

# “My patient is looking for some guidance, can I send her to you?”

a qualitative study on active referral of breast cancer patients and collaboration between oncology physiotherapists, Care Sport Connectors and the physical activity sector



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## Abstract

The survival chances of cancer patients are slowly increasing; however, survival causes consequences such as pain and mental issues. Physical activity (PA) has been found effective in reducing these negative effects. Unfortunately, cancer survivors often do not meet the recommended PA guidelines. Therefore, active referral to physical activities may be a solution. The Care Sport Connector can be a facilitator in this chain from primary care to PA. As breast cancer is highly prevalent the research question is as follows: *“Which barriers, facilitators and needs of oncology physiotherapists play a role in active referral of adult female breast cancer survivors by oncology physiotherapists to physical activity outside the health setting after or during rehabilitation?”*

Semi-structured interviews with 13 oncology physiotherapists were held. Purposive selection was done via Onconet in the regions Amsterdam and Nijmegen. Topics were based on the Healthy ALLiances (HALL) framework which conceptualizes the necessary factors for successful (intersectoral) collaboration. Additionally, the study was focused on the community and organizations level of the Social Ecological Model.

Results from the thematic content analysis indicated that participants were not in collaboration with the sports sector or a CSC yet. Major themes of the results consisted of; the need for communication, visibility, and an overview of sports options; barriers being motivation and dependence of the patients, funding, and policies; facilitators being capacities and knowledge; personal relationships, attitude and beliefs being mixed.

Referral seems to be an intricately linked mechanism with the patients, the participant’s (inter)personal factors, institutional factors, and organizational factors at its core. It is suggested that the initiation of collaboration is in the hands of the sports facilities and CSCs, because their low visibility hinders the oncology physiotherapists from connecting with them.

## 1. Background

On the 1st of January 2019 the prevalence of cancer patients in The Netherlands consisted of approximately 578.000 people (Volksgezondheidszorg.info, 2020). Cancer is among the top ten contributors to the burden of disease in The Netherlands (Volksgezondheidszorg.info, 2018). Fortunately, the incidence of cancer is stabilizing (Integraal Kankercentrum Nederland, 2020b) and the survival chances are slowly increasing (Integraal Kankercentrum Nederland, 2020c). However, many cancer survivors still have to cope with lasting damage in daily and social functioning, such as: fatigue, concentration- and memory issues, neuropathy (nerve damage), pain, anxiety (for return of disease) and depression (Vonk et al., 2016).

During- and after rehabilitation, physical activity<sup>1</sup> is recommended as treatment to counteract the negative effects of cancer and cancer treatments. Physical activity (PA) has been studied to have a significant positive effect on many different outcomes, including the consequences of cancer survival (D'Ascenzi et al., 2019). In a meta-analysis including 22 studies on breast-cancer survivors, PA before and after diagnosis was found to be associated with fewer cancer relapse events and lower tumor progression (Lahart et al., 2015). Additionally, they found a decrease in fatigue, anxiety and depression, and an increase in cognitive functioning (Juvet et al., 2017; Lahart et al., 2015; Riedl et al., 2017).

Unfortunately, cancer survivors are often less physically active than adults without cancer. Almost half (23-50% depending on the type of treatment) of the cancer survivors do not meet the recommended guidelines for physical activity due to several individual and interpersonal factors (Irwin et al., 2003). A systematic review by Ormel et al., (2017) found that extensiveness of the surgery, alcohol consumption, family support, skills, and previous exercise adherence were predictors of exercise adherence. Other studies found a strong predictor in knowledge about PA (Clifford et al., 2017) and motivation, with fatigue being the biggest barrier (Frikkel et al., 2020). A study by the Mulier Institute (De Jonge et al., 2019) found that exercising in a group setting is a facilitator as it increases the social support as well as accessibility in terms of a fitting starting level and minimal efforts to sign up, the same was found to be true for cancer patients (Hefferon et al., 2013; Midgaard et al., 2006).

Referral to physical activities by general practitioners (GP) or other healthcare

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<sup>1</sup> "Physical activity is defined as any bodily movement produced by skeletal muscles that results in energy expenditure" (Caspersen et al., 1985). In the current study several forms of physical activity are discussed: organized sports such as fitness, tennis or yoga, and unorganized sports such as hiking, cycling, running or at-home-workouts. Even though physical activities might also include household chores, in this study only organized and unorganized sports are meant by "physical activity" and "physical activities".

professionals can act as a sustainable stimulant to be physically active, probably because referral -and therefore advice- from a professional, is taken more seriously (De Jonge et al., 2019; Patel et al., 2011). However, an exploratory study by the Mulier Institute (Van der Sluys Veer, 2021) discovered that even with referral from a GP, the transition towards sports activities outside the healthcare sector is still too challenging for patients. Thus, GPs often refer to a physiotherapist first to exercise under supervision. Subsequently the physiotherapists can help with the transition towards physical activities outside the healthcare sector. Nevertheless, even though many survivors experience the benefits of physical activity, they seem unable to implement physical activity into their post-rehabilitation life (Friedenreich et al., 2009).

In the Netherlands the Care Sports Connectors<sup>2</sup> (CSC) (in Dutch: *Buurtsportcoach* with a focus on healthcare) can connect the healthcare sector to the local sports sector<sup>3</sup> (figure 1) (Leenaars et al., 2016a). CSCs can help patients to discover a physical activity that fits their preferences and needs (Schurink-van 't Klooster et al., 2019). However, GPs are often unaware of the existence of CSCs or the local physical activities. As a result, GPs only refer to a physiotherapist for PA, which causes the patients to stay in the healthcare sector to be physically active (De Jonge et al., 2019). In addition, physiotherapists are also not always familiar with local physical activities or CSCs, which keeps them from referring patients (Graham et al., 2007).

Aside from not knowing where to refer to, GPs and physiotherapists often use a passive type of referral too, by providing a pamphlet or giving advice. However, active referral seems to be more successful. This referral type consists of taking the time to help patients find appropriate resources. It might even involve making a phone call or planning an intake (with the party referred to), together with the patient, to ensure the start of a physical activity (e.g., outside the healthcare sector) (Boston University, n.d.).

As a result of passive referral, many patients seem to get lost outside the health sector post-rehabilitation as they are either not referred to regular organized sports groups or they do not commit to physical activities after rehabilitation is finished. Partly due to this, PA levels are

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<sup>2</sup> In 2012 the Dutch Ministry of Health, Welfare and Sport introduced the Neighborhood Sports Coach (NSC), with a broker role. Part of this broker role is to connect the primary care sector (i.e., GP, physiotherapist) and the PA sector (i.e., sports clubs, fitness centers, walking groups) in order to guide primary care patients into local sports facilities. NSCs with this particular line of work are also called Care Sports Connectors (CSC). NSCs (and therefore CSCs) are 40% funded by the state and 60% funded by the municipality and/or other local organizations (Ministerie van Volksgezondheid, Welzijn en Sport, 2011).

<sup>3</sup> According to a previous study done by Leenaars, et al. (2016b) collaboration between CSCs and primary care professionals in the referral of patients can be seen as a chain (figure 1). Primary care professionals refer patients to the CSCs and the CSCs guide them towards local physical activities.

fairly low in cancer survivors (Mason et al., 2013; Thraen-Borowski et al., 2017). As remaining active is crucial for cancer survivors (D'Ascenzi et al., 2019; Lahart et al., 2015) it is necessary to gain insight in the factors and needs that play a role in the active referral of cancer survivors by oncology physiotherapists to physical activity outside healthcare setting, during or at the end of rehabilitation.

A study by Din et al. (2014) found that there is often too little communication between healthcare- and sports professionals. Overall, the lack of guidance by a connector between the organizations leads to a collaboration barrier (Din et al., 2014). These factors on organizational and community levels have not been studied as much as the individual factors contributing to health behavior (Clifford et al., 2017; Frikkel et al., 2020; Ormel et al., 2017). Therefore, the organizational and community perspective of the Social Ecological Model (SEM) (appendix A) by Bronfenbrenner (1994) is used in this study. This model explains human health behavior based on various layers of influence outside of the individual. As the active referral between oncology physiotherapists and the sports sector or CSC has an indirect influence on the breast cancer patient, this is part of the organizational layer. Additionally, the fourth layer focuses on the collaboration between CSC and physiotherapists as organizations. To further understand the relations and collaboration within the organizational and community layer of the SEM, the Healthy ALLiances (HALL) framework (Koelen et al., 2012) (appendix B) is used. This framework conceptualizes the necessary factors for successful (intersectoral) collaboration in the clusters (inter)personal, institutional, and organizational, and can provide insights into the mechanisms that underlie the referral chain.

There might be a difference in barriers and facilitators for actively referring cancer survivors to sports outside healthcare, depending on the cancer type and its specific (physical) consequences (Smith et al., 2017). As female breast cancer has a prevalence of 118.000 women in The Netherlands, this study will focus on the experience of oncology physiotherapists, regarding their work with female breast cancer survivors (Integraal Kankercentrum Nederland, 2020a; Volksgezondheidszorg.info, 2020).

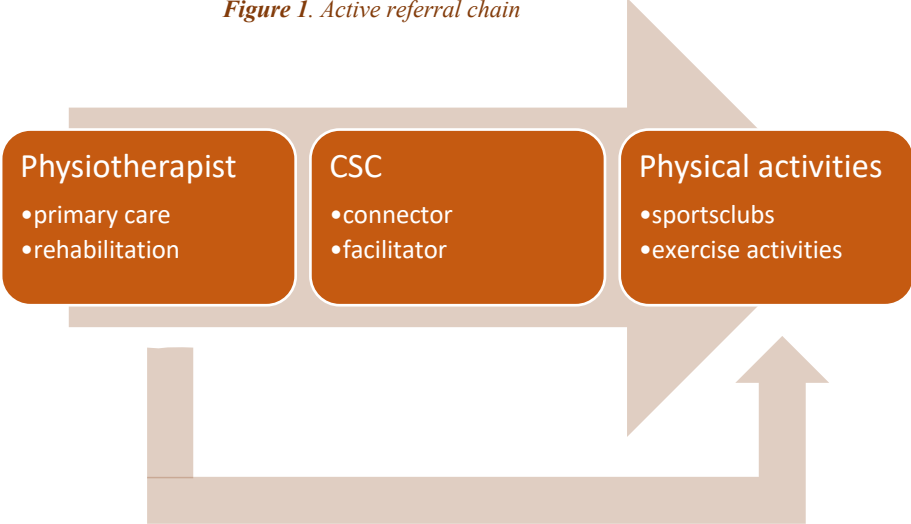
## **1.1 Study aim**

The aim of this study is to identify the barriers, facilitators and needs from the oncology physiotherapists' perspective, in the active referral of adult female breast cancer survivors to physical activity outside the health setting. This, to contribute to the way both oncology physiotherapists and CSCs can help the patient group to remain physically active outside the

health sector, during and after rehabilitation.

