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BOUNCE

Predicting Effective Adaptation to Breast Cancer to Help Women to BOUNCE Back

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0. Document Info

0.1. Authors

Authors	Organisation	E-mail	
Riikka-Leena Leskelä	NHG	riikka-leena.leskela@nhg.fi	
Siina Pamilo	NHG	siina.pamilo@nhg.fi	
Ira Haavisto	NHG	<u>ira.haavisto@nhg.fi</u>	
An Chen	NHG	an.chen@nhg.fi	
Anna-Maria Hiltunen	NHG	anna-maria.hiltunen@nhg.fi	
Suzan Ikävalko	HUS	<u>suzan.ikavalko@hus.fi</u>	

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Editor Address data	Name:	An Chen
	Partner:	NHG
	Address:	Vattuniemenranta 2, 00210 Helsinki, Finland
	E-mail:	an.chen@nhg.fi
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Executive Summary

This deliverable (D1.1) identifies the stakeholders and describes the value chain/network in the BOUNCE project by presenting a stakeholder value analysis and a map of the connections and information flows between the identified stakeholders as the task 1.1 result. The aim of this document is to describe the value that the project will deliver through its outcomes and results to its stakeholders. The aim is furthermore to understand how value can be created and delivered. The stakeholder value analysis will serve as a base for the following WPs and thus support the development of value propositions, the development of use cases and user requirements for the BOUNCE tool and furthermore function as a support when planning for targeted communication and outreach throughout the project.



2. Introduction

2.1. About the project

Coping with breast cancer more and more becomes a major socio-economic challenge not least due to the constantly increasing incidence of breast cancer in the developing world. There is a growing need for novel strategies to improve our understanding about resilience and capacity to predict resilience of women against the variety of stressful experiences and practical challenges related to breast cancer. This is a necessary step toward efficient recovery through personalized interventions: we need to know who is in need of support and what kind of support. BOUNCE will bring together modelling, medical, and social sciences experts to advance current knowledge on the dynamic nature of resilience as it relates to efficient recovery from breast cancer. BOUNCE will take into consideration clinical, cancer-related biological, lifestyle, and psychosocial parameters in order to predict individual resilience trajectories throughout the cancer continuum and eventually increase resilience in breast cancer survivors and help them remain/return in the workforce and enjoy a better quality of life.

BOUNCE will deploy a prospective multi-centre pilot at four major oncology centres (in Italy, Finland, Israel and Portugal), where a total of 660 women will be recruited in order to build tools that help increase patients' capacity to BOUNCE back during the highly stressful treatment and recovery period following diagnosis of breast cancer.

The final output of the project consists of a clinically operational algorithm as well as tools and services assessing individualized risk. The overreaching goal of BOUNCE is to incorporate elements of a dynamic, predictive model of patient outcomes in building a functional system that could be used in routine clinical practice to provide physicians and other health professionals with concrete, personalized recommendations.

2.2. About the task 1.1

According to the project proposal, task 1.1 deals with the definition of value in healthcare and the value chain of BOUNCE. In task 1.1 all scientific, technical, industrial and societal stakeholders, which could be potentially interested in, benefit from, and contribute to the project outcomes and results, are identified. Thus, the purpose is not to describe the value chain of breast cancer care, but rather the value of the BOUNCE tool in the context of breast cancer care. In the context of this task breast cancer-related stakeholders, particularly the stakeholders of the BOUNCE tools, are identified and presented.

2.3. Purpose of the document

This deliverable identifies scientific, technical, industrial and societal stakeholders, which could be potentially interested in, benefit from and contribute to the project outcomes and tool to be developed from the perspective of value-based healthcare. A stakeholder value analysis is conducted and presented in this document. The stakeholder value analysis will provide an overview of how value can be created and delivered for and/or by the stakeholders. This document presents identification and classification of stakeholders, a stakeholder value analysis, and the connections and potential information flows between the stakeholders. The stakeholder value analysis serves as a base for the other tasks and WPs and thus supports the development of value propositions, the development of use cases for the BOUNCE tool and furthermore functions as support when planning for targeted communication, dissemination and outreach.

2.4. Task 1.1. work methods

- Literature review: A structured literature review was conducted to identify current research on value-based healthcare as well as stakeholder mapping and analysis. By reviewing publications, stakeholder and value chain models and approaches were identified.
- Internal meetings and brainstorming: Meetings were organised between the project partners to ensure both comprehensive and country specific identification of stakeholders and the potential value perceived by them.
- Semi-structured interviews: Empirical data was gathered from stakeholders to further increase the understanding of what value is for each stakeholder group. Based on the stakeholder value analysis framework, interview questions were developed and empirical data collected via semi-structured interviews with identified stakeholders. Interview questions are presented in Appendix 2.
- **Expert consultations:** To validate preliminary findings in task 1.1. expert consultations took place throughout the task. Invited experts in breast cancer care and in value-based healthcare were invited to provide comments and suggestions on the work and the preliminary findings

2.5. Main content of the document

- Conceptual understanding of value in healthcare
- BOUNCE stakeholder map
- BOUNCE stakeholder value analysis
- Map of the connections and information flows between BOUNCE stakeholders

3. Value in healthcare

Although value has been discussed in various discourses and has been assigned multiple meanings, the fundamental notion of this concept typically implies a relation between the benefits ("what is received") and the sacrifices ("what is given") (Zeithaml 1988; Sánchez-Fernández, Iniesta-Bonillo and Holbrook 2009);(Reijonsaari 2013). In reality the definition of "value" is a multifaceted issue (Rantala and Karjaluoto 2016), so defining value is difficult. There is no unified definition for every situation, and even within the same situation, it is hard for different stakeholders with different perspectives to agree. Furthermore, in one system, stakeholders can sometimes have conflicting goals and value perceptions. What matters for one patient might not matter as much to another; what most patients can agree on regarding the benefits and costs of a given service or an episode of care could still be outside the scope of what the providers or payers would perceive as value.

