felt like attempting to create a community would have a lot of similarities with fora or social media websites for people with RA, and most of the participants indicated to have negative experiences with using social media or fora to connect with other people with RA. **Code: a sense of belonging and community**

Support a sense of community/belongingness, by for instance making the community salient. **Theme: relatedness supportive heuristics**	Asking participants about their views on having an idea-box added to the SDV landingspage (new possible feature),which led to participants to talk about possible other new features and/or aspects of SDV that could be added to enhance the sense of belongingness amongst the SDV users.	Having an idea-box on the landingspage of SDV where participants can share ideas for future research and see suggested ideas of others. With regards to possible new features or aspects being added to SDV to enhance the sense of belongingness, some of the participants mentioned that they would like to share experiences on SDV, stating that they wanted to share tips and tricks and experiences with RA with other participants, from which they could also profit. Possibly valuable to provide the opportunity to connect with other users of SDV and then maybe get the opportunity to share experiences with other participants through Zoom or a chat function. **Code: Social features and aspects SDV.**

Figure 5.

Example of the little i used in the daily RA questionnaire

Activiteit: Hoeveel uur van de afgelopen 24 uur heeft u besteed aan cognitieve activiteiten?

Benoem hier het aantal uren waarin u cognitief actief was. Denk hierbij aan vergaderingen of taken voor school/werk waarbij u veel moet nadenken, lezen of puzzelen, etc.

Als u tegelijkertijd fysiek en cognitief actief was (bijvoorbeeld een intensief gesprek voeren tijdens een wandeling), mag deze bij beide categorieën meetellen.

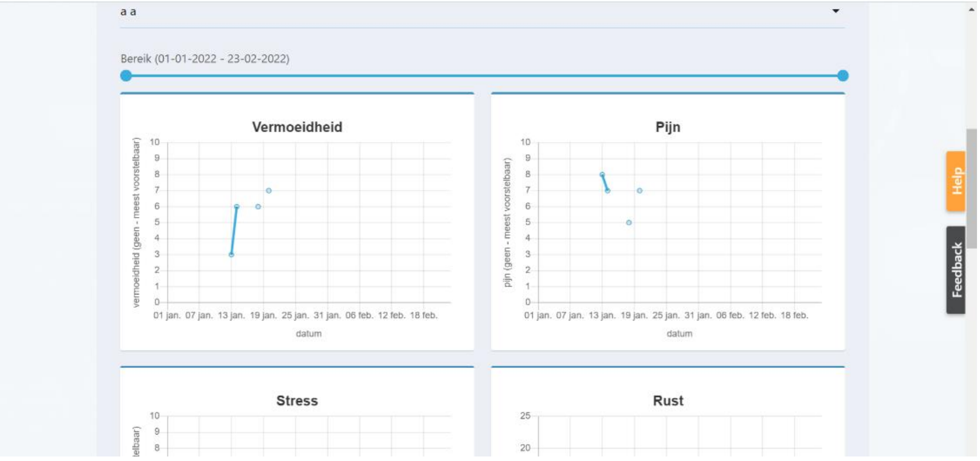
Activiteit: Hoeveel uur van de afgelopen 24 uur heeft u besteed aan rust?

0 Uren

0 Minuten

Figure 6.

Example of the analysis feature SDV



Autonomy supportive heuristics

The opinions of the participants for this theme were identified in expressions of participants while interacting with the interface of SDV (landingspage, questionnaire(s) and website), as well as in expressions of participants about (new possible) features and aspects for SDV relating to the autonomy need supportive heuristics such as evaluation. 7 codes were distinguished for this part, namely *accessibility*, *evaluation*, *information and explanation*, *consistent use*, *notifications*, *language and tone* and *energy*.

Accessibility. With regards to the opinions of the participants towards the accessibility of the landingspage of SDV, there were some different attitudes amongst the participants. Some participants found the lay-out, format, structure and overview of the landingspage easily accessible and fitting with the user-group (people with RA). As expressed by participant 2:*‘’It does, the structure is really pleasant I have to say. It is, you get a good impression of where you need to go straight away. I do find the blue [colors on the landingspage] nice’’*. Opposite to that were participants expressing that the landingspage lacked clarity in some parts and that it consisted of colors and letters which were hard to read, making the landingspage less accessible. With regards to the SDV website there were also some contradicting views. Some of the participants mentioned for instance that the clarity, structure, mobile (smartphone) friendliness made the website more accessible, as mentioned by participant 4:*‘’ Okay, yes, no it just, yes. He (the website) is just easy, clear and well-organized, quite a big font as well for people who have bad eyesight ’’.*

However, there were also participants who found the website to be overloaded with information and functions, making the website looking less calm. As well as participants having trouble with reading some of the letters on the website, because they were to light. With regards to the subject of making the website more accessible for people with RA with affected eyesight (which is quite common amongst people with RA, due to medication usage), one participant suggested that it might be useful to give users to options to change the brightness of the website (from light to darker). This provides participants with the opportunity to fit the brightness to their own eyesight.

Finally, with regards to fitting SDV with the intended user-group, some of the participants discussed the fact that it was difficult to include everyone in these kinds of online research projects. Especially people from the older age-group which are usually more prone to being diagnosed with RA, a lack of digital skills is prominent. Emphasizing how difficult it is to make the website accessible for everyone from this specific user-group.

Evaluation. One of the heuristics for supporting autonomy in a digital environment states that the frame of reference of the users needs to be taken into account. One strategy to ensure that people's frame of reference is taken into consideration, is providing people with ongoing opportunities to provide feedback and give input (Peters, 2021). In this study, participants were therefore asked what their opinions was about having opportunity to evaluate SDV during and/or after the collaborative research project (of three weeks) on fatigue and RA, and for future research projects on SDV. Overall, there was a positive attitude towards the possibility of evaluating SDV. An example of a participant stating this is:

Yes, I think that is very useful, because you often stumble upon things at the beginning and then you get used to it and then we as users in test-phase [people participating in the interviews of this study] know like [it works this and this way]. But for new users you forget to mention that [that there is an opportunity to evaluate SDV], so I think that is a very good one (Participant 1)

Besides this, participants also had different opinions on how and when they wanted to evaluate SDV. Most of the participants wanted to evaluate SDV after they used the website for three weeks. On the other side, there were also participants stating that the researchers should first enquire whether people want to evaluate the website and then at a certain time-point should ask the participants who want to evaluate to send their feedback to the researchers.