The research question is formulated as follows: “Which barriers, facilitators and needs of oncology physiotherapists play a role in active referral of adult female breast cancer survivors by oncology physiotherapists to physical activity outside the health setting after or during rehabilitation?”

Figure 1. Active referral chain



## 2. Method

### 2.1 Design

To gain a comprehensive insight into the perceptions of oncology physiotherapists on active referral to PA outside healthcare, possibly via a CSC, a qualitative study design was used. The study has an exploratory aim and was therefore conducted using semi-structured interviews and both a deductive and inductive approach to ensure enough room for individual experiences and perspectives.

### 2.2 Setting and participant selection

The intention was to have 15 participants (or until saturation was met). The oncology physiotherapists were selected through purposive sampling via the Onconet website (Onconet, 2021). Two regions were chosen in collaboration with researchers from the NKI/Radboud UMC, to ensure the collection of data that was meaningful to their research as well. The used regions were the municipalities Nijmegen and Amsterdam, with a surrounding range of 10km. Within these regions the Healthcare Search Engine (in Dutch: *Zorgzoeker*) selected several (14) practices and their (21) physiotherapists.

After the first selection was completed, a second selection was done using the practice's website and the municipalities' website to determine whether the physiotherapists should be included. Selection criteria for the participants were, 1. Oncology physiotherapist; 2. Working in a municipality with a CSC present; 3. Working with a majority of breast cancer patients. In case there were more than two oncology physiotherapists working at one practice, only two physiotherapists were chosen at random to ensure that new themes emerged from the data.

After selection, 18 physiotherapists were sent an e-mail, consisting of a brief invitation and more elaborate information on the study in the attachment. The physiotherapists were asked to reply to the e-mail if they agreed to participate. After a week the physiotherapists who did not reply were called through their practice's phone number. Three contacted physiotherapists had been replaced by new physiotherapists in the practice, which meant the invite was re-sent to the new oncology physiotherapist. Out of the 21 physiotherapists that have been approached, 13 agreed to participate and 8 refused the invitation.

## **2.5 Ethics**

After accepting the invitation to participate in the study, participants were sent an informed consent (appendix E), where they gave permission to record the interview, which had to be signed before the interview took place. Participation was voluntary and all participants were free to withdraw their participation if they so wished.

All documents concerning the participants (e.g., invitation, informed consent, interview guide) have been reviewed before use by two researchers of the Mulier Institute and two members of the board of Onconet. Interview recordings will be deleted six months after finishing the study.

All names of persons, practices and places were made anonymous in the transcription process and names of the participants were changed into codenames ranging from FY1 to FY13. These codenames were used in all products of the interviews: transcripts, recordings, informed consents. One document consisting of the contact information of the participants was kept, secured with a password lock. This document was also the only overview of the codenames linked to the participants.

## **2.3 Data collection**

### ***2.3.1 Data collection procedure***

To gain a perspective on barriers, facilitators and needs in the active referral by oncology physiotherapists, the selected participants were interviewed in April and May 2021. The interviews were conducted in Dutch, were semi-structured, lasted for 30 to 70 minutes and were done one-on-one via online Microsoft Teams (Microsoft, 2021) calls, as COVID-19 regulations made it difficult to visit the participants. Before conducting the interviews, they were informed about audio recording and anonymity during the data analysis and informed consents were signed by all participants. Afterwards, the audio recordings were used to transcribe the interviews.

### ***2.3.2 Data collection topics: HALL framework***

The interview started with an introduction of the study and a moment for the interviewer and

participant to introduce themselves and to build rapport.

To further understand the relations and organization the Healthy ALLiances (HALL) framework (figure 2) was used to create themes for the interviews and the analysis. This framework can provide insights into the mechanisms that underlie the referral chain. Secondly, the framework aids in a deeper understanding of the interrelatedness of the concepts as the HALL framework aims to conceptualize the necessary factors for successful (intersectoral) collaboration. In order to do this, the framework includes three clusters of factors that influence the success of collaboration: 1. Institutional factors, 2. Interpersonal factors, 3. Organizational factors of the alliance (or collaboration). For a more elaborate explanation of the HALL framework, see appendix B.

Initially, the themes from cluster 2 and 3 of this framework were used to create a first conceptual topic list with specified questions per HALL framework theme, as these clusters were deemed most important and most influenceable by the participants. Subsequently the questions were changed to more broad, open-ended questions, also including the three factors of the research question: barriers, facilitators and needs that play a role in active referral. The questions ranged from experiences and perspectives to needs and practical solutions regarding referral to sports facilities outside the health sector (Appendix C). The interview guide was not used to ask the questions in a literal sense from paper, but to guide the interview and to remind the researchers what topics should be asked about and how.

After eight interviews, institutional themes emerged from the first round of analysis, which caused a new question about the influence of policy and funding to be added to the last

*Figure 2. Healthy ALLiances framework*



five interviews.

Table 1 presents an overview of the questions and the topics it originated from. Bold fonts represent topics from the research question, italic represents the HALL framework themes. The presentation of Table 1 was used to clarify with which topics in mind the question was created, with this, further explanation was deemed unnecessary.

*Table 1. Topic list interview questions*

<b>Topics from research question</b> <i>Topics from HALL framework</i>	<b>Interview question</b>
<b>Unthemed</b>	“What is your experience with active referral of breast cancer survivors to sports facilities?”
<b>Care Sports Connector</b> <i>Visibility</i>	“Do you know what a CSC is?” If applicable: “What is needed to increase the visibility of the CSC?”
<i>Building on capacities, attitudes &amp; beliefs, shared mission</i>	“What is the added value of a CSC according to you?”
<i>(Needs) Roles &amp; responsibilities, building on capacities, attitudes &amp; beliefs</i>	“What CSC role is of more added value to you: the connector or the performer?”
<b>Barriers, facilitators Care Sports Connector</b> <i>Attitudes &amp; beliefs, relationships, social identity</i>	“What is your view on collaborating with/ referring to a CSC?”
<b>Needs</b> <i>Communication structure, management, flexible time frames, visibility</i>	“What is needed for active referral/collaboration with the CSC?”
<i>Communication structure, roles &amp; responsibilities, building on capacities, flexible time frame, funding, planning horizons, policy, relationships, management, visibility, attitudes &amp; beliefs</i>	“What would the ideal collaboration with CSC/sports facilities look like?”
<b>Barriers, facilitators, added to last five interviews</b> <i>Funding, policy, planning horizons</i>	“What role does funding, policy or future plans play in the decision to actively refer patients to physical activity outside healthcare?”
<b>Barriers, facilitators, needs</b> <i>Roles &amp; responsibilities, building on capacities, flexible time frame, funding, planning horizons, policy, self-efficacy</i>	“Whose role is it to motivate patients to be physically active?”
<i>Funding, planning horizons, policy, flexible time frame, building on capacities</i>	“What is necessary to sustainably implement PA in the patient’s life?”

**Unthemed, probe for possible new themes**

“Do you have any questions yourself?”  
“Do you want to add anything else?”

## **2.4 Data analysis**

The interviews were recorded and transcribed intelligent verbatim style, using the transcription program F4transkript (Dr. Dresing & Pehl GmbH, 2020).

A thematic content analysis was used with a combination of deductive and inductive approaches (Green & Thorogood, 2004); deductive by fitting the HALL-framework themes and the themes from the research question to the data, inductive by allowing the data to determine new themes. Additionally, analyzing the transcripts was done with a semantic approach: analyzing the explicit content i.e., the stated opinions and perspectives (Liamputtong, 2019).

The interview transcripts were coded using the program MAXQDA (VERBI Software, 2019). First, the transcripts were read repeatedly to become familiar with the texts and were open coded by attaching in vivo codes or keywords to relevant fragments of the text. Three transcripts were read independently and coded by at least two individual researchers and discussed until consensus was met. Then, the codes were structured by axial coding, identifying relationships between the codes in the structure of the HALL framework, or when necessary, creating a new code group. Lastly, in the selective coding phase, the codes within the HALL framework or the new code group were (if possible) grouped into three major themes: barriers, facilitators and needs.

## **2.5 Quality criteria**

To secure the quality of the study, the quality criteria by Frambach et al. (2013) were used in conducting this study. These criteria describe the requirements needed to increase the quality of a study, such as credibility, transferability, dependability, and confirmability. The tools used to meet these criteria are described below.

To increase credibility and confirmability, data analysis was discussed with fellow researchers on several moments during the analyzing stage. Meaning three transcripts were independently read and coded by at least two individual researchers and discussed until consensus was met. In addition, when uncertain about a part of the coding process, the fellow researchers were consulted.

Dependability was increased by collecting as much data as possible within the

timeframe and sample range, having data analysis inform the data collection process, remaining flexible and open towards the process and topic and through re-examining data using insights gained from the analysis.

During the whole process an audit trail was kept, with a reflexivity diary used to reflect upon the interviews and the researcher's experience, to be transparent about the researcher's role and influence. The reflections (appendix D) were used to understand why some data is chosen and to minimize the tendency to value one interview over the other, thus, to increase confirmability.