However, the broadly adopted definition of value in healthcare is given by the Harvard economist Michael Porter, who defines value in health care as "health outcomes per dollar spent" (Porter 2010). It indicates the scarcity of resources in healthcare and the need to increase cost-effectiveness, with the aim of improving the outcomes by using limited resources. Defining outcomes and which costs to include, is essential when striving to understand and when assessing value in healthcare. The work in BOUNCE is based on Porter's (2010) work and his definition of value.

Thus in BOUNCE, value of health care is defined according to stakeholders' perceptions, and value perceived by different stakeholders in a given health service or a care episode needs to be systematically linked (Eklund et al. 2015). In this task of identifying the value of BOUNCE result and service, we first explore the value perceived by stakeholders in terms of benefit and cost. Throughout the BOUNCE project, value is understood as something that is co-created in a network and thus an even more integrated value network will be developed during the project.

3.1. Value co-creation network in healthcare

The generic value chain model was introduced by Michael E. Porter in 1985 (Porter 1985). It has been widely used as a tool or mechanism for the last 30 years to portray, understand and analyse the chained linkage of value-added activities and processes that exist in the physical world within traditional industries, particularly in manufacturing (Porter 1985; Peppard and Rylander 2006). With the end product as the focal, the value chain helps to think about value creation, identify the primary activities that add value to the final product directly and support activities that add value indirectly, and make the gaps between firm performance and a competitor's performance visible (Peppard and Rylander 2006). The logic behind the value chain is Goods-Dominant (G-D) logic, in which the economic exchange is fundamentally concerned with units of output that are loaded with value during the manufacturing process. In G-D logic, the production ideally takes place in isolation from the customer, and the results are standardized, inventoriable goods (Vargo and Lusch 2008a).



The value chain has later been modified to suit service production (see Figure 1). The value chain contains the activities done by the service provider in each phase of the breast cancer episode from prevention/screening to monitoring and managing of the patient after active breast cancer care ends. The value chain also differentiates between breast cancer specialists and other service providers in the value chain. However, the role of the patient is not considered. Also, the breast cancer process is seen as a linear chain. In reality the process can be complex and there can be many service providers, who provide services alongside the treatment process.

Health care value chain



Breast Cancer Care

Figure 1 Value chain for breast cancer treatment (Porter and Teisberg 2006)

Differentiated from traditional manufacturing industries, service industry has a more complex production and consumption environment, where products become dematerialised, intangible, perishable and variable, customer has been an essential part of the value creation process, and collaboration of multiple players becomes substantial in service production (Parolini 1999; Campbell and Wilson 1996; Håkansson and Snehota 1989; Normann and Ramirez 1993; Stabell and Fjeldstad 1998). Since the value chain, a linear model, is limited by tangible resources and outputs transactions, treats customers as final users who are neglected in value co-creation, and does not account for the nature of collaboration and alliances, it becomes an inappropriate device with which to analyse many industries today and uncover sources of value (Prahalad and Ramaswamy 2004; Vargo and Lusch 2004). Therefore, in this new environment, a new perspective or approach is needed to enable a holistic view that takes into account the parts of



the system and their interconnections and analyse value at network level. It is critical to shift the view from supplier and single customer dyadic interaction to multi-player collaboration(Madhavan, Koka and Prescott 1998; Pinho et al. 2014).

With the growing recognition of customer's active role and potential in a service process, the concepts of value co-creation and Service-Dominant (S-D) logic have been widely used in industrial services and the collaborative nature of service production and value creation becomes prominent and substantial at the heart of service system design and development (Zhang et al. 2015). S-D logic (Lusch and Vargo 2006; Vargo and Lusch 2008b) provides the notion that all actors engage in the value co-creation or collaborative process and produce desired outcomes. It highlights that value creation is no longer only within firms' boundaries but value is co-created among various actors within the service network (Pinho et al. 2014). From a value network perspective, value creation goes beyond the firm and customer dyad to a broader perspective where all participants (e.g. companies, customers, suppliers, employees, stockholders, and other network partners) collaborate and integrate resources to create value for themselves and for others (Vargo and Lusch 2008b). The value co-creation network concept is now being widely applied in service systems including health care and ICT service sectors (Reijonsaari 2013; Peppard and Rylander 2006; Zhang et al. 2015). BOUNCE lies in the intersect of these two areas. Therefore, for capturing and analysing the value of BOUNCE results we employ throughout the project the concept of value co-creation network.

We follow the basic idea of Network Value Analysis (NVA) introduced by Peppard and Rylander in 2006 (Peppard and Rylander 2006) throughout BOUNCE. With NVA, the aim is to generate a comprehensive description of stakeholders, visualizing where value lies and how value is created in the BOUNCE network. There are five steps in developing the value co-creation network:

- 1. **Define the network and the focal.** The network focal could be an economic unit whose business model relies on the network under consideration (Peppard and Rylander 2006). In our case, the network focal is the products and services as the results of the BOUNCE project, in this case the BOUNCE tool. We understand the BOUNCE value co-creation network as consisting of all those actors or organizations of people that exist in the network focal's current network environment and have a direct or indirect influence on, or are affected by BOUNCE project results
- 2. Identify network entities (stakeholders). This step includes the work of identifying network participants (stakeholders) who could be potentially interested in, benefit from and contribute to the BOUNCE project results, and classifying the stakeholders.
- 3. Define the value each entity (stakeholder) perceives from being a network member. In this step, we try to capture the value perceived by the different stakeholders and develop a clear understanding of the value that is desired or expected by BOUNCE stakeholders. Value is described in both a positive sense (benefits) and a negative sense (costs, inconveniences or challenges).
- 4. Define value linkages and interactions between stakeholders. We try to analyse the network influences or value flow by identifying the connections (i.e. people or organizations that the stakeholder mostly works with when using the BOUNCE products and services) and activities (i.e. the tasks that the stakeholder is trying to perform and complete when using the BOUNCE products and services) of each stakeholder relevant to BOUNCE results.