Lastly, methods for the evaluation which seemed feasible to the participants were: an evaluation questionnaire (send by the researchers), having participants send an email with feedback themselves (where they can provide feedback whenever they want) and/or evaluate SDV in an online (group)meeting.

Information and explanation. In general, there were different opinions amongst the participants with regards to whether the SDV website, landingspage and questionnaires provided them with sufficient information and explanation. Participants who felt that SDV offered them sufficient information and explanation stated that the information on the landingspage helped them understand the SDV website better. As well as the explanatory functions of the questionnaires, such as the little *i* (see Figure 5) helping them to understand the questions from the questionnaire better.

However, some of the participants felt that there was room of improvement with regards to the information and explanation given on the website, the landingspage and the questionnaires. Improvements mentioned were: providing more information on the landingspage on why someone should want to participate in this research and what participating would mean for them, as well as more general information about the collaborative research project.

Furthermore, participants felt that information about the subject of privacy and data sharing should have a more prominent place on the landingspage as well as on the SDV website. Users should for example be informed about what it means to share data, with who this data is going to be shared and if personal details are visible to others.

Lastly, participants felt it would be valuable to add more little i's to different parts of the website and in the questionnaires. Examples of participants mentioning this improvement are:

Not specifically looking at myself, but more for others. I would then that a little icon with an I with extra information, that would be useful. Yes, when they for example do not know anymore what something is for [such as a function or page] or whatever (Participant 4)

Consistent use. In order to ensure consistent use of SDV during the collaborative research project of fatigue and RA (and future research) project, using the right incentives (such as giving feedback on progress) could be useful to ensure consistent use (Peters, 2021). Therefore, participants were asked what they need to ensure that would use SDV consistently during the three week research period, as well as for possible future research projects on SDV.

Overall, participants had different opinions on which features and aspects of SDV could ensure consistent use. With regards to constant use of SDV during the three weeks research period on RA and fatigue, most of the participants indicated that receiving a daily notification or reminder to fill out the questionnaires was enough for them to use SDV on a constant bases. Participants also experienced the fact that SDV is mobile-friendly as something that supports a constant use, because it makes it easier to fill out the questionnaires. There were also participants who felt that they would be motivated to use SDV on constant bases (in the three week research period) if they would receive update(s) on how the research is going and what the general experience of other participants are.

Furthermore, when talking about future research projects on SDV, multiple participants felt that getting something back from the researchers about the progress of the research and their own progress was a really good motivator to use SDV on a consistent bases. As mentioned by this participant: *''Yes, at some point you need to feel like you get* *something back from it [from SDV] and you have to see that you can use it and that you really see the advantages of using it ''(Participant 8).*

Notifications. Another heuristic to support autonomy in a digital environment is avoiding communicating in a controlling way. Communicating in this case means not only the language used, but also the way that for instance notifications are conveyed. For example, a notification can be seen as controlling when it comes too frequent or comes at the wrong time (Peters, 2021). Therefore, the participants were asked what they thought about the notification system of SDV (used for this collaborative research project, because it might be different for future research projects), and whether they valued it if they could make their own choices with regards to setting notifications.

Overall, during the interviews the participants found the notification system used on SDV for this collaborative research project to be fitting with their needs. Currently, participants receive a link of the questionnaires via email or SMS, usually between 7 and 8 PM every day for the daily RA questionnaire. Participants expressed that they liked that they received these notifications everyday and also mentioned that they liked that participants have their own choice on whether they want to receive notifications via SMS or email.

Although participants found the notifications on SDV to be fitting with their needs, some participants did feel like the time-window for when to receive the notifications should be a bit broader, for example between 6 PM and 10PM. Because a participant might not always be available between 7 and 8 PM every day.

Language and tone. As in the former code (notifications), if the communication used in a digital environment is perceived as controlling, it could influence the feelings of autonomy of the user (Peters, 2021). Therefore, the participants were asked what they thought about the language and tone used on SDV, as well wat kind of language and tone they preferred.

In general, participants preferred an open and informal tone because it made them feel like they are doing the research together with the researchers. Furthermore, some participants mentioned that is really important to be fitting the language to the user-group. Meaning for example that the researchers should not use difficult words (e.g., jargon) as well many different words meaning one thing (e.g., is a citizen the same as a practical expert?) to prevent confusing the users.

Energy. Autonomy can be supported by applying the heuristic of supporting mindful attention, by which it ensured that using a digital environment does not take to much effort and energy (Peters, 2021). Therefore, the topic on how much energy using SDV costed the participants was discussed, as well as which features and aspects of SDV played a role in this. As well as what they needed to minimize the amount of energy expanded.

In general, the participants expressed that the website did not cost them a lot of energy and did not have a big cognitive load. SDV was reported to have a calm appearance, require little thinking and being easy to use daily. In order to prevent the website from having to high of a cognitive load. the participants suggested to be careful with using to much text and too many different colors as well as reducing the amount of clicking people need to do when using the website.

Competence related topics

The opinions of the participants for this part were mostly identified in the interaction between the participants and the interface of SDV, as well as in expression of participants about (possible new) features and aspects that will support (or undermine) their feelings of being capable and effective when using SDV, as well as their feeling that they can learn something from using SDV. 2 codes were distinguished for this part, namely user *user-friendliness* and *opportunity to learn.*

User-friendliness. During the exploration of the website, landingspage and questionnaires by the participants, different aspects and features of SDV were discussed to be influencing the functionality and ease-of-use (user-friendliness). Overall, some participants perceived some features and aspects of SDV to be user-friendly, but also participants who perceived some features and aspects to be less user-friendly and wanting them to be improved. For example, a part of the participants experienced the questionnaires to be easy to fill out in a short amount of time, as well expressing that they found the controls in the questionnaires to be easy to use. Such as the little slider in the daily RA questionnaire or the controls in the SQUASH-questionnaire (see Figures 7 and 8).