### 3. Results

After participant selection, 13 out of 21 oncology physiotherapists agreed to participate. Reasons not to participate were mostly; no longer working at the practice, being too busy with work or personal issues, or being new in the practice and not having enough experience with the topic. Reasons to participate varied from: having research experience and understanding the difficulties of obtaining enough participants, to being interested in the topic or having a lot of experience with the subject. All participants were female, six participants worked in the Nijmegen region, seven in the Amsterdam region. Their working experience ranged from 3 to 44 years and most participants liked to exercise (see table 2).

*Table 2. Descriptive table of the 13 participants*

<b>Participant code</b>	<b>Working experience (years)</b>	<b>Affinity with sports</b>
<b>FY1</b>	16	Rides bicycle to work, likes to hike
<b>FY2</b>	3	Likes to be active, love-hate relationship with running
<b>FY3</b>	41	Has done sports on a high level
<b>FY4</b>	28	Exercises on a regular level
<b>FY5</b>	20	Fitness and cycling
<b>FY6</b>	6	Running, swimming, boxing, and hiking
<b>FY7</b>	28	Yoga, tennis, has been a PE teacher
<b>FY8</b>	30	Likes to stay active
<b>FY9</b>	15	Likes to exercise, does athletics and coaches as well
<b>FY10</b>	44	Was a high-level tennis player, exercises on a regular level
<b>FY11</b>	36	Tennis, running, mountain biking
<b>FY12</b>	40	Likes to exercise, staying active is important
<b>FY13</b>	10	Was a high-level volleyball player

The interviews offered an insight into the research question “Which barriers, facilitators and needs play a role in active referral of adult female breast cancer survivors by oncology physiotherapists to physical activity outside the health setting after or during rehabilitation?” For a summary of the results, tables 3 and 4 present the barriers, facilitators and needs of oncology physiotherapists that play a role in active referral. The themes are further described in the following paragraphs, a definition of the new subthemes can be found in appendix F and the original Dutch list of codes can be found in appendix G.

*Table 3. Oncology physiotherapists' perception of barriers and facilitators in active referral*

<b>Theme</b>	<b>Subtheme</b>	<b><u>Barriers</u></b>	<b><u>Facilitators</u></b>
<b>Patients (new)*</b>	<i>Motivation</i>	Return to old habits Not reaching old fitness level Time/money	Previous PA experience Enjoying exercise Exercising in a group Fellow-sufferers Physical progress
	<i>Dependence</i>	Scared to exercise without supervision	
<b>Organizational</b>	<i>Communication structures</i>	No contact with CSC	Accessible methods of communication with PA sector/CSC
	<i>Roles and responsibilities</i>	Referral ≠ task of physiotherapists	Guidance = task of physiotherapists
	<i>Knowledge of CSC/trainer (new)*</i>	Doubts about qualifications CSC/trainer	Knowledge unnecessary, patients know their limits
	<i>Building on capacities</i>		CSC is solution to lack of time CSC's accessibility to PA Network of CSCs/PA
	<i>Visibility</i>	No contact yet with CSC/PA	Word of mouth Knowing and success = referrals
	<i>Overview of options (new)*</i>		Current supply = sufficient Supply = known by physiotherapist/patient
<b>(Inter)personal</b>	<i>Relationships</i>	Tailored approach Hard to let go of patients	Tailored approach Faith in CSC/trainer
	<i>Attitude &amp; beliefs</i>	View on patient and PA Added value of CSC	View on patient and PA Added value of CSC

<b>Institutional</b>	<i>Policy</i>	Internal sports facilities	Internal sports facilities
	<i>Funding</i>	Time paid by insurance	

\*New themes, added to the existing themes of the HALL framework

*Table 4. Oncology physiotherapists' perception of needs to start active referral*

<b>Theme</b>	<b>Subtheme</b>	<b><u>Needs</u></b>
<b>Patients (new)*</b>	<i>Motivation</i>	Educate patients on importance of PA
		Tailored PA
<b>Organizational</b>	<i>Roles and responsibilities</i>	Accessibility (location, duration, financial)
		Tasks assigned to CSC/trainer
	Agree upon task division	
	<i>Visibility</i>	Active acquisition of patients by PA sector/CSC
		Initiative of physiotherapist
	<i>Communication structures</i>	Visibility due to CSC
		Needs for collaboration
Design of collaboration		
<b>(Inter)personal</b>	<i>Overview of options (new)*</i>	Feedback from patient
		Feedback from CSC
	<i>Relationships</i>	Overview of PA options made by CSCs
		Tailored approach
<i>Attitude &amp; beliefs</i>	Added value of CSC	

\*New themes, added to the existing themes of the HALL framework

### **3.1 Referral dependent on motivation and dependence of the patient group**

The participants found the patients to be an important factor in the active referral to PA outside healthcare, especially their motivation.

According to the oncology physiotherapists, motivation of the patient group is the biggest determining factor in patients independently taking on physical activities. Referral of a patient is therefore based on whether the patient's motivation to be physically active must be and can be influenced. When a patient has previous experience with physical activity they will usually return to their old sports or exercise habits, therefore they do not need a referral, according to the oncology physiotherapists.

FY1 "What I usually see is the people that are already a fanatic sign up (...) and they usually go back to the sports they already did. (...) But the group that is sent by their doctor (...) that is usually a very tough group."

However, when inexperienced patients learn the importance of being physically active, they can be encouraged to start exercising and they will get referred. Experiencing physical progress, positive effects, having fun, a positive social environment or exercising with a fellow-sufferer can all facilitate an increased motivation.

FY4 “I notice that people really stay more motivated when they exercise with someone else. And at the beginning it is nice if they are fellow-sufferers.”

Nevertheless, some patients do not reach their previous physical fitness level anymore, due to physical complaints, which lowers their motivation. Others are seen to fall back into their old pattern or are scared off by the prospect of exercising unsupervised.

FY7 “Well, the people who are looking for more guidance, or looking for someone to hold their hand, those are the ones that usually stay.”

The participants concluded that the following is needed to stay motivated: physical activity that fits their needs and preferences, accessibility in level of PA, time and location, knowledge and understanding about their own bodies and the importance of PA. Lastly, the need for affordable sports is high as many patients get demotivated by the cost. Participants mentioned that, ultimately, the patient is -and needs to be- responsible for their own lifestyle. They have had enough practice to exercise unsupervised and need to trust their own skills and knowledge. Patients are taught to know their limits and, if need be, they can always get in touch with their physiotherapist again.

FY11 “You tell them that they should come back when they have physical complaints, the door is always open. Some of them do, others don't, but in the end it's their own responsibility to stay active.”

Patients who lack motivation are seen as the most difficult yet most important group to refer to physical activities or a CSC. Hence, the following results will be based on the patient group that is less motivated, or not motivated at all, and the motivated patients are disregarded.

### **3.2 Organizational themes for successful referral**

#### ***3.2.1 The influence of roles and responsibilities, capacities, and knowledge***

Participants have stated not to be in contact with a CSC, or to be working with a sports club. However, they have referred their patients to several physical activities, such as: (oncology) swimming groups, nearby gyms, sports clubs, medical training programs in their practice, the “Counterforce” (in Dutch “Tegenkracht”) program, or home-exercise apps. Most referrals are passive and done via advice or flyer. When the supply of local physical activities is high and visible to the patient, referral can even be unnecessary. Since the participants do not have a

collaboration with a CSC or physical activities outside of healthcare yet, the following results are based on their opinion of the ideal collaboration and their preferences on how to make it work.

The participants describe their main task to be educating the patient on the importance of physical activity. They are responsible for guiding, teaching, and coaching the patient until the end of the treatment course, after that their responsibility stops. Tasks they assign to- and need from the CSCs: supporting patients with financial arrangements, initiating new sports groups (meet the demand), and guiding the patients out of healthcare into regular physical activities. Most important is to agree upon task division, as this is seen to be the best way to determine what the roles and responsibilities of both parties entail.

FY2 “Of course, during the personal introduction we’d have to agree upon some things, like how are we going to do this, what do you have to offer, what do you need from me, what do I need from you? Really agree upon task division and those things.”

During the interviews, a few participants mentioned the CSC’s capacities to be a facilitator in the referral of patients. However, opinions on the sports coach’s/CSC’s (medical) knowledge and skills varied. Several participants described the lack of medical knowledge to be a barrier in referring patients to CSCs or physical activities, as they might not know how to train an ex-cancer patient and which residual symptoms are common or harmful. Others just want the sports coach/CSC to contact them in case of questions and want the patients to know and respect their limits or consult a healthcare professional.

FY5 “Especially the ones with some scar tissue, you shouldn’t let them do all kinds of hand exercises, or that someone is telling them ‘come on, you can do this!’ and that it results in more damage. Because usually in the gyms it’s easier to pass your limits (...) so if there is more education and knowledge, more faith in them, then I’d refer more often.

### ***3.2.2 The big need for visibility, communication, and an overview of options***

The main subthemes in the interviews have been visibility, communication, and the new subtheme: overview of options.

Participants have difficulty finding the CSCs/physical activities and therefore want them to take the first step towards getting acquainted. When they are in contact with a CSC or sports coach and they have positive experiences with referring to them, the acquaintance and word of mouth would be enough to keep referring to them. The biggest barrier is not being in

contact with a CSC/sports coach, even though not a lot of communication is needed to collaborate. The participants stress the need for a personal introduction meeting, to start the collaboration. During this meeting they would like to agree upon the design of their collaboration and the communication media. The biggest need is secured accessible communication, via media such as e-mail, Care-mail (in Dutch: Zorgmail), phone calls, or the Siilo app (a secured texting app). This helps with keeping the lines of communication as short as possible, which is a communicative facilitator and will make an active referral easier as they can communicate some background information on the patient.

FY4 "Short communication lines, truly know each other, for example that you text someone via Siilo and you can easily communicate to them 'I have someone who's looking for some guidance, can I send her to you?'"

The participants would even like to invite a sports coach/CSC to meet the patient in the practice, to ensure visibility and approachability. They would like feedback on the outcome of referrals from either the sports coach/CSC or the patient itself. However, a few participants state their preference to passive referral, they only need a flyer, contact info or website to refer their patients to and do not need further contact with the other party.