4. Stakeholder Identification and Network

4.1. Framework for mapping the stakeholders

Stakeholders in the context of this task are understood as organizations or individuals, who could be potentially interested in, benefit from and contribute to the outcomes and results of BOUNCE project, including the BOUNCE computational model for predicting resilience in breast cancer patients, and the offered services. We identify the key stakeholders that are related to the BOUNCE value network by using the ecosystem framework presented in the webpage of European Connected Health Alliance Ecosystem (https://echalliance.com/?page=Ecosystems). It helps to bring together all key stakeholders across specific geographic regions and business sectors. We apply its two-tier principle of grouping and categorizing the stakeholders and make contextually some adjustments. Through brainstorming and internal meetings within the project team and interviewing relevant people (e.g. patients, healthcare professionals and patient organizations), we have identified nine categories of stakeholders in the BOUNCE network: patient, health and social service providers, family, employers of the patient, ICT service providers, third sector organizations, education & research organizations, authorities and healthcare financers. Under each category, except patient and employer, different groups of organizations or people are identified. Stakeholders are also divided into local stakeholders and global/EU stakeholders. The stakeholders in the categories of patient, health and social service providers, family, and employers of patient are mainly local, while the ones in the rest of the categories, i.e. third sector organizations, education & research organizations, ICT service providers, authorities and healthcare financers, can be local or global stakeholders. Figure 2 maps the categories and groups of the stakeholders in the BOUNCE value network.



Figure 2 A framework for mapping the stakeholders in the BOUNCE value network

4.2. Local (for each BOUNCE country) and global stakeholders

The local stakeholders were identified by the partners in Finland, Italy, Israel, and Portugal. Stakeholders were identified using several methods. First, BOUNCE consortium partners in each country identified stakeholders. Second, internal meetings between the project members were arranged and consultations with experts conducted to complete and verify the lists. Furthermore, global stakeholders were jointly identified by the partners in all of the four countries. The lists of local and global stakeholders are presented in Appendix 1. The lists of organisations having a stake in breast cancer care will serve as an important base for the rest of the BOUNCE project. Some of the identified stakeholders were interviewed to further elaborate on how value can be perceived in the BOUNCE project. The identification of the stakeholders also supported task 1.2, where user requirements for the BOUNCE tool were specified. A proper identification of BOUNCE stakeholders is important to ensure targeted communication and dissemination of BOUNCE findings and results.

4.2.1. Local stakeholders

In all four countries the most important local stakeholders are the healthcare professionals together with the patients and their loved ones, who will be the core users of BOUNCE tool and eventually benefit from the project results. User cases and requirements should be identified and defined from the perspectives of these three stakeholder categories. For the purpose of the Bounce project, the key stakeholders are the clinics and the professionals working in the clinics participating in the project (e.g. oncologists, nurses, and psychologists). For the dissemination of the BOUNCE results, the partners in these four countries identified also other hospitals and oncology clinics together with other stakeholders regarded as supporters or contributors in the course of improving patient's resilience. However, these non-core stakeholders and their importance vary across countries. For example, in some countries there are many cancer-related charities whereas in Finland charities are uncommon.

4.2.2. Global stakeholders

BOUNCE partners in the four countries jointly identified many global or international stakeholders that mainly fall under the categories of third sector organizations, education & research organizations, ICT service providers, authorities and healthcare financers. Although global stakeholders are not the main users of the BOUNCE tool, they can contribute in the development phase of the tool and/or benefit from the project results. Many of the identified global stakeholders, e.g. national societies of healthcare professionals, World Health Organization, European Commission, European Commission Initiative on Breast Cancer, European Breast Cancer Network, and Europa Donna, are important contributors in the BOUNCE value network and should be considered in the dissemination of the BOUNCE results.



5. Stakeholder Value Analysis

5.1. Value analysis framework

In this task, we try to capture the value perceived by each stakeholder in terms of benefits and costs for being in the BOUNCE network. We also try to identify the connections and information flows between the stakeholders in the BOUNCE network. Learning from Osterwalder and Pigneur's bestselling 2010 book *Business Model Generation (BMG)* (Osterwalder and Pigneur 2010) and their publication in 2014 *Value Proposition Design (VPD)* (Osterwalder et al. 2014), we develop a framework to analyse the value for each stakeholder in four dimensions: benefits, costs, activities, and connections to other stakeholders. Benefits refer to what the stakeholder can get by using BOUNCE products and services; costs dimension includes the costs in monetary terms or in time that the stakeholder spends to receive the product or service, as well as the risks the stakeholder will take, or the challenges the stakeholder might face when using BOUNCE products and services. Connections refer to people or organizations that the stakeholder mostly works or has connections with when using the BOUNCE products and services. Figure 3 illustrates the framework for analysing the value for BOUNCE stakeholders.