Figure 7.

Slider used in the daily RA questionnaire

Vermoeidheid: Hoe hevig was uw vermoeidheid gemiddeld vandaag?

Figure 8.

Controls in the SQUASH-questionnaire

Lopen van en naar werk of school
Dagen/week

Vul het aantal dagen in

Vul dit veld in.

Uren en Minuten / dag

Fietsen van en naar werk of school
Dagen/week

But on the other hand, there were also participants who felt that these features (from the questionnaires) might be to difficult to use for people with RA. Participants felt that the ease-of-use of these questionnaires would improve when users would have to click and drag less. A participant suggested to make the decimals not to specific (e.g., only being able to fill out a 7, 7.5 or 8 as a fatigue score, instead of 6.3 or 7.9), to prevent to much dragging.

This divide in opinions of participants about the ease-of-use and functionality was also identified when the participants explored the SDV website and/or landingspage. One part of the participants experienced the website and/or landingspage to have easy to use controls and being well-organized. However, there were also participants who expressed that using the

SDV website and its functionalities required to many clicks, which according to the participants negatively influences the user-friendliness. As expressed by this participant in the following statement: *'' No, no, I find that, I am in favor of clicking as least as possible. If people have to click to much, they will stop sooner [with using SDV]'' (Participant 2).*

This was also the case for the landingspage, where one participants expressed that it could be useful to inform participants about the fact that they have to scroll down on the landingspage, because the participants felt that on the landingspage people could miss out on important information if they were not made aware that they could scroll down on the page.

Opportunity to learn. One of the factors that have been shown to enhance a person's sense of competence is the opportunity to learn (Peters, 2021). Therefore the participants were asked whether SDV offered them sufficient opportunities gain insight and learn something about their condition, and what they would need (and could be added to) SDV to support them in this regard.

In general, participants felt that the analysis feature of the SDV website provided them with sufficient opportunity to learn about their condition. This analysis feature gives participants an opportunity to give insight in the data they filled out in their daily RA questionnaires. This feature consists of a dashboard with different graphs showing the data-points for every day that a participants has filled out the daily RA-questionnaire. In the example in Figure 6, you can see examples of these graphs for the reported levels of fatigue and pain.

The participants expressed that this feature could help them gain insight into trends (e.g., what is the relation between my fatigue and my RA symptoms?) and help them learn new things about their condition. Although there was a general positive attitude towards the opportunity to gain insight into their condition through SDV, some participants felt that gaining insights in the data was mostly for the researchers to do. The interpretation from the researchers could then later on be used to learn from.

Relatedness supportive heuristics

The opinions of the participants for this part were mostly identified in participants descriptions of whether they valued it to being able to share and compare data from SDV with other participants of SDV (and if so, how they would want to do this), as well as the opinions of the participants about whether they valued experiencing that community-feel (a sense of belonging) when using SDV. And how this sense of community could be created on SDV (if they found it to be valuable). As well as asking the participants about their views on having an idea-box added to the SDV landingspage (new possible feature), where participants can leave ideas for future collaborative research projects on SDV. Which also led to participants talking about other possible other new features and/or aspects of SDV that could be added to enhance the sense of belongingness amongst the SDV users. 3 codes were identified for this part, namely *sharing and comparing data, a sense of belonging and community* and *social features and aspects SDV*

Sharing and comparing data. One of the relatedness supportive heuristics is to ensure caring for others (other users), this can for instance be done by providing opportunities to contribute or share (data/information) with others when using the specific technology (Peters, 2021). On the SDV website, there is a sharing button which participants can use to share the data for instance with other participants and the researchers. Knowing this, the participants were asked about their opinions about having the opportunity to share their data (which they filled out in the questionnaires) with other participants of the collaborative research project. Furthermore, the participants were also asked what their opinion was on the value of comparing data (data from the questionnaires) with other participants of the collaborative research project.

In general, most of the participants valued the opportunity to share data with other participants. Participants expressing this positive attitude, wanted to share data with other users to help them deal with their condition on a daily bases.

With regards to comparing data with other participants of SDV (and how they would want this comparing), there we mixed views on whether comparing data with others users would be advantageous. Participants expressing that they valued comparing data to a lesser extend, mostly talked about the fact that comparing data on an individual level does not really have any value, because participant generally experienced that there are big differences between people with RA. What works for one person, might not for work for someone else provides an overall summary of the opinion of participants on this, as expressed by this participant:

Look in principle, I do not have a problem with sharing. But the question stands: what is the added value of this? Because I have no use for the information of how someone else experiences it or whatever. Because I also do not know how they think, so that is really difficult, really subjective to like compare with other patients'' (Participant 8).

Instead of this, participants talked about the option of comparing their own data to the mean scores of the data of the entire population (e.g., comparing their stress-level with the mean stress-level of the entire research population of SDV) being more useful. There were also participants who felt that comparing data might also have some negative consequences such as: leading to people feeling ashamed about themselves and/or causing them to be overly competitive. Lastly there were also participants expressing to just be interested in participating in the research (and not comparing) and/or just getting their own data.

A sense of belonging and community. Another relatedness supportive heuristic is that of supporting a sense of community/belongingness, by for instance making the community salient (Peters, 2021). Based on this heuristic, the participants were asked about their opinions about whether they valued having that community-feel (a sense of belonging) when using SDV and how this sense of community then could be created on SDV (if they valued this). When this was discussed with the participants, most of them immediately had a negative association with creating a sense of community in digital environments. Most of them felt like attempting to create a community would have a lot of similarities with fora or social media websites for people with RA. And most of these participants indicated to have negative experiences with using social media (e.g., RA Facebook groups) or RA fora to connect with other people with RA. Some of these participants also indicated that they usually were either already part of some social RA community, had never really though about the importance of connecting with others as well as some stating that connecting with others was not priority number one.