FY1 "Usually I communicate that people want that. If people are indecisive, I always ask [the coach] whether they turned up or not, because if not I always call them [the patient] and ask 'how are you? Did you start?' And they would say 'I haven't started yet...'. And then you can discuss this with them hoping they will start doing something."

The participants expressed their need for an overview of options for physical activities outside healthcare. They would like to know what their municipality has to offer and where to refer to. Being able to refer to a CSC is seen as an asset but being able to refer directly to physical activities with minimum effort seems to be a bigger facilitator for active referral.

FY13 "If I receive it [an overview] on a silver platter in my inbox, which I can print and give to my patients, that would be a lot easier."

### **3.3 The role of (inter)personal and institutional factors**

#### ***3.3.1 The value of relationships and the impact of attitude & beliefs***

Participants admit to keeping a patient too long in their care, as the timing of referral can be difficult and their trust in the sports facilities is not always high enough. They state the importance of a relationship of trust with the sports coach/CSC and want to know their skills and knowledge, as well as how the sports coach/CSC will treat their patients.

FY5 “That one person is not the other. (...) of course, you have those sports groups with a common factor, but still you have them [patients] individually, so if you are going to generalize, like telling them you should go there because there are more like you... (...) [It is important] that those personal things are really listened to.”

The participants stated that they find it very important that their patients stay active. They encourage all oncology patients to continue exercising, as it is beneficial to their body and mind. According to them there are few reasons not to take on physical activity, even with severe physical complaints some type of exercise is still possible. Several participants also stress that physical activity can and should take place outside healthcare, to decrease medicalization of the patient’s life and let them live their lives again.

FY12 “Yes, it is something that also helps you relax mentally. Of course, that is also an important part. What I always see with these patients is that the physical recovery is always ahead of the mental recovery. They often struggle with anxiety and anxiety for the future and that comes and goes. So, for them to find something that helps them relax mentally, I think that is very important. (...) Let them just live their life again with things they like. Resume their working life, their family life, choosing a sport.”

The participants discuss the need for PA with their patients, but few of them truly refer them to physical activities. A barrier to active referral is that they do not see it as their job to organize the transfer, or actively refer the patients, as that is the patient’s own responsibility and they have given enough advice and guidance in what to do.

FY3 “I do give them some sort of advice or guide, try this or that, but I’m not going to organize it for them.”

When the concept of a CSC was explained the participants were enthusiastic about working with a CSC. It can save time and a CSC has far more knowledge on local physical activities. However, a few were not so keen on deploying the CSCs for motivating the patient group, as they see it as their job and can even enjoy it.

FY5 “I absolutely think that could be of added value, because the CSC would be much better informed [about sports facilities].”

The CSC would come in handy for lowering the threshold to start with physical activities, as they could set up some free classes or a trial period, while also helping and stimulating the patient transfer out of healthcare and into regular sports, in the form of an assisted steppingstone.

FY1 “I think that when people know that that’s a steppingstone, that it might make it easier to nevertheless get active.”

### ***3.3.2 Funding and policy as indirect influence***

At first, the institutional themes had not been actively used in the interviews, but during data collection some institutional aspects were mentioned.

Participants mentioned that financing and insurance play a role in the mechanisms of referral. Practices are bound by the income from insurance and physiotherapists are only paid for appointments with patients. As these appointments only last 30 minutes, participants feel there is limited time for research on local physical activities or contact with sports coaches/CSCs for an active referral. However, they do use the time to educate patients on PA and to discuss the patient’s preferences and options in physical activities.

FY2 “The barrier is really the financial structures through which I get paid. I get paid by the insurance, I don’t get paid by the practice and that really is a problem, because I can’t just claim a treatment because I also have to justify it towards the insurance company.”

Some patients are not sufficiently insured and must quit physical therapy before experiencing the positive effects or learning the importance of exercise. Therefore, financing structures and insurance policies are seen as barriers in active referral of patients to physical activity outside healthcare. Some practices offer fitness classes to give patients the opportunity to experience sports this way, but this can also hinder patients from seeking physical activity outside a health setting.

#### 4. Discussion

The Oncology physiotherapists interviewed for this study, believe that physical activity is important for their breast cancer patients, in order to stay healthy and to decrease the negative effects of cancer and cancer treatments. However, none of them have an active collaboration with sports coaches/CSCs yet. The participants consider motivating their patients to become physically active as part of their job, but they do not feel responsible for the implementation of physical activities in the patient's lifestyle. Even so, they are open to actively referring the patients to physical activities outside healthcare. According to the oncology physiotherapists, current barriers of active referral are the motivation and financial possibilities of the patient group, consultation time, current funding, and insurance policies. The participant's personal beliefs are seen as both barrier and facilitator in active referral of breast cancer patients. To establish a collaboration, the participants indicate the need for clear communication, better visibility of the physical activities, and more information in the form of an overview of local PA options.

A notable finding in the current study and a study by Leemrijse et al. (2015) is the healthcare professional's attitudes towards promoting PA. Similar to the beliefs of the oncology physiotherapists, physicians believe PA to be important for their patients, however this does not always mean they will actually refer them. Thus, it seems that beliefs and actions might not always add up, or the physicians do not know their options of referral. Most of the participants state that it is not their job to arrange for physical activities to be implemented in the patient's life, which might be the added value of a CSC.

Additionally, the oncology physiotherapists participating in the study believe the patient's motivation has an important role in the referral towards physical activities outside healthcare. These findings are consistent with previous research done by Kunstler et al. (2018) among physiotherapists, and a study of Huijg et al. (2014) among physicians, where a lack of motivation is a barrier for giving advice on increasing PA. The physiotherapists in the study of Kunstler et al. (2018) also stated that they felt they could damage their rapport when discussing PA with their patients, causing them to delay the discussion or to not discuss it at all. This is unfortunate, as the advice of a health professional is known to be taken more seriously (Bird et al., 2019; Birtwistle et al., 2018). In order to keep a good relationship with the patient, they would either have to discuss the topic early on, or a CSC might be a good alternative for the advice of a health professional, to further stimulate the patient.

In addition to this, the patient's financial possibilities are among the barriers mentioned.

This is a known influence on PA participation in many studies (Franco et al., 2015; Venn & Strazdins, 2017). A study by Steenhuis et al. (2009) stated that pricing strategies could lower the barrier to PA, if individual barriers, needs, and preferences are also taken into account. Additionally, other studies state that lack of time might be even more limiting than a low income (Spinney & Millward, 2010; Venn & Strazdins, 2017). However, in the current study, oncology physiotherapists have mentioned that there are still enough options for physical activity to be done at home or in the unorganized sports sector (e.g., walking, cycling, exercise tutorials online) to overcome these barriers. On the other hand, exercising alone, at home, might cause a different barrier to return as their motivation might decrease without the stimulation of a social environment (Hefferon et al., 2013). They can possibly overcome this barrier by joining an unorganized sports group, like a walking group, provided that the people in this group stimulate each other to stay active.

In line with the study done by Leemrijse et al. (2015) is the need for more information on local PA options. The great need for an overview of local PA options has also been mentioned by other healthcare professionals in several studies on collaboration between healthcare and the sports sector (Den Hartog et al., 2013; Parjanen, 2020). As well as the need for a relationship with the party referred to, as is stated by Helmink (2012) and by all participants of the current study. A CSC can be the answer to these needs, with knowledge of the local sports facilities and a broker role to connect the sectors.

In order to build this collaboration and to provide for these needs, several factors play a role. The themes that emerged in the current study are similar to other studies on intersectoral collaboration (Koelen et al., 2012; Roussos & Fawcett, 2000). Therefore, the use of the HALL framework was an appropriate fit. However, not all themes from the framework emerged from the data and some new themes were not found in the framework. Thus, it seems that the framework must be altered for this particular context, as the collaboration is not just between the healthcare- and sports professional, but also involves a patient. The themes “social identity” “self-efficacy” and “planning horizons” did not emerge from the data and have therefore not been used. However, a new theme “patients” and new subthemes “overview of options” “knowledge of CSC/sports coach” and “local PA options used” have been added, as these emerged from all interviews and seemed to be an important addition to the used framework and research question or to describe the context. This adjustment to the themes provides a deeper understanding of the mechanisms and factors involved in collaboration in this specific context.

### *Strengths and limitations*

A strength of this study is the use of semi-structured interviews, which provided the participants to share their perspective and experiences with active referral and collaboration with physical activities or CSCs. Additionally, by analyzing data during the data collection phase dependability could be increased as data analyzation formed new topics for the interviews. By remaining open during data analysis, new themes could emerge from the data, which were added to the already existing themes of the HALL framework, and some existing themes that were not discussed were excluded. This new composition of themes provided a deeper understanding of the mechanisms in collaboration in this specific context. Furthermore, by having the data inform the results, instead of the framework, the study remained more open and flexible instead of trying to fit the results in a framework.

Credibility was increased through researcher's triangulation, as three transcripts have been coded by two or more researchers, followed by a discussion about the codes until consensus was reached. Doing a focus group with CSCs (appendix H) is not comparable to member checking. However, it did provide some form of reflection on the results from the other party, which has led to a better understanding of the context and challenges surrounding active referral and collaboration and might therefore increase the credibility.

Unfortunately, the study was conducted with a relatively small group of participants (N = 13). During the last interviews a few new topics came up, therefore data saturation might have almost been reached. It is unclear why only female oncology physiotherapists were found in the selected practices. It is possible that the oncology specialization is dominated by female physiotherapists. Nevertheless, the lack of male oncology physiotherapists included might have altered the data saturation and therefore the results.

Additionally, due to the interviews being held in Dutch, the quotes had to be translated to English for the article. Therefore, it is possible that some meanings of the quotes were lost in the translation process.

Another limitation is the use of a thematic content analysis. Because of this method, the data has been analyzed more horizontally than vertically. This means the data of the interviews has been analyzed by taking a step back and looking at it as a whole, instead of comparing data within the interviews (Gaudet & Robert, 2018). Horizontal analysis generates an iterative interpretation of the whole material, but with this also decreases the depth of the results and context.