Benefits

the benefits that the stakeholder will get from Bounce and the outputs

• Activities the tasks that the stakeholder is trying to perform and complete

Costs

the costs that the stakeholder needs to pay, the risks the stakeholder will take, or the challenges the stakeholder has to face

Connections

People or organizations that the stakeholder mostly works with

Figure 3 Value analysis framework



5.2. Interview and interview questions

Interviews with relevant stakeholders were conducted to further increase the understanding of the potential value for each stakeholder group. Based on the value analysis framework, we developed interview questions, which can be found in Appendix 2. The questions are slightly different for different stakeholder groups. NHG and the clinical partners outside Finland conducted the interviews with the local stakeholders. In Finland, altogether twelve interviews were conducted: with one oncologist, two nurses, three patients, one husband of a patient, one sister of a patient, as well as representatives from an ICT service company (Noona Healthcare), an NGO (Europa Donna), an insurance company (AIG), and a research institute (Turku University Hospital, TYKS). In Italy, four interviews were conducted: with one psychologist, one oncologist, one nurse, and one patient. In Israel, representatives from two research institutes (Hebrew University and Ariel University) were interviewed. An overview of the interviewed stakeholders is presented in Table I.

Country	Stakeholder	Stakeholder	Gender	Age	Occupation	Institution/
Finland (12)	Health and social service providers	Oncologist	Female	-	Specialist in oncology	HUS Cancer Centre
	Health and social service providers	BC nurse	Female	-	BC nurse	HUS Cancer Centre
	Health and social service providers	Nurse	Female	-	Nurse	HUS Cancer Centre
	Patient	Patient	Female	59	Expert/Specialist	-
	Patient	Patient	Female	48	Works in the financial sector	-
	Patient	Patient	Female	58	Import assistant	-
	Family	Husband	Male	59	Management consultant	-
	Family	Sister	Female	57	-	-
	ICT service provider	ICT service company	Male	-	COO	Noona Healthcare
	Third sector organizations	NGO	Female	-	Head of Operations	Europa Donna
	Healthcare financers	Insurance company	Female	-	Marketing chief	AIG Europe Limited
	Research and education	Research institute / hospital	Female	-	Development manager	Western Cancer Centre, TYKS
Italy (4)	Health and social service providers	Oncologist	Female	-	Medical doctor in oncology, Researcher	IEO

Table 1 Overview of the interviewed stakeholders



	Health and social service providers	Nurse	Female	-	Research nurse	IEO
	Health and social service providers	Psychologist	Male	-	Clinical psychologist	IEO
	Patient	Patient	Female	49	Immigration consultant	-
Israel (2)	Education & research organizations	University	Female	-	Lecturer	School of Social Work, Hebrew University
	Education & research organizations	University	-	-	Researcher	Ariel Centre for Applied Cancer Research, Ariel University

5.3. Stakeholder analysis: benefits, costs, activities and connections

Table 2 presents the results of stakeholder value analysis, based on interview notes, brainstorming, internal meetings, and expert consultations, with four dimensions outlining the characteristics of each stakeholder group: benefits, costs, activities, and connections. The table contains only those stakeholders that have a direct interest in the BOUNCE tool.

The main benefits perceived by the stakeholders include:

- improving understanding on patients' resilience
- being able to group and segment patients according to resilience level and risk
- customizing and personalizing health care and social services to enhance patients' resilience and quality of life
- optimizing resource allocation, saving time and money
- reducing sick leave days
- advancing the research on well-being and quality of life of breast cancer patients
- increasing know-how on guiding, helping, and communicating with patients

The main costs perceived by the stakeholders are

- additional time and effort put into familiarizing oneself with the new system/tool and collecting additional information from different sources
- integrating the tool into the current processes and systems
- the risk of false evaluation and prediction
- rearranging the patient process and changing current work protocols

In the interviews, stakeholders reflected that collaboration and cooperation with other stakeholders is important when using the tool.



Health service providers, more specifically the doctors, nurses and other professionals treating the patients, are the core stakeholder group within the BOUNCE value network. BOUNCE tool can evaluate patients' resilience level and predict its changes, which could help health and social service providers to better understand the status and needs of the patients. Assisted by the tool, health and social service providers are able to identify the real problems, guide patients to right direction and offer evidence-based help and support, including psychological support. Thanks to the resilience-building intervention recommendations provided by the tool, health and social service providers can optimize the time and resources dedicated to each single patient and provide personalized services. However, there are some costs and challenges the stakeholders are concerned of, e.g. the cost of integrating the algorithm in the electronic medical record of the hospital, the time and effort spent by the health and social service providers to get acquainted with the new tool, and changing the current work protocols. After the tool is introduced, there may be some licence fees, the health and social service providers may need to do some additional work, e.g. collect additional data from the patients compared to current practice (e.g. diagnostic tests and spend time on interviews of the patients), read and analyse resilience-related reports of the patients, and communicate relevant information to the patients. Health and social service providers may even need to make an extra effort to communicate with and help the patients' families, who play an important role in supporting and taking care of the patients. Meanwhile, when using the tool, health and social service providers need comprehensive information about the patient collected from different sources, e.g. from the patient and her family.

The other core stakeholder groups are the patients and their families. They benefit from the tool through the more individualized and targeted interventions that support the wellbeing of the patient. It has not yet been decided whether the resilience level given by the tool should only be visible to the healthcare professionals or whether the patients would also have access to it. However, if the patients would have access to their resilience level, checking and monitoring their resilience level and its changes would help them to actively participate in making decisions on the possible interventions, seek for appropriate support, and go through the intervention programmes in an informed way. Family members could better understand how to help and support the patient. However, patients and their families also need to put extra time and effort in providing additional information and responding to questionnaires. One risk is that the anxiety level of the patients might increase if they get negative information about their resilience level, which is why it might be better if it was visible only to the healthcare professionals. Another risk is that the tool could give incorrect information about the resilience level.