However, despite all of this, some of the participants felt that creating a community could be valuable, but only under certain conditions. Conditions for creating the community would then be: make sure that it is positive and can have a positive impact, by giving people the opportunity to share valuable experiences with RA, share tips and tricks and create opportunities for face-to-face contact (see quote below). There was also a part of these participants (who had a negative association with creating a community), who felt that just did not want to have this community on SDV or who just wanted to participate for themselves.

Yes, I am as well a member of a RA Facebook group, but you indeed rarely see anything positive on there […] And I think it works better when you are face to face in a group together, because then you can actually discuss with one another. It is also really *difficult to get your message across […] Because typing something, that, yes, you never really get your feelings and emotions across. That is really difficult (Participant 8).*

Social features and aspects SDV. To gain insight into the opinions of the participants about possible new social features and or aspects that could be added to SDV to enhance the sense of belongingness amongst the SDV users, the participants were first asked about their views on having an idea-box added to the SDV landingspage (new possible feature), where participants can leave ideas for future collaborative research projects on SDV. Asking this question about the idea-box, also led to participants talking about others possible new features and/or aspects that could be added to enhance the sense of belongingness amongst the SDV users.

In general, there were mostly positive opinions with regards to having an idea-box on the landingspage of SDV where participants can share ideas for future research and see suggested ideas of others. This is for example illustrated in the following statement:

Yes, on the previous website you guys had that and I really liked that. That you could contact the website developer for ideas. Well, I really liked that, because yes, young people are having more and more ideas and maybe you can make a separate block of ideas that can be used for research (Participant 3).

With regards to possible new features or aspects being added to SDV to enhance the sense of belongingness, some of the participants mentioned that they would like to share experiences on SDV, stating that they wanted to share tips and tricks (e.g., what should you do? when you cannot open a bottle?) and experiences (e.g., with rheumatologists) with RA with other participants, as well as expressing that they also would like to profit from other people sharing this type of data. Furthermore, these participants also mentioned that they would value the opportunity to connect with other users of SDV and then maybe get the opportunity to share experiences with other participants through Zoom or a chat function.

Discussion

The goal of this interview study was to explore the role of motivations in patient engagement in research in the context of the collaborative research project on an online crowdsourcing intervention called SDV. Below, the most important findings regarding the motivations of participants to use SDV and the opinions of the participants about features and aspects of SDV are discussed.

Motivations of participants SDV in context of patient engagement in research

The findings of this interview study show that the core motivations for participants to be willing to use the online SDV crowdsourcing intervention mainly revolve around prosocial and altruistic values and motivations to learn about their condition (RA).

When looking at other studies exploring the motivations of patients to engage in research in a wide variety of contexts (from participation in clinical trails to participation in crowdsourcing based health research). The findings of this interview study are quite consistent with the findings from these other contexts. For example, amongst patient-groups with varying conditions (e.g., cancer, neurological, metabolic, psychological, cardiovascular conditions), commonly identified motivations are mostly prosocial and altruistic in nature. Also, beside prosocial and altruistic motives, quite often patients also participate out of self-interest in the sense of wanting to learn about their condition to possibly improving and/or managing their condition better (Bradley et al., 2016; Estcourt et al., 2016; Sheridan et al., 2020).

Furthermore, when exploring studies regarding the context of online crowdsourcing interventions for health research, wanting to help others (prosocial/altruism), wanting to figure out underlying mechanisms of their diseases, wanting to engage with researchers on the specific topic and wanting to advance science were amongst the main motivators (Bradley et al., 2016; Créquit et al., 2018).

The findings from this interview study, and those from other studies learn us about what is important for patients in their decisions to become engaged in face-to-face and online research contexts. As discussed by McCarron et al. (2019), knowing about what draws in patients to engage in research can help us inform effective strategies for patient engagement.

Knowing from this interview study (and other studies) that altruistic/prosocial and self-fulfilling (e.g., learning about one’s condition) motivations are quite often the most commonly mentioned motivations to engage for patients, it is recommendable for the TOPFIT Citizenlab as well as for researchers of other patient engaged research project to developing strategies that lend itself to these kinds of motivations.

Examples of engagement strategies to draw in patients with altruistic/prosocial motives are emphasizing the benefit participating could have for others or drawing in patients by promising that it can learn the, something new about their condition, or that participating can shape possible tools to deal with their specific condition (Sheridan et al., 2020).

Important to take into account when applying these strategies to those specific motivations, it the variability in the expressions of these motivations. Interesting for example is the variety in ways people tend to be altruistic, some are altruistically motivated to progress science or benefit healthcare, some to help others (e.g., family members, other patients), and some because they want feel good about oneself (Hemphill et al., 2020; Sheridan et al., 2020).

Therefore, when employing strategies to draw in patients, it is important to be aware of the variability of the expressions of these motivations and tailor those strategies to these specific motivations. For example, when having patients who are altruistically motivated to help other patients, it is important for researchers to put an emphasis on the fact that participating might benefit other patients.

Opinions of participants about features and aspects of SDV

With regards to current features and aspects of SDV, there were some contradicting views as well as some similair views. For example, contradicting views regarding the accessibility of SDV revolved around some of the participants finding the lay-out, format and structure of the SDV landingspage to be accessible for the user-group, while others participants finding the landingspage to be lacking clarity and having difficult colors and letters to read. This was also the case for the user-friendliness of SDV. The similair opinions regarding the current features and aspects revolved around theme's such as the language and tone, energy, the opportunity to learn through the data-analysis feature and having the opportunity to share data on SDV.

The features and aspects that were discussed with the participants that are not currently an actual part of the online SDV environment (such as an idea-box on the landingspage or the opportunity to evaluate the SDV after/during the collaborative research project), there were again similar as well as contradicting opinions.