Lastly, the quality of this study could have been enhanced by coding all transcripts with two or more researchers, instead of only three transcripts.

It is unclear how much the COVID-19 circumstances have limited the study in some ways, for example the interviews had to be done over Teams Online video calls, which could have hindered participants to participate. Additionally, the online environment might have made it more difficult for participants to connect with the researchers and build rapport, and unstable internet connections have disturbed the interviews a few times as well as causing inaudible parts in the recordings. However, according to Archibald et al. (2019) online video calls might also have had a positive impact on participation, as it is easily accessible, and it takes less time and organization than a face-to-face meeting.

### *Implications for practice and further research*

To our knowledge, this is the first study to explore the barriers, facilitators and needs for active referral among oncology physiotherapists, especially with this specific patient group. This is valuable information for professionals in order to initiate and build a collaboration between different sectors, such as healthcare and organized sports. For example, it is useful for the oncology physiotherapists to know a CSC can help create an overview of local sports facilities. Additionally, it is helpful for CSCs/sport coaches to know that the physiotherapists are waiting for them to initiate collaboration. Based on the results it might be helpful to design an implementation-tool focused on creating a connection between physiotherapists and the sports sector. For example, a website where physiotherapists can find a CSC in their municipality, or all the sports clubs in the local area. On this website, the physiotherapists should be able to quickly find contact information or start a message via Siilo to get connected with the CSC or sports coach. This way collaboration can become more accessible and stimulate active referrals.

During this study a small focus group was held to discuss the current results with CSCs (appendix H), this sparked an interest in their perspective of the collaboration. Therefore, further research is needed to gain insight into the mechanism of referral to PA outside healthcare, especially into the perspective of the sports facilities and CSCs. As well as more studies on the collaboration between healthcare and physical activity outside healthcare. Additionally, it is recommended to experiment with the implementation of, for example, an overview of options and whether this truly increases active referral. This can contribute to a

higher rate of collaborations and active referrals, as there are many more patient groups in need of an active lifestyle.

## 5. Conclusion

The aim of this study was to gain insight into the barriers, facilitators and needs of oncology physiotherapists in the active referral of adult female breast cancer survivors to PA outside the health setting, and the role of the CSC. Referral seems to be an intricately linked mechanism with the patient group, (inter)personal factors of the participants, institutional factors, and organizational factors at its core. With motivation of the patients, time, current funding and insurance policies as barriers, participant's personal beliefs as both barrier and facilitator, communication and an overview of options as biggest needs, there is no active collaboration between health care and sports facilities/CSCs yet to be found among the participants. It is suggested that the initiation of collaboration is in the hands of the sports facilities and CSCs, because their low visibility hinders the oncology physiotherapists from connecting with them. After a personal introduction meeting and agreement upon task division and collaboration design, active referral can take place via digital communication media. Together with a patient who is open to change, this will be enough to start a sustainable collaboration. Similar as to what has been stated by Den Hartog et al. (2013) "alliances do not develop just because they are needed. They have to be initiated and built." In this case the same can be applied to active referrals, in order for them to work, a collaboration must be initiated and built first. The current study can contribute to the work that is needed to initiate and build these collaborations.

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## APPENDIX A. The Social Ecological Model

The focus point of this study is partly based on the Social Ecological Model (SEM) (figure 3) by Bronfenbrenner (1994). This model explains human health behavior based on various layers of influence outside of the individual. The first layer, the individual, contains the strongest influences and interactions with the individual. The second layer, interpersonal, contains the personal relationships that surround the individual. The organizational layer impacts the individual indirectly by exerting positive or negative interacting forces on the individual through social institutions and organizations. The fourth layer contains the community, the cultural, societal and religious values and influences. And lastly, the public policy layer, this consists of national influences through laws and policies.

In this study the focus is mostly on the third and fourth layer, the organizational and community part of the model. As the intersectoral collaboration between oncology physiotherapists and the CSC has an indirect influence on the breast cancer patient, this is part of the organizational layer. Additionally, the fourth layer focuses on the collaboration between CSC and physiotherapists as organizations.

There is already a lot known about the individual and interpersonal influences on the behavior of the individual (Clifford et al., 2017; Frikkel et al., 2020; Ormel et al., 2017). Yet there is still research to be done to understand the organizational and community influence on the PA levels of breast cancer survivors, and how to positively influence the organizational aspects.

*Figure 3. Social Ecological Model*



## APPENDIX B. The Healthy ALLiances (HALL) Framework

To further understand the relations and organization within the community and organizational layer of the Social Ecological Model, the Healthy ALLiances (HALL) framework (figure 2) was used to create themes for the interviews and the analysis. This framework can provide insights into the mechanisms that underlie the referral chain. Secondly, the framework might aid in a deeper understanding of the interrelatedness of the concepts as the HALL framework aims to conceptualize the necessary factors for successful (intersectoral) collaboration. In order to do this, the framework includes three clusters of factors that influence the success of collaboration: 1. Institutional factors, 2. Interpersonal factors, 3. Organizational factors of the alliance (or collaboration).

The institutional factors are part of the individual organizations and include their policies, planning and funding. Institutional factors were not used in this study, as the institutional factors are partly dependent on the public policy level, which is why it was not a theme focused on at first.

The interpersonal factors are part of the individual organizations and focus on attitudes and beliefs in regard to collaboration, self-efficacy to feel confident in working with other sectors, social identity to be able to get to a shared identity, and relationships with trust and acceptance.

The third cluster includes the factors that are most important and needed to make the alliance successful when combining the first two clusters. This includes the need for flexible time frames in both parties, clear roles and responsibilities, communication structures that are rich in sharing ideas and experiences, management with a facilitating and empowering style, a shared mission to have common ground, building on capacities by contributing with what the parties are good at, and visibility to increase involvement and sustainability (Koelen et al., 2012).

## APPENDIX C. Interview Guide

Welke barrières, facilitators en benodigdheden spelen een rol bij doorgeleiding van volwassen vrouwen met en na borstkanker door oncologie fysiotherapeuten naar fysieke activiteiten buiten de zorg, tijdens of na behandeling?

### START

- Introductie zelf, bedankt voor tijd deelname, waarom doen we dit onderzoek, wat is rol FT hoeveel deelnemers? Dit interview gaat over het volgende: uw ervaringen met het doorverwijzen naar sport en bewegen buiten de zorg, de bestaande of potentiële rol van een buurtsportcoach, en de mogelijkheden voor de doelgroep borstkanker patiënten (tijdens of na medische behandeling en/of fysio traject).
- Eerst even de randvoorwaarden: ben je akkoord met (audio) opnemen interview, want dit wordt gebruikt om het interview uit te typen en te analyseren.

### --Start opnemen --

- Alles getekend en akkoord?
- Ik behoud me het recht voor om vragen te weigeren of op elk moment zonder opgaaf van redenen mijn deelname te beëindigen. Als ik besluit te stoppen worden mijn gegevens niet in het onderzoek meegenomen.
- De audio-opname van het interview zijn uitsluitend bedoeld voor analyse en rapportage door het Mulier Instituut.
- Citaten uit het interview kunnen als illustratie in een rapportage worden opgenomen. Deze citaten zijn op geen enkele manier tot mij of mijn organisatie herleidbaar. Dit geldt ook voor de andere resultaten in de rapportage.
- Het Mulier Instituut garandeert een zorgvuldige omgang met mijn antwoorden en persoonsgegevens. Zonder mijn uitdrukkelijke schriftelijke toestemming worden deze nooit aan derden verstrekt ([www.mulierinstituut.nl/privacy](http://www.mulierinstituut.nl/privacy)).
- In een rapport komt geen lijst met namen van de deelnemers aan het onderzoek.
- Akkoord?
  
- Introductie participant (werkduur deze praktijk/gemeente, ervaring, specialisaties, patiëntengroepen, sporter?)
  
- Wat zijn uw ervaringen met doorgeleiden van borstkankerpatiënten naar bewegen en/of sport buiten de zorg om ervoor te zorgen dat zij duurzaam gaan bewegen als onderdeel van hun leven? Hoe kijkt u daar tegenaan?
  
- Welke borstkankerpatiënten zijn volgens u geschikt om door te stromen naar sport en bewegen buiten de zorg? (Ziekteverloop, soort persoon, leeftijd, conditie?)
- Hoe bepaalt u of (borstkanker)patiënten klaar zijn om door te stromen? Klinimetrie? Onderbuikgevoel? Welke criteria? En waarom? (is het nodig om vast te leggen?)
- Zou bovenstaande ook voor andere patiënten gelden?

### MIDDENDEEL

#### Doorverwijzen

- Naar welke sportprofessionals heeft u weleens doorverwezen? // Heeft u weleens een patient ondersteunt bij het gaan bewegen buiten de zorg? (Indien nee: hoe komt dit? Wat zijn belemmeringen?)
- Wat gaat er goed bij het doorverwijzen naar sporten buiten de zorg?
- Wat gaat er minder goed bij het doorverwijzen naar sporten buiten de zorg?

- Wat zijn redenen om wel door te verwijzen?
- Wat zijn redenen om niet door te verwijzen?
- Is het nodig om vaker te verwijzen en zo ja: Wat is er nodig om vaker te verwijzen? (Bijv. online doorverwijs formulier? Een keer meekijken) motivatie? MI gebruikt?
- In welke mate vind je medische kennis van de sportsector een rol spelen? en wat is daarin nodig? → Vertrouwen?