Table 2 BOUNCE stakeholder analysis: benefits, costs, activities and connections

Stakeholder	Benefit	Cost/challenge	Activity
Health and social service providers (healthcare professionals, social work professionals, hospitals & clinics, primary health care facilities, other service providers)	 Increased understanding of resilience Increased capability to measure and evaluate the development of patients' resilience Increased understanding of underlying reasons to low resilience Identifying variables predictive of resilience Identifying variables predictive of resilience Deeper understanding of patients' reactions to stress and treatments Knowledge of patients' resilience status already before their visit Providing better support and service to the patient Grouping and segmentation of the patients Evidence-based personalized support at the right time Supporting patients to get back to work and providing suggestions for suitable workload Fewer concerns from the patients after the treatments 	 Risk of false evaluation and prediction Risk of false negatives/false positives Risk of under- or over-interpretation of the results Additional time and effort put in familiarizing with and using the tool Time and effort of integrating the tool to everyday work Time and effort to explain the risk level meaning to patients Challenge of motivating personnel to use the tool Additional time and cost in collecting the parameters for the algorithm Cost in Euros The cost of purchasing, installing and implementing the tool Privacy issues: who gets to view and use the information Uncertainty of how to use the resilience information in every day 	 Inputting patient data Explaining the meaning of resilience and the risk score to patients Integrating the tool into every-day work Focusing on and guiding patients with poor resilience Asking targeted and relevant questions from patients Suggesting resilience-building interventions to patients with poor resilience Changing work policies / practices Giving user feedback to the tool developer



	 Better ability to ask right/relevant questions Better decision making throughout the care path Decision support Improved cost-effectiveness of services Appropriate allocation of resources 	practice and how to deal with different groups of patients	
Patient	 Getting a better understanding of one's own resilience level and associated risks and recognizing the need for support Getting customized and personalized support and help Evidence-based resilience-building interventions Motivation from a good resilience level prediction Returning back to work faster Reduced fears Better self-esteem and quality of life Making better decisions regarding work and family life Better understanding on one's own resources and how to better adapt to the illness Understanding why certain interventions are meaningful 	 Time and effort put in filling in forms and answering questionnaires ICT skills needed, effort is big for those without them Anxiety caused by the questions asked in the questionnaires Uncertainty and risks Worry about over- or under- estimation of subjective measures Possible false predictions made by the tool Data confidentiality 	 Responding to inquiries and questionnaires Arranging work and family life according to one's own resources Following the suggested interventions



Family (husband/partner, relatives)	 Better understanding of the patient's situation and what kind of support she needs Being able to support the patient better and be more involved in the care Improved relationship with the patient Being able to cope better in everyday life 	 Time and effort put in learning to use the tool and responding to the questionnaires 	 Responding to questionnaires (if included in the algorithm) Helping and supporting the patient Communicating with health service providers Getting trained on how to help and support the patient
Employer	 Reduced sick leave days Better human resource management 	 Time and effort put in arranging/rearranging patient's work and finding replacement 	 Helping patient and her colleagues to arrange/rearrange the work load
ICT service providers (health-related software and application providers, telecom service companies)	 Possible license fees payed by hospitals to ICT providers Improved brand value for having such progressive tools available 	• Time and effort put to integrating the BOUNCE tool to the current system	 Creating an interface for the tool Integrating the BOUNCE tool or the data produced by the tool into the current electronic medical systems



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Third sector organizations (NGOs for patients and/or clinicians, open source platforms/communities, patient registry data organizations, foundations of health & social care, charities)	 Providing better targeted support and services to the patient based on the segmentation done by the healthcare provider Better resource allocation More effective lobbying and marketing activities 	 Time and effort put in developing new services 	 Using the information about factors affecting resilience and different patient groups/use cases in developing new services Providing input in the development phase of the tool
Education & research organizations (academic and educational associations, universities and schools, research centres)	 Advancing the research on the resilience, well-being and quality of life of breast cancer patients 	 Time and effort put into data collection and analysis 	 Conducting new research Incorporating BOUNCE results into new research
Authorities (governments and policy makers, authorities)	 Improved public services for the patient Improved quality of life for the relevant citizens (patient, family, etc.) 	 Time and effort put in developing privacy policies and reviewing whether such a tool is in accordance with current legislations 	 Certificating and authenticating BOUNCE results Providing standards and regulations Giving permissions Facilitating the dissemination and cooperation

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Healthcare financers (public financers and private insurance companies)	 Better quality of life for breast cancer patients Potential cost savings from reduced use of inefficient services or service use and sick leaves caused by low resilience Improved understanding of services needed e.g. information on what kind of services can be added to an insurance product 	 Time and effort put in developing new services/products Cost of the BOUNCE tool Cost of the new services 	 Developing new services or approving new services in the service portfolio covered by public money / insurance Updating the pricing of products (e.g. insurances) Updating the marketing message

6. Connections between stakeholders

Based on the interviews and expert analysis, we developed a map of the connections and information flows between the stakeholders (Figure 4). The patient is linked to almost all of the stakeholder groups, except for the authorities and education and research institutes. The patient mostly answers questionnaires and provides information about herself and her health status and receives different kinds of support. The health and social service providers are also connected to all other stakeholder categories, except for the employers of the patient and the healthcare financers. They mostly provide other stakeholders information about the patient and her support needs and receive different kinds of information, for example information about resilience and resilience-building support, and ICT services. The most "isolated" stakeholders are the employers and healthcare financers, who are connected only to the patient. The patient, health and social service providers, families, ICT service providers, and education and research institutes have direct connections to the BOUNCE tool itself.