Amongst the participants there were similair views regarding having the opportunity to evaluate SDV after/during the collaborative research project. Also placing a idea-box on the landingspage for ideas for future research projects was seen as a valuable social feature to be added to SDV.

A noteworthy divide in opinions was about how valuable creating a RA community for SDV-users would be. One part of the participants had a lot of negative associations with being part of a (RA) community, while others indicated that they were still open to creating a RA community on SDV under certain conditions (i.e., spreading positivity and having a positive impact). It was also interesting that despite the divide in opinions on this topic, some participants still did suggestions for possible social features that could be added to SDV to enhance the feelings of belonging and community (e.g., chat-box or sharing experiences).

Findings of this interview study demonstrate that the opinions of the participants about the features and aspects of SDV vary widely and are even contradicting at times. These findings are quite consistent with findings from others studies exploring the opinions, wishes and needs of patients about different functionalities and features of digital environments (see Wannheden, 2021; Ekstedt, 2022).

A possible solution to meet the varying needs and preferences of patients in digital health is by focusing on personalization and adaptability of online environments. In case of SDV, an example of applying this principle is by adapting a personalized user-interface. This could for example be applied to the adapt to the variability in eye-sight amongst people with RA. This adaptive user interface would for example give users the option to increase the size of the fonts and adapt the brightness of the pages to their specific needs (Deuschel & Scully, 2016). Such a feature is not only useful in case of SDV, but could also be adapted to other digital research environments for people who have an impaired vision due to their chronic condition (e.g., Diabetes Type 2). Such a personalization strategy could also be utilized to adapt to the differing opinions of the participants of this interview study (as well in other digital health environments) on the value of community building and having social features (e.g., use a system whereby users can switch of social features)

Limitations

Although the study yielded some important insights that can be used for further improvement of the online SDV crowdsourcing intervention, this interview study was not without its limitations. First, a relatively small sample (*n*=10) of people of RA was involved in this study. Although time constraints were the reason that a relatively small sample was acquired, the small sample (n=10) was not enough to reach saturation and the results should therefore be considered with care before generalizing (or transferring) it to other contexts and settings.

Second, the participants involved in this study might not provided a full representation of the ‘typical’ person with RA. As was also mentioned by some patients in the interviews, people participating in this study might be more digitally-able and vital when compared to other patients with RA, decreasing the chance that the findings represent the full spectrum of patients with RA. A disadvantage of this is that patients with RA who might struggle the most with fatigue as a symptom (and might not be able to participate due to health constraints or a lack of digital skills, do not get the chance the benefit from initiatives like the collaborative research on SDV.

Third, the way the main interviewer asked the questions (and used probes to go more in-depth) and applied the think-aloud method differently over the time-span of the 10 interviews could have negatively influenced the reliability of the results of the interviews. For example, in some of the interviews, the main interviewer used more probes and thus got more in-depth answers and in other interviews asked questions in more of a suggestive manner. Leading perhaps to more socially desirable answers.

Future research directions

First, as discussed by Rotman et al. (2012), motivations in these type of crowdsourcing projects are dynamic and temporal in nature, meaning that motivations are facilitators of engagement and come to fruition in different stages of the collaborative process. Since people tend to drop out of prolonged crowdsourcing projects it is important for the researchers of TOPFIT Citizenlab to consider the dynamic nature of the motivations of the participants (by for instance asking the participants how their motivations changed over time when participating in the collaborative research project on RA and fatigue). Gaining insights in these motivations for continued participation could help the researchers of TOPFIT Citizenlab formulate strategies to address the dynamic nature of motivation and increase the chance that participants will long-term engage in future research projects on SDV.

Second, in this interview study, the SDT based paper of Peters (2021) was only applied to shape the topics and methods for the interview questions. Knowing that there is a wide array of empirical evidence showing the usefulness of the BNT mini-theory for evaluation and design of digital environments, it would be useful to use the BNT in a more extensive manner (Peters et al., 2018; Ryan & Deci, 2017; Vansteenkiste & Ryan, 2013). SDT based frameworks that could be used are the once again the heuristics of Peters (2021) or SDT based Motivation, Engagement, and Thriving in User Experience (METUX) model from Peters et al. (2018). The METUX model could for example be applied in the manner that Wannheden et al. (2021) did in this study to analyze which features of a digital health intervention for self-monitoring were experienced by a group of Swedish patients to be need satisfying or undermining. An advantage of this approach is that using the METUX-model provides more of detailed insight into which parts of the user experience (e.g., interaction with the interface) are mostly influenced by the design of a website. Which can help inform different design strategies which can influence these different parts of the user experience.

Conclusions

Motivation plays an important role in drawing patients into participating into research as well influencing the sustainability of long-term research partnership. Therefore, the goal of this interview study was to explore the role of motivations in patient engagement in research in the context of the collaborative research project on an online crowdsourcing intervention called SDV. Two aspects were explored in this study, one, the motivations of the participants for using SDV (and thus deciding to participate in the collaborative research project about RA and fatigue) and second, because characteristics of a digital environment can directly and indirectly influence the motivation to use and keep on using a digital environment, the opinions of the participants about the features and aspects of SDV were explored.

The results show that the main motivations to use SDV revolve around altruistic/prosocial values and a motivation to learn about their condition (RA), and that the opinions of the participants about the features and aspects of online SDV environment vary widely and are even contradicting at times.

The motivational perspective adapted in this interview study emphasizes two main things, one: the need for researchers of TOPFIT Citizenlab (and researchers organizing other patient engaged research projects) to develop engagement strategies that lend itself to the specific motivations of patients (e.g., emphasizing the benefit of participating for others to draw in altruistically driven patients to engage in research), and two: the varying and contradicting opinions of participants of this interview study emphasized the need for researchers of TOPFIT Citizenlab and other research projects to think about design strategies such as applying an adaptive interface to their digital environments to fit with the varying needs and wishes of individual patients (Deuschel & Scully, 2016).