### **BSC/bewegmakelaar**

- Is de BSC bekend?  
Indien nodig: uitleggen wat het is  
*Buurtsportcoach/bewegmakelaar werkt als een facilitator voor de gemeente. Zij hebben een overzicht van alle sportfaciliteiten, organiseren vaak allerlei sportevenementen, helpen verenigingen, zetten workshops en sportgroepen op, en kunnen individuen met een sport verbinden door in gesprek te gaan over hun wensen en vaardigheden. Op deze manier zet een BSC zich in voor een meer bewegrijke gemeente. Is de verbinder van verschillende domeinen, kinderen, zorg, etc. Maar kan ook uitvoerder zijn door het vormen en trainen van sportgroepjes.*
- Wat is volgens u de meerwaarde van een BSC voor het doorgeleiden van borstkanker patiënten vanuit de fysiotherapie naar bewegen buiten de zorg?
- Hoe kijk je aan tegen samenwerken met/doorsturen naar een BSC? Ervaringen? Resultaten?
- Indien van toepassing: Wat zou er moeten gebeuren om de BSC bekender te maken?
- Meer behoefte aan BSC als verbinder of als uitvoerder?
- Wat is er **nodig** voor een goede doorgeleiding/samenwerking met de bsc?
  - Communicatie? Via welk medium? Vanuit wie?
  - Terugkoppeling? Hoe en vanuit wie? Alleen vanuit BSC voldoende, of ook vanuit sportaanbieder?
  - Hoe vaak een terugkoppeling?

Wiens rol is het om patienten te laten sporten?

### **Benodigheden om over te praten/checken**

- Zijn stappen duidelijk?
- Lijntjes kort genoeg?
- Voldoende contact met/zichtbaarheid BSC om te onthouden?
- Overdracht soepel?
- Bekend met sportaanbod? Is het aansluitend bij patiënt?

### **EIND**

- Wat is volgens u nodig om tot duurzame FA over te gaan?
- Hoe zou de ideale samenwerking eruitzien in 2022? Wat heeft u daarvoor op korte termijn (in praktische zin) voor nodig? Wat gaat u daarvoor doen?

### **Zelf nog toevoegingen of vragen?**

*Bedankt voor het meedoen aan het onderzoek, ik zal een concept van alle resultaten terugkoppelen in mei. Ik stop nu de opname. Afsluiten etc.*

Contactgegevens verzamelen:

Naam:

Naam praktijk:

Adres praktijk:

*E-mail adres:*  
*Telefoonnummer:*

## APPENDIX D. Reflection on interviews (Dutch)

1. Aanloop: hoe is het interview tot stand gekomen? Bv. hoe je aan contactgegevens kwam, welk contact jullie hebben gehad (telefonisch/mail/...), hoe dat verliep en hoe die persoon daarop reageerde.
2. Setting: waar vond het plaats? Bv. typelocatie, hoe jullie ten opzichte van elkaar zaten, of er anderen aanwezig waren, hoe de locatie ‘aanvoelde’ (kil/klinisch/warm/rustig/druk/vrolijk/somber/etc).
3. Sfeer: hoe verliep het? Bv. hoe de interactie was, hoe diegene op jouw reageerde, of hij/zij makkelijk praatte of dat je erg moest trekken, wat voor type persoon (dominant of juist niet) het was.
4. Recorder: Wat is er buiten de opname om gezegd?
5. Jijzelf: hoe ging je het gesprek in en uit? Bv. of je zenuwachtig van te voren was, of je geconcentreerd was of niet, hoe je direct na afloop over het gesprek dacht, in hoeverre je je ‘eigen’ verhaal hebt ingebracht.

### **FY1**

*Via onconet kwam ik aan de gegevens. Vervolgens heb ik haar gemaaild en dit accepteerde ze vrijwel direct, zij heeft zelf een mail teruggestuurd met haar deelname en was hier proactief in. We spraken elkaar in Teams, online, dit maakte het iets ongezelliger, maar uiteindelijk maakte dit wel dat het een hele rustige omgeving was. Het was een prettig en goed inhoudelijk gesprek. De participant was rustig en praatte er niet omheen, ging gelijk de diepte in. Ze reageerde makkelijk op mijn vragen en was betrokken in het gesprek. Ze was niet per se heel dominant, wachtte ook mijn vragen af. Soms praatten we door elkaar heen, maar dat kan ook aan het online praten gelegen hebben, waardoor je deze interrupties pas later doorhebt. Buiten de opname om is alleen gesproken over wie ik ben en waarom ik dit doe, zijn contactgegevens besproken en is er nog gesproken over haar ervaring omtrent zelf onderzoek doen. Ik was best nerveus, zeker omdat het mijn eerste interview was, ik was hierdoor gefocust maar merkte ook dat ik niet altijd goed genoeg luisterde omdat ik zoveel aan het nadenken was over de vragen die ik wilde stellen. Ik heb voor mijn gevoel niet heel erg mijn eigen verhaal ingebracht, maar dat zie ik wellicht pas als ik aan het transcriberen ben.*

### **FY2**

*Via onconet kwam ik aan de gegevens. Vervolgens heb ik haar gemaaild en dit accepteerde ze vrijwel direct, zij heeft zelf een mail teruggestuurd met haar deelname en was hier proactief in. We spraken elkaar in Teams, online, dit maakte het iets ongezelliger, maar uiteindelijk maakte dit wel dat het een hele rustige omgeving was. Het was een prettig en bijna informeel gesprek, ze was heel open en werkte graag mee. We hebben fijn kunnen praten en sparren en het voelde al een stuk minder als een interview en veel meer als een gesprek uit nieuwsgierigheid. Buiten de opname om is alleen gesproken over haar studie en de mijne en dat het zo fijn is als mensen direct deelnemen aan onderzoeken. Daarnaast is het nog een beetje gegaan over hoe druk ze verder is en wat COVID doet met haar werk. Ik was nog een beetje nerveus, maar ik denk dat ik me nu beter heb kunnen focussen op haar verhaal en ik was minder bezig met mijn volgende vraag. Het voelde na afloop als een heel prettig gesprek waar veel goede info uit naar voren was gekomen.*

### **FY3**

*Via onconet kwam ik aan de gegevens. Vervolgens heb ik haar gemaaild hier reageerde ze niet direct op, ik heb de praktijk gebeld en een dag later belde zij mij terug. Ze had op dat moment niet veel ruimte voor een afspraak met mij alleen diezelfde en de volgende dag, maar het moest niet te lang duren. We spraken elkaar in Teams, online, het geluid van haar kant was niet heel goed, echode heel erg. Het was een vrij gehaast gesprek. Tijdens het inplannen al*

*merkte ik dat het niet lang mocht duren en dat maakte dat ik zelf ook sneller door het interview heen ging. De toon was daarnaast ook niet heel geduldig of positief, vrij dominante persoon. Buiten de opname om is alleen gesproken over eventuele contactgegevens. Ik was een beetje opgejaagd, was voor mijn gevoel wel helderder in mijn taalgebruik, maar ik merkte dat ik wat zwart-wittere uitspraken ging doen, deels om haar een beetje te porren, deels omdat de participant ook vrij rechtlijnig over kwam.*

#### **FY4**

*Via onconet kwam ik aan de gegevens. Vervolgens heb ik haar gemailld en dit accepteerde ze vrijwel direct, zij heeft zelf een mail teruggestuurd met haar deelname en was hier proactief in. We spraken elkaar in Teams, online, zij was thuis dit maakte de sfeer wat informeler. Het was een prettig en goed inhoudelijk gesprek. De participant was rustig. Ze reageerde makkelijk op mijn vragen en was betrokken in het gesprek. Ze was niet per se heel dominant, wachtte ook mijn vragen af. Soms praatten we door elkaar heen, maar dat kan ook aan het online praten gelegen hebben, waardoor je deze interrupties pas later doorhebt. Buiten de opname om is alleen gesproken over wie ik ben en waarom ik dit doe, zijn contactgegevens besproken. Het was een prima gesprek, hier en daar had ik wel het idee dat ik wellicht wat meer "gestuurd" heb omdat sommige vragen er wat dichter/suggestiever uitkwamen dan de bedoeling was.*

#### **FY5**

*Via onconet kwam ik aan de gegevens. Vervolgens heb ik haar gemailld en gebeld, waarna ik eerst alleen een collega sprak en met die collega maakte ik voor hen beide een afspraak. Vervolgens mailde zij zelf dat ze voor hen allebei wilde afzeggen ivm geen patiënten zien op dit moment. Ik heb haar toen gevraagd toch mee te doen ivm waardevolle informatie, hiermee ging ze akkoord maar alleen voor haar en haar collega mocht niet meedoen. Ze kwam in het mailtje een beetje gepikeerd over. We spraken elkaar in Teams, online, dit maakte het iets ongezelliger, ik kon haar gezicht ook niet zien ivm slecht licht, hierdoor voelde het als een heel anoniem gesprek. Het was een lichtelijk gehaast gesprek van mijn kant, ik had door de mailtjes het gevoel dat ze niet zo open stond voor het interview en dat werkte door in mijn tempo en nervositeit. Ik hoefde niet heel veel te trekken aan de antwoorden, ze was een vrij makkelijke prater, maar ook doordat ik haar gezicht slecht kon zien voelde het toch als een beetje dominant van haar kant. Buiten de opname om zijn contactgegevens besproken. Ik merkte dat ik hier en daar een beetje aan het sturen was op antwoorden omdat ik die al eerder gehoord had en die wilde bevestigen bij deze participant.*

#### **FY6**

*Via onconet kwam ik aan de gegevens. Vervolgens heb ik haar gemailld en gebeld, waarna ik een afspraak met haar heb kunnen maken. Ze reageerde niet meer op de mails, dus voor het interview dacht ik ook even dat ze niet zou komen opdagen. We spraken elkaar in Teams, online, haar verbinding was heel traag waardoor we lang op elkaars antwoord zaten te wachten steeds. Ze liep ook een aantal keer vast. Dit maakte het gesprek lastig. Haar verbinding was heel traag waardoor we lang op elkaars antwoord zaten te wachten steeds. Ze liep ook een aantal keer vast. Dit maakte het gesprek lastig. Ik denk dat ze hierdoor ook minder uitgebreide antwoorden is gaan geven, want ik moest best wel trekken. Het interview was dan ook de kortste tot nu toe. Buiten de opname om zijn contactgegevens besproken. Het was lastig gesprekvoeren door de slechte kwaliteit van de verbinding, ik merkte dat ik het gesprek daarom niet goed in kon duiken en het ook vrij snel weer kon afronden want we hadden niet zoveel te zeggen.*