Figure 4 Connections and information flows between the BOUNCE stakeholders



7. Discussion and conclusions

This document identifies stakeholders of BOUNCE results and provides an overview of the value created within the BOUNCE stakeholder network. We understand value as the balance between the perceived benefits and costs. We employed the stakeholder value framework to identify and classify the stakeholders of BOUNCE and characterized the stakeholders in four aspects: benefits, costs, activities and connections. By organizing meetings within BOUNCE consortium, and conducting interviews with the stakeholders, we developed a comprehensive understanding of the value induced by BOUNCE products and services and discovered the connections and information flows between the stakeholders. Nine categories of stakeholders in the BOUNCE network were identified:

- patient
- health and social service providers
- family
- employer(s) of the patient
- ICT service providers
- third sector organizations
- education & research organizations
- authorities
- healthcare financers

The key stakeholders, who could be the core users of the BOUNCE tool, are healthcare providers, patients and their families. According to our analysis, the main benefits that the stakeholders can gain by using the BOUNCE tool seem to be improvement in understanding the patient's resilience and need for support and the advancement in decision-making of personalized support to patients. The main costs identified are the time and effort put into learning the new tool, and the time and effort it will take to collect the new information needed by the BOUNCE tool. Also, time and effort will be needed to learn to use the tool and change the current processes to allow for more individualized solutions.

The stakeholder value analysis serves as a base for the other tasks and WPs and thus supports the development of value propositions and the development of use cases and user requirements for the BOUNCE tool (task 1.2). Furthermore, the findings presented here function as a support when planning targeted communication and outreach throughout the project. Communication can now be targeted throughout BOUNCE to specific stakeholder groups and meetings and seminars can be planned. The core stakeholder groups - healthcare and social service provider, patients, and the families - will throughout BOUNCE have an active role both in the development of the tool and in the validation of the findings. Furthermore, the connections to NGO organisations were identified as strong and thus they will in the future of BOUNCE be even more actively included as potential service providers of targeted interventions.



8. References

- Campbell, Alexandra J, and David T Wilson (1996), "Managed Networks: Creating Strategic Advantage," *Networks in marketing*, 125-43.
- Eklund, Fredrik, Suzan Ikävalko, Marie Krag, Anna Maksimainen, and Alexandra Treschow. Value-Based Procurement in Social and Healthcare Vabpro: Nordic Healthcare Group, Oy, 2015.
- Håkansson, Håkan, and Ivan Snehota (1989), "No Business Is an Island: The Network Concept of Business Strategy," *Scandinavian journal of management*, 5 (3), 187-200.
- Lusch, Robert F., and Stephen L. Vargo (2006), "Service-Dominant Logic: Reactions, Reflections and Refinements," *Marketing theory*, 6 (3), 281-88.
- Madhavan, Ravindranath, Balaji R Koka, and John E Prescott (1998), "Networks in Transition: How Industry Events (Re) Shape Interfirm Relationships," *Strategic Management Journal*, 439-59.
- Normann, Richard, and Rafael Ramirez (1993), "From Value Chain to Value Constellation: Designing Interactive Strategy," *Harvard Business Review*, 71 (4), 65-77.
- Osterwalder, Alexander, and Yves Pigneur (2010), *Business Model Generation: A Handbook for Visionaries, Game Changers, and Challengers*: John Wiley & Sons.
- Osterwalder, Alexander, Yves Pigneur, Gregory Bernarda, and Alan Smith (2014), Value Proposition Design: How to Create Products and Services Customers Want: John Wiley & Sons.
- Parolini, Cinzia (1999), The Value Net: A Tool for Competitive Strategy: Wiley.
- Peppard, Joe, and Anna Rylander (2006), "From Value Chain to Value Network:: Insights for Mobile Operators," *European management journal*, 24 (2-3), 128-41.
- Pinho, Nelson, Gabriela Beirão, Lia Patrício, and Raymond P. Fisk (2014), "Understanding Value Co-Creation in Complex Services with Many Actors," *Journal of Service Management*, 25 (4), 470-93.
- Porter, Michael E. "Competitive Advantage: Creating and Sustaining Superior Performance. 1985." New York: Free Press, 1985.
- ——— (2010), "What Is Value in Health Care?," *New England Journal of Medicine*, 363 (26), 2477-81.
- Porter, Michael E, and Elizabeth Olmsted Teisberg (2006), *Redefining Health Care: Creating Value-Based Competition on Results*: Harvard Business Press.
- Prahalad, Coimbatore K, and Venkat Ramaswamy (2004), "Co-Creating Unique Value with Customers," *Strategy & leadership*, 32 (3), 4-9.
- Rantala, Katja, and Heikki Karjaluoto. "Value Co-Creation in Health Care: Insights into the Transformation from Value Creation to Value Co-Creation through Digitization." Paper presented at the Proceedings of the 20th International Academic Mindtrek Conference, 2016.
- Reijonsaari, Karita. "Co-Creating Health-Examining the Effects of Co-Creation in a Lifestyle Intervention Service Targeting Physical Activity." 2013.
- Sánchez-Fernández, Raquel, M Ángeles Iniesta-Bonillo, and Morris B Holbrook (2009), "The Conceptualisation and Measurement of Consumer Value in Services," *International Journal of Market Research*, 51 (1), 1-17.
- Stabell, Charles B, and Øystein D Fjeldstad (1998), "Configuring Value for Competitive Advantage: On Chains, Shops, and Networks," *Strategic Management Journal*, 413-37.