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Appendix A: Interview script

Interview script

Table A1

Interview script sample (translated from Dutch to English

Time in minutes	What	Comments	Extra
-0.05-00.00	Zoom meeting with the participant	Researcher (student) does interview together with one of the researchers of TOPFIT Citizenlab (in order to keep continuity/community within research TOPFIT Citizenlab). Student takes the lead in the interview.	The following things are for needed for the interview: • The link of the Zoom meeting is send tot he participant via email. • A test account on outlook as well as on SDV is created. The log-in details are: **(Anonymized)** • Before the beginning of the meeting, the researchers have the screen of the landingspage of SDV as well as the outlook account open, where the link to the test-questionnaire will be. • During the interview, the researcher of TOPFIT Citizenlab keeps an eye on the time • Before every interview, the interviewer has to make sure he sends the link of test-questionnaire to the outlook account **one day before the interview.**
00.00-00.05	Introduction and informed consent	Introduction and informed consent	**Introduction** Everyone in the meeting room introduces oneself. The student starts, then the participant followed by the other researcher [participant asked to tell about what they do in their daily lives, what their age is and when they were diagnosed with RA. [After the introduction, the other researchers provide an introduction, which contains of information about TOPFIT Citizenlab, the research project with people with RA, Citizen science website, Sport Data Valley and Share Data Valley and the goal of this interview].

			Student interviewer talks about goal of the study, then the informed consent whereby the participant is asked whether he or she is aware of the following things: • That the interview will be recorded • The data will be anonymized • That the participant can stop with the interview whenever he or she wants and that not every question needs to answered. [If participants consented, he or she was asked to repeat this after the recording was started by one of the researchers].
00.05-00.15	Explanation about structure interview + question 1		**Part 1** [Student explains part of interview to participant] Part 1: Motivations Part 2: (flexible) think-aloud part Part 3: Open-ended questions about different topics related to the SDV. [Any questions before we begin?] **Question part 1:** What are your motivations for using the citizen science website?/what are/what is your reason(s) for using the citizen science website? What are/what is your motive for using the citizen science website?
00.15-00.45	Part 2: Interview: Usability + Acceptability	Flexible Think-aloud method	**Deel 2** Explanation of part, as explained in Appendix B1 think-aloud method was adapted over time into flexible format, since participants struggled a bit with stringent format. **Think-aloud part:** Points of attention for me as interviewer: • Keep remembering people to say out loud when something about SDV catches your attention. • Give the participant freedom to explore. • If participant is stuck give him or her the next thing or task to explore. Steps that needed to be undertaken before interview:

			1. Screens of outlook mail with link to test-questionnaire) and landing page are shared with the participants. Also make sure that researchers are not automatically logged-in into SDV. 2. From the landing page the participants are asked to log-in into SDV, the log-in details will be shared by the researchers. 3. When participant is asked to fill out questionnaire, he or she should go to outlook where the link to the questionnaire will be. When participant is finished with questionnaire, he or she will end up on the SDV website. Explanation of the part, more flexible think-aloud method applied in later interviews (see Appendix B, Table B1). Participant gets certain tasks on landingspage, website and questionnaire and is asked to expressed thoughts and experiences with regards to these Features. **Start of part 2, screen and controls given to the participant** Tasks given to the participant: • Going to the landingspage of SDV • Log-in into the SDV website • Explore SDV website freely • Filling-out the questionnaire Bonus (depending on time): • Look at your own data • Look at the group-page • Give feedback about SDV After part, participant can choose whether to leave the shared screens open.
00.45-01.20	Part 3 Interview: Opinions participants about features and aspects SDV explored	Open-ended questions	Part 3: [Explain to the participant that this is the last part of the interview, open-ended questions about the website, landingspage, questionnaire and the research project in general] [Ask if the participants has any questions beforehand]. Questions: [If the participant did not talk about his or her general impression of the website, the participant was asked about his/her general impressions, which parts he/she liked, what he/she would add etc.].

Open-ended questions:

1. Do you need to be able to evaluate the website after February/March/April (start of the research)? If yes/no, why/why not? How often would you like to do this and how would you like to evaluate the website? Would you like to do that for future research projects on SDV as well?

Heuristics (and strategies) used to inspire question:

Emphasize with the user's frame of reference (strategy: Provide ongoing opportunities for user feedback and input)

2. Do you need explanation on the website? (for example, you can think of an explanation about why research is being done into RA and fatigue, why you are asked to fill in a certain questionnaire or why you should press a certain button).

Heuristics (and strategies) used to inspire question:

Provide meaningful rationale (strategy: provide optional levels of explanatory detail)

3. Do you need to be able to set preferences on the website yourself? For example, you can think of changing when you receive notifications from the website for, for example, completing questionnaires, how you receive the link to a questionnaire or whether you can choose which of your data that you have shared appears in a graph? [format of questions evolved during data-collection process, most of these questions turned into do you value…]

Heuristics (and strategies) used to inspire question:

Communicate in autonomy-supportive rather than controlling ways (strategy: provide controls over notifications and communication)

4. Do you think it is important that you can share data/data with other people with RA [to a high degree] why do you think this is important? (And do you also find it interesting, for example, to compare your own data with others?) [to a low degree], why do you think it is less important? Would you then prefer the option that only parts of your data are visible to others or only to the researchers? How much control would you like to have over the data/data you share? [format of questions evolved during data-collection process, most of these questions turned into do you value…]

Heuristics (and strategies) used to inspire question:

Support caring for others (strategy: provide opportunities to contribute or share with others)

5. What do you think of the language/tone used for the text on the website, on the landingspage and with the questionnaire(s)?

[if it could be done differently, what could be done differently?]

Heuristics (and strategies) used to inspire question:

Communicate in autonomy-supportive rather than controlling ways (strategy: provide feedback and guidance rather than directives)

6. How can the website boost your motivation (i.e. the urge to use it more often or want to use it more often)? If difficult: would you like to receive a daily/weekly update of the research, that you can save points, that you get encouragement from researchers, etc.?