#### **FY7**

*Via onconet kwam ik aan de gegevens. Vervolgens heb ik haar gemaïld en dit accepteerde ze. We hebben een afspraak gemaakt via de telefoon, verliep allemaal prima. We spraken elkaar in Teams, online, zij was thuis en er kwamen af en toe mensen thuis of er belde een kind, het zorgde wel dat het warm en vrolijk aanvoelde. Het was een prettig gesprek, al was het vrij kort aangezien ze heel weinig met het onderwerp deed. De interactie was verder prima, geen sterke rolverdeling, een ontspannen gesprek. Buiten de opname om is alleen gesproken over contactgegevens. Het ging prima, ik ging het gesprek ontspannen in, merkte dat ik het wat lastiger vond om goed door te vragen aangezien ze niet veel met het onderwerp deed, dat maakte me iets nerveuzer, maar verder geen problemen.*

#### **FY8**

*Via onconet kwam ik aan de gegevens. Vervolgens heb ik haar gemaïld en dit accepteerde ze, zij heeft zelf een mail teruggestuurd met haar deelname en was hier proactief in. We spraken elkaar in Teams, online, dit maakte het iets ongezelliger, maar uiteindelijk maakte dit wel dat het een hele rustige omgeving was. Mijn stagebegeleider was hier ook bij aanwezig. Het was een prettig en goed inhoudelijk gesprek. De participant was rustig en praatte er niet omheen. Het was voor mij even schakelen omdat ze niet aan doorverwijzen deed, waardoor ik de leidraad anders moest gebruiken. Ze reageerde makkelijk op mijn vragen en was betrokken in het gesprek. Ze was niet per se heel dominant, wachtte ook mijn vragen af. Ze had zelf ook best wat vragen. Buiten de opname om is alleen gesproken over contactgegevens. Ik was best nerveus, omdat mijn stagebegeleider mee keek had ik toch het gevoel dat ik een soort van op mijn woorden en vragen moest letten, uiteindelijk was het echter wel een heel leuk gesprek.*

#### **FY9**

*Via onconet kwam ik aan de gegevens. Vervolgens heb ik haar gemaïld en dit accepteerde ze, zij heeft zelf een mail teruggestuurd met haar deelname en was hier proactief in. Ze was echter onze afspraak vergeten in de ochtend, waarna ik na een tijd wachten contact met haar kreeg en we onze afspraak naar de middag hebben verplaatst. We spraken elkaar in Teams, online, zij belde in vanuit huis wat het een warmere omgeving en sfeer gaf. Het lastige was dat het videobeeld al na 5 minuten vastliep waardoor ik het hele interview tegen een stilstaand beeld keek en niet kon inschatten hoe zij keek en of zij mij kon verstaan/begrijpen. Het was een prima gesprek, al moest ik regelmatig een beetje trekken voor wat meer antwoord, aangezien ze bij open vragen vaak in een zin antwoordde. Ze was niet dominant, wel vrij afwachtend met haar antwoorden en eigen opmerkingen/vragen. Buiten de opname om zijn alleen contactgegevens besproken en een laatste woord van dank. Doordat het interview opeens verplaatst werd was ik niet erg zenuwachtig maar was ik wel een beetje uit mijn concentratie flow gehaald, hierdoor voelde ik me een beetje warrig en had ik het gevoel dat ik me niet helemaal goed kon concentreren op haar verhaal.*

#### **FY10**

*Via onconet kwam ik aan de gegevens. Vervolgens heb ik haar gemaïld en daarna nog eens gebeld voor een reactie. Ze reageerde goed op de vraag om deelname. We spraken elkaar in Teams, online, dit maakte het iets ongezelliger, maar uiteindelijk maakte dit wel dat het een hele rustige omgeving was, ze was niet altijd even goed te horen. Het was een prettig gesprek. De participant was echter graag veel aan het vertellen en week graag af van de vragen om andere dingen te vertellen. Ze was daarin ook vrij dominant en liet zich niet zomaar stoppen. Buiten de opname om is alleen gesproken over contactgegevens. Ik heb moeilijk tussen haar verhaal kunnen komen dus een eigen verhaal heb ik niet ingebracht, ik was al blij als ik mijn vragen kon stellen.*

#### **FY11**

*Via onconet kwam ik aan de gegevens. Vervolgens heb ik haar gemaïld en gebeld, maar ze was te druk. Na een tijdje contact en afwachten had zij wel tijd voor deelname. We spraken*

*elkaar in Teams, online, beiden vanuit huis, dit maakte het een wat warmere omgeving. Het was een prettig en vlot gesprek. De participant kon veel vertellen en deed haar best de vragen goed te beantwoorden. Ze kon echter niet veel vertellen over de BSC en praatte ook best snel, waardoor ik soms moeite moest doen om even een stilte te laten vallen, ze gaf de indruk snel door te willen en het niet nodig te vinden om eea te herhalen. Het was duidelijk weer begin van de week en het eerste interview van de week. Het was ook einde van de dag dus ik was al iets minder gefocust of “wakker” waardoor ik het soms lastig vond om door te vragen waar dat wellicht wel kon. Ik had het idee dat veel van haar antwoorden al stonden als een huis en er weinig door te vragen was. Maar ik nam ook niet de tijd om er goed over na te denken.*

#### **FY12**

*Via onconet kwam ik aan de gegevens. Vervolgens heb ik haar gemaïld en later gebeld voor een afspraak, ze twijfelde erg om mee te doen, maar toen ze eenmaal ja had gezegd vond ze dat ze het ook niet meer af mocht zeggen. Het ging de eerste keer mis omdat ze dacht dat ik haar telefonisch zou bellen, waardoor ik haar miste. We hebben toen een nieuwe afspraak gemaakt, maar ze vond het een drempel dat ik het ook op ging nemen en woord voor woord ging uitschrijven, dat het op zwart-wit zou staan. Tijdens het interview zelf zei ze echter dat ze gewoon erg gestrest was geweest, en begreep dat ik het moest opnemen. We spraken elkaar in Teams, online, ze wilde haar camera niet aan, hierdoor leek het meer op een telefoontje. Ik had mijn beeld wel aan, maar het voelde wel een beetje raar om haar niet te zien. Het was een goed inhoudelijk gesprek. De participant was wel lichtelijk haastig en begon ook met: “nou laten we maar snel beginnen” Hierdoor voelde ik me een beetje opgezweept en heb ik niet de rust en tijd genomen die ik wilde nemen voor het interview. Ik was een beetje gehaast en op mijn hoede omdat ik wist dat ze hier een beetje tegenop zag en ik het gevoel kreeg dat het niet lang mocht duren, hierdoor heb ik minder de rust genomen om mijn vragen te stellen. Er kwamen echter wel nieuwe dingen uit, dus ik ben blij dat het wel voor de saturatie nog eea heeft opgeleverd!*

#### **FY13**

*Via onconet kwam ik aan de gegevens. Vervolgens heb ik haar gemaïld en gebeld. Ik werd naar haar doorgestuurd via een collega, omdat zij vervangend fysio was van een collega die niet meer in de praktijk werkte. Na een paar keer bellen/mailen kregen we contact. We spraken elkaar in Teams, online, zij was thuis en het was later op de avond, waardoor zij soms in de weer was met haar kinderen. Het was een prettig gesprek, de participant vertelde veel, ik hoefde bijna niet door te vragen, met een stilte begon ze zelf haar antwoord al aan te vullen. Niks, de recorder is pas na einde van interview afgesloten. Ik was best nerveus, omdat mijn begeleider weer meekeek en ik ergens anders dan normaal aan het werk was. De internetverbinding viel ook halverwege uit, wat mij nog iets nerveuzer maakte. Ik kreeg het gevoel dat ik niet heel goed kon doorvragen door dit alles, al zei mijn begeleider dat dit prima ging.*

## APPENDIX E. Informed Consent

### **Toestemmingsverklaring onderzoek: Doorgeleiding (ex)borstkankerpatiënten naar sport buiten de zorg.**

#### **Toelichting onderzoek**

Het Mulier Instituut voert een onderzoek uit naar belemmerende en bevorderende factoren en benodigdheden bij het doorgeleiden van (ex)borstkankerpatiënten vanuit de fysiotherapie naar sport en bewegen buiten de zorg. Dit interview zal gaan over uw ervaringen met de doorgeleiding van deze doelgroep naar sport- en beweegaanbod buiten de zorg en de bestaande of potentiële rol van de buurtsportcoach bij doorgeleiding. Het doel van dit onderzoek is een bijdrage te leveren aan het verbeteren van samenwerkingsverbanden met bijvoorbeeld buurtsportcoaches en de sport- en beweeg aanbieders buiten de zorg, om (ex)borstkankerpatiënten in beweging te houden.

#### **Contactgegevens:**

Fenne Folkersma (onderzoeksstagiair), T xxxxxxxxxxx, f.folkersma@mulierinstituut.nl

Dorine Collard (Senior onderzoeker), T xxxxxxxxxxx, d.collard@mulierinstituut.nl

#### **Rechten van de deelnemer**

- Ik behoud me het recht voor om vragen te weigeren of op elk moment zonder opgave van redenen mijn deelname te beëindigen. Als ik besluit te stoppen worden mijn gegevens niet in het onderzoek meegenomen.
- De audio-opname van het interview zijn uitsluitend bedoeld voor analyse en rapportage door het Mulier Instituut.
- Citaten uit het interview kunnen als illustratie in een rapportage worden opgenomen. Deze citaten zijn op geen enkele manier tot mij of mijn organisatie herleidbaar. Dit geldt ook voor de andere resultaten in de rapportage.
- Het Mulier Instituut garandeert een zorgvuldige omgang met mijn antwoorden en persoonsgegevens. De verzamelde data worden beschermd en anoniem opgeslagen en worden 6 maanden na oplevering van het eindproduct verwijderd. Zonder mijn uitdrukkelijke schriftelijke toestemming worden deze nooit aan derden verstrekt ([www.mulierinstituut.nl/privacy](http://www.mulierinstituut.nl/privacy)).
- In een rapport komt geen lijst met namen van de deelnemers aan het onderzoek.