- Vargo, Stephen L, and Robert F Lusch (2004), "Evolving to a New Dominant Logic for Marketing," *Journal of Marketing*, 68 (1), 1-17.
- ——— (2008a), "From Goods to Service (S): Divergences and Convergences of Logics," Industrial Marketing Management, 37 (3), 254-59.
- Vargo, Stephen L., and Robert F. Lusch (2008b), "Service-Dominant Logic: Continuing the Evolution," *Journal of the Academy of marketing Science*, 36 (1), 1-10.
- Zeithaml, Valarie A (1988), "Consumer Perceptions of Price, Quality, and Value: A Means-End Model and Synthesis of Evidence," *The Journal of Marketing*, 2-22.
- Zhang, Le, Hangjun Tong, H Onan Demirel, Vincent G Duffy, Yuehwern Yih, and Balmatee Bidassie (2015), "A Practical Model of Value Co-Creation in Healthcare Service," *Procedia Manufacturing*, 3 200-07.



9. Appendices

Appendix 1 Local and global stakeholders

Stakeholders in Finland

A list of local stakeholders in Finland		
Stakeholder class	Stakeholders	Local stakeholders
Patient	Patient	N/A
Health and social service providers	Healthcare professionals	 Specialists in Helsinki University Hospital Comprehensive Cancer Center (HUS CCC) HUS CCC physicians HUS CCC nurses HUS CCC psychologists and psychiatrics HUS Social work professionals
	Social work professionals	 Social work professionals in Helsinki and Uusimaa area Social work professionals in other university hospitals Social work professionals in health and social service providers in municipalities
	Hospitals & clinics, primary health care facilities	 HUS CCC: Helsinki University Hospital Comprehensive Cancer Center Cancer clinics on other university and central hospitals Helsinki Breast and Melanoma Centre (Laser Tilkka) Blueprint Genetics Docrates Terveystalo Mehiläinen PlusTerveys Eiran sairaala VITA lääkäriasema Lääkärikeskus Aava Doctagon Private psychotherapy providers (e,g. Vastaamo, Komppi)
	Other service providers, e.g. exercise services, nutritional services, etc.	Numerous small providers and gym chains
Family	Husband/partner	N/A
	Relatives	N/A
Employers	Employers of patient	N/A
ICT service providers	Health-related software and application providers	 Noona Healthcare Oy KELA Kanta Kaiku Health Apotti



		• Electronic medical record providers (Epic, CGI, Tieto + smaller ones)
	Telecom service companies	 Elisa Oyj Telia DNA
Third sector organizations	NGOs for patients and/or clinicians	 fuckcancer.fi Cancer Society in Finland Europa Donna Siskot
	Open source platforms/community	 Skosmos coss.fi
		•
	Charities	Syöpäsäätiö: Cancer Foundation
	Foundations of health & social care	 Syöpäsäätiö: Cancer Foundation Jenny and Antti Wihuri Foundation
Education & research organizations	Academic and educational associations	 Cancer Society in Finland Suomen syöpäsairaanhoitajat Suomen onkologiayhdistys The Finnish Medical Society Duodecim Hoitotyön tutkimussäätiö Lääkäriliitto Finnish nurses association
	Universities and schools	 University of Helsinki Faculty of Medicine Aalto University University of Turku University of Tampere
	Research centers	 The National Institute for Health and Welfare (THL) Finnish Cancer Registry HEMA: Institute of Healthcare Engineering, Management and Architecture Finnish Centre for Evidence-Based Health Care NRF: Nursing Research Foundation (Hotus)
Authorities	Governmental & national agencies and policy makers	Ministry of Social Affairs and Health in Finland
	Patient -registry data organizations	 Finnish Cancer Registry THL: National Institute for Health and Welfare KELA: Social Insurance Institution
	Authorities	 The National Institute for Health and Welfare (THL) FinOHTA – Finnish Office for Health Technology Assessment
Financers of healthcare	Public financers of healthcare	 Municipalities in the Uusimaa region Social Insurance Institution of Finland (KELA)
	Private financers of healthcare	 OP: Pohjola Insurance Ltd If P&C Insurance LähiTäpiola



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Stakeholders in Italy

A list of local stakeholders in Italy		
Stakeholder class	Stakeholders	Local stakeholders
Patient	Patient	N/A
Health and social service providers	Healthcare professionals	 IEO specialists IEO Physicians IEO Nurses IEO Psychologists Healthcare professionals in Milano area Healthcare professionals in other university and central hospitals Healthcare professionals in health service providers in primary healthcare Healthcare professionals in private sector
	Social work professionals	 IEO Social work professionals Social work professionals in Milano area Social work professionals in other university hospitals Social work professionals in health and social service providers in municipalities
	Hospitals & clinics, primary health care facilities	 IEO INT: Istituto Nazionale dei Tumori Ospedale San Raffaele Ospedale Niguarda Gruppo Multimedica – Breast Unit Fondazione Ca' Granda – Ospedale Maggiore Policlinico Humanitas Cancer Center Ospedale Sanco – Polo Universitario Ospedale San Gerardo (Monza) Ospedale San Carlo Borromeo Others university hospital and cancer clinics in Italy Gruppo Multimedica – Breast Unit Columbus clinic center Humanitas - San Pio X Ospedale San Raffaele Humanitas Cancer Center Ospedale Sanco – Polo Universitario Ospedale Sanco – Polo Universitario Ospedale Sanco – Polo Universitario Ospedale San Carlo Borromeo Ospedale San Carlo Borromeo
	Other service providers,	 Numerous small providers as well as gym chains