Heuristics and strategies used to inspire question:

Ensure rewards are autonomy supportive (strategy: focus on process rather than outcomes)

7. Does using the website cost you a lot of energy? If so, what makes the website cost you a lot of energy? If not, what makes the website cost you little energy? How could we possibly improve this?

Heuristics (and strategies) used to inspire question:

Support mindful attention (strategies: simplify the interface to support focus/minimize interruptions)

8. Do you think the website has all the features you could want? If so, which ones are particularly valuable to you? If not, which one are you still missing and why is it important?

Heuristics (and strategies) used to inspire question:

Emphasize with the user's frame of reference (strategy: Provide ongoing opportunities for user feedback and input)

9. As the website is now set up, do you think this will give you the insight you are looking for? If not, what might need to be added? (information/graphs, etc). If so, what do you think will give you the most insight?

Heuristics (and strategies) used to inspire question:

Provide non-evaluative feedback (strategy: provide informational feedback)

10. Would you like to be kept informed of the progress of the research? If so, what would you like to know about the progress of the research (if this is stated on the website)? If not, what is your reason for this?

Heuristics (and strategies) used to inspire question:

Support a sense of belonging (strategy: make the community salient)

11. Would you like to be kept informed of your own research progress? If so, what would you like to know about your own progress in the research (if stated on the website)? If not, what is your reason for this?

Heuristics (and strategies) used to inspire question:

Provide non-evaluative feedback (strategy: provide informational feedback)

12. Would you like to be kept informed about the progress of other participants in this study? If so, what would you like to know about the other participants in this study (if this is stated on the website)? If not, what is your reason for this?

Heuristics (and strategies) used to inspire question:

Support a sense of belonging (strategy: make the community salient)

13. Do you feel like you are part of a group? If yes/no, do you like it? Why do you think this is important and why not? Do you need the website to create a sense of belonging and community among participants? If so, why? And how could we create this? If not, why not?

Heuristics (and strategies) used to inspire question:

Support caring for others (strategy: provide opportunities to contribute or share with others/make the community salient)

14. Do you think that the way the website now stands that you will use it on a constant basis? If so, what makes that so? And how often and in what way? About what? If not, why not? If not, why? And what would you need from the researchers/website to continue using the website on a constant basis? (e.g. an update from researchers on how the research is going? What would this look like?)

Heuristics (and strategies) used to inspire question:

Ensure rewards are autonomy supportive (strategy: focus on process rather than outcomes)

15. The researchers want to place a section on the landing page where you have the opportunity to contribute new research ideas, what do you think?

Heuristics (and strategies) used to inspire question:

Support caring for others (strategy: provide opportunities to contribute or share with others

[Thank participant for input, if not yet really discussed, some of the bonus-questions below were asked]:

1. Is the website as you expected? (If yes or no, why or not).

2. How will you use the website? (only for filling in the questions or also for other things such as checking the answers of others or checking the progress of others?)

3. What benefits could it have for you to use the website more often?

4. What possible disadvantages could there be for you to using the website more often? /negative consequences? (e.g. comparing with others might make me feel bad/negative of myself)

			5. At the moment there is of course only one investigation, as we are still in the start-up phase. What frequency of surveys would you like in terms of offer? Do you want to be able to participate in several projects at the same time, or would you rather see a longer period between 2 studies? In what way would you like the website to have an impact on living with RA? How would you like the website to influence your life with RA?
01.20-1.30	Questions + Closing		**Closing** [Thank participant – ask if he or she wants to receive a summary of the results – explain that participant receives coupon worth 10 euros, ask how the participant found the interview – final questions from the participants].

Appendix B: Decision trails, coding scheme and reflexive journal

Appendices Data-analysis

Table B1.

Coding scheme data-analysis RQ 2

Concept	Definition
User-friendliness	Answers reflecting the opinions of the participants about features and aspects that influence the ease-of-use of the SDV website, landingspage and questionnaires.
Accessibility	Answers reflecting opinions of the participants about features and aspects of SDV relating to accessibility of the website, such as colors, lay-out and clarity of the interface.
Evaluation	Answers reflecting the opinions of participants about having the opportunity to evaluate SDV during and/or after the collaborative research project (of three weeks) on fatigue and RA, and for future collaborative research projects on SDV.
Explanation and information	Answers reflecting the opinions of participants about the features and aspects of SDV that give information and explanation (e.g., little *i* to explain what a question in a questionnaire means).
Notifications	Answers reflecting opinions of participants about the notification system used on SDV, as well as the opinions of the participants about having the choice to set their own preferences regarding notifications on the SDV website.
Sharing and/or comparing data	Answers reflecting the opinions about the value of being able to share and compare data from SDV with other participants of SDV and how they would want to do this.
Language and tone	Answers reflecting the opinions about the participants about the language and tone used on SDV, and which kind of language and tone they prefer for SDV.
Consistent use	Answers reflecting the opinion of participants about possible new features and aspects that can be taken into account in order to stimulate consistent use of SDV (during the three-week research period as well in future research projects).
Energy	Answers reflecting the opinions about how much energy it costed for the participants to use (test) SDV.
Community	Answers reflecting as well as the opinions of the participants about whether they valued experiencing that community-feel (a sense of belonging) when using SDV. And how this sense of community could be created on SDV (if they found it to be valuable).
Social features	Answers reflecting the opinions of participants about having an idea-box added to the SDV landingspage (new possible feature), and possible other suggestions for social features.

Learning	Answers reflecting the opinions participants whether SDV provides them with sufficient opportunity to learn (and what could be added to SDV to support them in this regard).