Ik ben voldoende ingelicht over het doel van het onderzoek en mijn rechten voor dit onderzoek en stem in met deelname.

Naam deelnemer: .....

Datum: ..... Handtekening deelnemer: .....

#### **Plichten voor de onderzoeker**

Ik heb het onderzoek zo goed mogelijk toegelicht. Als een deelnemer met het interview wil stoppen dan kan dat op elk moment. De tot dan toe verzamelde gegevens zullen we vernietigen. Informatie over het stoppen zal met niemand buiten het projectteam worden gedeeld. Dit betreft ook de naam van de deelnemer.

Naam onderzoeker: Fenne Folkersma

Datum: 19-03-2021

Handtekening onderzoeker:

## APPENDIX F. Coding scheme

*Table 5. Overview of (sub)themes and definitions*

Theme	Subtheme	Definition
<b>Patients (new)</b>	Motivation	The factors influencing the patient's motivation for PA
	Dependence	The influence of the patient's dependence on PA
<b>Organizational</b>	Roles and responsibilities	The roles and responsibilities the physiotherapists assign to themselves, to the CSCs/sports trainers or the patients, as well as the influence of these roles and responsibilities
	Knowledge of CSC/trainer (new)	The influence of the CSC's/trainer's knowledge on referral of patients by oncology physiotherapists
	Building on capacities	What capacities of the physiotherapists/CSCs/sports trainers are valued by the physiotherapists and which will be used.
	Visibility	Visibility of the local PA options/trainers/CSCs for the physiotherapists and what can be done to increase visibility
	Communication structures	Protocols, designs and communication media that are needed/influence collaboration and referral according to physiotherapists
	Overview of options (new)	The need for an overview of sports facilities
<b>(inter)personal</b>	Relationships	The influence of the physiotherapists' relationships with CSCs/Sports trainers and patients on collaboration/referral
	Attitude & beliefs	The attitude/beliefs of the physiotherapists on PA, patients and CSCs/sports trainers and their influence on collaboration/referral
<b>Institutional</b>	Policy	The influence of the practices' policies on collaboration/referral
	Funding	The influence of funding structures on referral by physiotherapists

## APPENDIX G. Original Dutch list of codes

Code System	Frequency
Code System	1003
Fysiotherapeuten	0
PERSOONLIJK	0
kennis	15
FY affiniteit met sport	15
sociale identiteit	0
relationships	0
FY loslaten pt	3
belemmering doorverwijzen in de zorg houden	3
belemmering doorverwijzen, mensen kwijtraken	3
kwijtraken	3
rekening houden met iemand	9
facilitator vertrouwen in BSC/fitnesstrainer, goed kennen	6
attitude & beliefs	165
visie pt en sport	36
verwijs niet door, maar afstemmen met pt	4
advies geven, maar niet regelen	19
visie FY, sporten kan buiten de zorg	9
FY gaat sport gesprek aan pt	7
Meerwaarde BSC/fitnesstrainer	0
BSC /fitnesstrainer als tussenstap	7
opstartende rol	3
verbindende rol	6
uitvoerende rol/inspelen op behoefte	7
misschien niet nodig voor bkpt?	6
pt kan vrijblijvend sport proberen	3
voor ongemotiveerde groep	14
scheelt tijd	3
BSC weet meer over sportfaciliteiten	14

visie FY op BSC	19
samenwerken hoeft van mij niet	4
INSTITUTIONEEL	0
planning horizons?	0
vergoeding	16
beleid	11
interne sportfaciliteiten	16
ORGANISATIONEEL	0
NIEUW sportfaciliteiten naar doorverwezen	16
voorwaarde voor doorsturen	2
bepaalde conditie	32
sportfaciliteiten oncologie	4
pt vindt zelf (groot aanbod)	6
ROLLEN en verantwoordelijkheden	41
taken FY	17
zelf naar sportfaciliteit toe	3
pt in contact brengen met BSC	1
uitleg belang bewegen	6
taken voor FY, educatie	3
afstemmen	8
Taken BSC	16
overgang fysiosport naar regulier	1
financiële steun regelen groepjes/pt	2
educatie bewegen kind en oudere	1
BSC voor beetje ondersteuning	4
oncologie sportgroepje	5
fitnesstrainer oncologie	1
NIEUW KENNIS BSC/fitnesstrainer	32
vraagtekens over kwalificatie/kennis sportbegeleider	5
slechte kennis trainer belemmert doorverwijzen	6
vertrouwen in kunde	4
kennis BSC niet nodig, pt kent grenzen	4
capaciteiten benutten	7

BSC is oplossing tijdsprobleem FY	2
laagdrempelig sporten via BSC	3
netwerk BSC/sport	2
flexibele tijdsplanning	1
samenwerken beweegeducatie	1
<b>ZICHTBAARHEID</b>	<b>59</b>
actieve acquisitie	2
BSC zelf naar praktijken toe	4
mond-tot-mond reclame	4
succeservaring = meer doorverwijzen	5
kennen is contact onderhouden	8
Initiatief FY om BSC/sport te zoeken	13
Zichtbaarheid vanuit BSC/sport	22
zichtbaarheid voor pt	1
<b>COMMUNICATIE</b>	<b>190</b>
belemmering, geen contact met BSC	4
geen communicatie/info	2
weet niet of er hier een is, geen contact mee	3
benodigdheden samenwerking	34
veel contact niet nodig	5
meer contact nodig	6
nodig: laagdrempelig contact	15
Communicatie doorverwijzen naar BSC/fitnesstrainer	8
makkelijke veilige communicatiemedia	2
facilitator, laagdrempelige communicatie	17
NIEUW Vormgeving doorverwijzen naar BSC/fitnesstrainer	29
sportfaciliteiten bij de praktijk in de buurt	7
NIEUW ideale samenwerking	3
bsc verwijst naar FY	4
FY verwijst naar bsc	2
warme overdracht	5
belemmering doorverwijspad sport/BSC/fitnesstrainer	4
Terugkoppeling vanuit FY met pt	20

feedback vanuit pt	3
terugkoppeling voor vertrouwen	2
niet afgesproken terugkoppeling, toeval	2
terugkoppeling vanuit BSC/fitnesstrainer	20
nadeel geen terugkoppeling=geen succeservaring	1
terugkoppeling vanuit BSC voor vertrouwen	4
NIEUW Overzicht en aanbod	24
aanbod is aanwezig	2
aanbod kennen	1
alternatieven voor sport buiten zorg	1
Overzicht sportmogelijkheden	20
geen overzicht sportaanbod	4
tijd en moeite	3
NIEUW DOELGROEP	0
motivatie	22
facilitators	0
sociale omgeving	15
fysieke vooruitgang	3
lotgenoten contact	6
overtuigd van belang/nut bewegen	4
succeservaring	7
ervaring met sport	3
leren fitness kennen blijven dat doen	3
pt terug naar oude sport	17
Plezier in sporten	12
leeftijd/ziekteverloop geen belemmering	6
sportervaring	12
Afspraken naleven pt	4
ongemotiveerde pt komt al niet naar FY	4
benodigdheden	0
zelfstandigheid	8
vertrouwen	3
backup, contact fysio	7

voldoende geoefend	8
kennis van grenzen	5
financieel	23
te vroeg behandelingen op	4
doelgroep financiële middelen	5
passende sport/beweging	27
juist geen lotgenoten	6
benadering	2
fitheid/conditie	1
laagdrempelig sporten/financieel	5
makkelijk toegankelijk (locatie)	3
moet in dagelijks leven opgenomen worden	3
educatie kinderen	2
goede begeleiding	7
doel	2
inzicht, kennis en ervoor open staan	10
Barrières	0
komen niet meer op oude niveau	3
geen behoefte	2
zien nut niet in	3
vervallen in oude patronen	11
niet snel naar sportschool gaan, behoefte aan bekende omgeving	14
leeftijd: fitnessschool vaak jongere pt's	1
drempel voor patient, fitte figuren in sportschool	5
niet alleen maar fitte figuren	2
sporten alleen in de praktijk	1
fysieke klachten	6
tijd	5
geen plezier in sport	3
belemmering, pt blijft hangen in zorg	10
spannend	3

## APPENDIX H. Results from a focus group among CSCs

### *Textbox 1 Results from a focus group among CSCs*

#### **A Focus Group Among CSCs**

*On the 28th of May 2021 a small focus group was held. Three CSCs from the regions Amsterdam and Den Bosch participated in the online focus group, to talk about the results of the current study. During the group discussion the themes roles and tasks, visibility and communication, and knowledge were discussed. The CSCs were not specifically involved in the oncology patient group but did work with the healthcare sector one way or another.*

First off, they were asked what they thought physiotherapists valued most about CSCs. They thought of capacities such as their knowledge and network, their information about sports options and their guidance towards sports or their initiation of new sports groups. An example was their knowledge on funds for people who could not afford sports, as opposed to the physiotherapists who mainly know everything within their care. Additionally, the CSCs talked about their visibility and their role to be proactive in presenting themselves towards the physiotherapists. As the physiotherapists might not know where to find them, or what they can do. CSCs stated that they already try to increase visibility by handing out cards, having a Facebook page and joining meetings etc. The CSCs recognized the fact that collaborations with a physiotherapist are still rare. They suggested this was due to the physiotherapists' way of working, they are focused on delivering care, but not (yet) on collaborating with different sectors and therefore also do not receive time for that. Additionally, there is the need for a secure communication platform, which is stressed by both the physiotherapists and CSCs. Regarding knowledge, the CSCs think that new, young, CSCs might be insecure about working with the oncology patient group, as they are not schooled with knowledge on the topic. All participants indicated the need for more knowledge on all severe diseases, either in the form of text(books), workshops, protocols, or a step-by-step guide. These mediums would help the CSCs to support these patients, by being able to give advice, make a plan and understand the red flags. Lastly, a problem in collaborations and referral is the CSC's time. They stated that they do not have enough time on their hands to help future referred patients, as they only get limited working hours from their municipality. Additionally, collaborations with healthcare are still unknown territory. Solutions for this lay in the extending of paid hours by the municipality as well as really giving priority to this collaboration.