Table B2

Decision-trail interviews

Interview number(s)	Procedure and events	Changes before interview
1	Interview done according to script, think-aloud method strictly utilized. Utilized two outlook mail addresses, one for people to join the link for the starting page of SDV and one including a link with a test-questionnaire Participant struggled with thinking-out loud and was asking questions a lot during think-aloud part about the website and background of the research. Think-aloud asks for a minimum of interaction between the interviewer and participant. But due to many questions, it was decided to ask participant to think-out loud as much as the person could do as well as just answering the questions the participant asked during the think-aloud method to provide more clarity.	Script was adapted based on input/feedback gathered during test-interview. Mostly technical components were changed.
2	Open-ended questions in script adapted based on feedback session with supervisors of the thesis. More probes were added and the questions were formulated in a more open manner. When the participant got control over screen, the participant struggled to scroll down the page, researcher helped participant with controlling the website. Also found out that one outlook account was sufficient enough since the procedure of receiving a link and then going to the starting page of SDV was deemed unnecessary and did not match with real-life use.	In interview 2 it was decided to tell the participant more about background research and the workings of the website. Answering these Questions helps in gathering more input about website. Participant was also informed that he/she could ask questions during any part of the interview (also during the think-aloud part). Thus, a more flexible think-aloud method was adapted. Meaning thinking-out loud as much as possible, participant not reminded anymore to think-out loud all the time.
3 till 6	Changes were made and script for questions utilized in interview 2 was used for interview 3 till 6. Till then a standardized example questionnaire was used for the think-aloud part of the interview, from interview 6 onwards a new questionnaire was implemented.	Decided that if person would be doing the Zoom-interview on his or her phone or had trouble with controlling the screen, we as researchers were allowed to control the website and in that case ask the participant to tell the researchers were they should click or scroll. Only two tabs on the screen were open: one with the email including a questionnaire link and the starting page of SDV.
6	Same procedure utilized as before on interview 3 till 6 with slight changes (see ‘changes before interview’).	Daily questionnaire which the participants will fill out during the actual research on SDV was implemented from interview 6 onwards. This was done because the researchers of TOPFIT Citizenlab believed this would help gather more valuable input about the usability of the website for the actual research on the website.
7 till 10	Same procedure utilized as before on interview 3 till 6 with slight changes (see ‘changes before interview’).	From interview 7 onwards it was decided to mention in the invitation email for the interviews, participants would be asked if they could do their interviews on their laptop of computer. Because it was noticed during interview 6 and 7 that if people were not able to really scroll down the website or control it, it would impact the amount of feedback they actually would be able to give about the usability of the website.

Table B3

Reflexive journal

During the research process, I had a place where I made notes about things during the research process which were noteworthy, needed improving or were going well. Important notes are displayed in this table.

Phase of research process	Date	Notes
Preparing script/interviews	(around) 10-12-2021	Points of improvement during the making of the interview script: - Could have used more literature for the making of the interview script, especially regarding the questions relating to the SDT. - Focusing more on making the script out of what do I want to know? Instead of looking (only) into the literature for types of questions.
Preparing script/interviews: pilot interview	15-12-2021	Points of improvements after doing the pilot interview: - Make the questions fit a bit more to the user-group, some of the questions were hard to understand. - Use more probes and ask less suggestive style questions, make them more open. Positive point from doing the pilot interview: - Gave a lot of confidence for doing the actual interviews. - Gave insight in the technical side of things (which screen to share, when to start the recording).
Data collection, first three interviews have been done	Between 17-12 and 22-12 2021	Points of improvements after doing the first three interviews: - The first participant had a lot of questions regarding the set-up of the research project on fatigue and RA and SDV itself. Decided that for the next interviews we would give more explanation beforehand, as well as when participants had questions during the interview. Even during the think-aloud part. - The first three interviews consisted of questions which were asked in suggestive ways, thinking about changing reformulating the questions a bit so that they are easier to ask.
Data collection, evaluating the first interviews with second supervisor	23-12-2021	Discussed with the supervisor: - How much changes can you make during the data-collection process, for example to the interviews script and whether we could alter the think-aloud method used. - Received some feedback: maybe ask more general questions about the experiences with SDV, as well as again making the questions more easy for the participants to understand. - Transcript was read by the supervisor, she stated that it would be useful to read and mark some important parts of the interview already. Also to make a clear distinguishment in which parts of the interviews are going to answer which research question.
Data collection	13-01-2022 and	Some reflection on interview 6 and 7, as well as shortly on the interviews before that: - During the first five interviews (especially the first three) more suggestive questions were asked. This changed and got better after let’s say the third interview.

	14-01-2022	- In interviews 6 and 7 the participants were less willing (or capable to talk, these were difficult interviews. Tried to use probes as much as possible, felt like we got a lot of socially desirable questions.
Data collection	Between 18-01 and 20-01	Last few interviews were a bit longer and the participants talked a lot, hard to distinguish important and less important aspects mentioned by participants.
Data-analysis	Started from 15-12-2021 onwards	Points of improvement: - Could have prepared the data-analysis a bit better. From planning when to transcribe which interviews to how I was actually going to analyze the data. When using Atlas, I should be more precise and detailed in marking statements, instead of marking an entire statement of a participant, I should have marked more precise. Made dividing answers over codes easier.
Data-analysis/writing up the results and interpreting the results	28-01-2022 to now	Last notes and points of improvement written down in this phase: - After a while I got to many codes and I did not keep a consistent structure. Required ordering the codes a bit. - Could have kept a more detailed account of ideas that came up during the analysis process, would made drawing-up the results and writing the discussions more easy. - It was useful that I made a distinguishment in codes for RQ 2 in supporting and undermining quotes, made finding the right quotes easier. - Drawing-up the results did cost a lot of work, I think mostly because the codes and themes in Atlas needed some ordering and because I had a hard time distinguishing the important aspects from the data from the less important aspects of the data. Needed to reflect a lot and evaluate a lot on how to draw-up the results in a clear manner. - Should have had more of a clear and structured approach on how to search for literature regarding the discussions.
Greenlight for colloquium, processing feedback supervisors	16-03 till 04-04-2022	- Feedback mainly revolved around RQ 2 and generalizing the results to other contexts beyond only the SDV context. - A lot of adaptations were made to the actual use of the SDT, RQ 2 was adapted. - This changing of the explanation of the actual use of SDV made processing the feedback really stressfull and demanding. Did not get out of my thesis what I wanted in the end.