	e.g. exercise services, nutritional services, etc.	
Family	Husband/partner	N/A
	Relatives	N/A
Employers	Employers of patient	N/A
ICT service providers	Health-related software and application providers	 Noona Healthcare Oy Kaiku Health iManageCancer Portal iPHR: Personal Health Record myHealthAvatar iMangeMyHealth
	Telecom service companies	 Vodafone TIM Wind Fastweb Postemobile
Third sector organizations	NGOs for patients and/or clinicians	 Europa Donna AIRC: Associazione Italiana per la Ricerca sul Cancro AIMaC: Associazione Italiana Malati di Cancro La forza e il sorriso We will care Associazioni di volontariato: "Sottovoce" SIPO: Società Italiana di Psiconcologia FUV: Fondazione Umberto Veronesi FIEO: Fondazione IEO AIOM: Associazione Italiana di Oncologia Medica
	Open source platforms/community	N/A
	Patient -registry data organizations	 AIRTUM: Associazione Italiana Registri Tumori Istituto Superiore di Sanita
	Charities	 Europa Donna AIRC: Associazione Italiana per la Ricerca sul Cancro AIMaC: Associazione Italiana Malati di Cancro La forza e il sorriso We will care FUV: Fondazione Umberto Veronesi Susan G. Komen FIEO: Fondazione IEO CCM
	Foundations of health & social care	 FUV: Fondazione Umberto Veronesi FIEO: Fondazione IEO CCM
Education & research organizations	Academic and educational associations	 SIPO: Società Italiana di Psiconcologia AIRC: Associazione Italiana per la Ricerca sul Cancro AIMaC: Associazione Italiana Malati di Cancro AIOM: Associazione Italiana di Oncologia Medica



	Universities and schools	 Università degli studi di Milano Università degli studi di Padova SEMM: European School of Molecular Medicine School of Specialization in Oncology/Scuola di Specializzazione in Oncologia Università Cattolica del Sacro Cuore, Milan Università degli studi di Pavia Humanitas University Università San Raffaele
	Research centers	 Istituto Europeo di Oncologia IEO IFOM: FIRC Institute of Molecular Oncology Foundation IOV: Istituto Oncologico Veneto, Padova CRO: Centro di Riferimento Oncologico, Aviano
Authorities	Governments and policy makers	Ministero della Salute
	Authorities	 City of Milan; AIRTUM: Associazione Italiana Registri Tumori
Financers of healthcare	Public or private	 Allianz Global Assistance Generali Assirete Srl Insiemesalute Banca Popolare Milano Mapfre Blue Assistance S.P.A. Medic4all Italia Spa Casagit My Assitance C.A.S.P.I.E. Previmedical Spa Consorzio Musa Sistemi Sanitari Scrl Europassistance Societa' Nazionale Di Mutuo Soccorso Cesare Pozzo Fasi Unisalute Fondo Assistenza E Benessere Vanbreda International Fondo Sanitario Integrativo Del Gruppo Intesa San Paolo Winsalute/Coopsalute Gruppo Filo Diretto Service Aldac (Fasdac) Day Medical Aldai E.M.Assist.Commercianti Anla Fasen Asem Fida Cral: Banca Popolare Comm.& Ind.



	F.I.M.I.V. Banca Popolare Italiana Fisdaf C.A.D.G.I. Fisde Campa Inter Partner Credito Artigiano Fondo Integrativo Ass.Mal.Dip.
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Stakeholders in Israel

A list of local stakeholders in Israel		
Stakeholder class	Stakeholders	Local stakeholders
Patient	Patient	N/A
Health and social service providers	Healthcare professionals	 Physicians Nurses Psychologists
	Social work professionals	• Social workers in 6 universities, hospitals and services
	Hospitals & clinics, primary health care facilities	 Hadassah Medical Center – Psycho-Oncology Unit Shaare Zedek Medical Center Davidoff Center Kaplan Hospital
	Other service providers, e.g. exercise services, nutritional services, etc.	 Numerous small providers and gym chains
Family	Husband/partner	N/A
	Relatives	N/A
Employers	Employers of patient	N/A
ICT service providers	Health-related software and application providers	Noona Healthcare Oy
	Telecom service companies	N/A
Third sector organizations	NGOs for patients and/or clinicians	 ICA : The Israel Cancer Association IPAS: Israel Psycho-Oncology Association One in Nine
	Open source platforms/community	 OFAKIM Social Science network - Humanities-net@listserver.cc.huji.ac.il
	Patient -registry data organizations	N/A



	Charities	N/A
	Foundations of health & social care	N/A
Education & research organizations	Academic and educational associations	• IDC, Tel Aviv Academic College
	Universities and schools	• Psychology and Social work departments in 6 Universities and colleges: Hebrew University of Jerusalem, Tel Aviv U, Bar-Ilan U, Haifa U, Ben- Gurion U, Ariel U
	Research centers	ACACR: Ariel Center for Applied Cancer Research
Authorities	Governments and policy makers	Ministry of Health
	Authorities	N/A
Financers of healthcare	Public or private	 Clalit Leumit Maccabi Meuhedet

Stakeholders in Portugal

A list of local stakeholders in Portugal		
Stakeholder class	Stakeholders	Local stakeholders
Patient	Patient	 Mamahelp Evita Laço Viva Mulher Viva Europa Donna- Portugal Movimento Vencer e Viver APAMCM - Associação Portuguesa de Apoio à Mulher com Cancro da Mama Amigas do Peito
Health and social service providers	Healthcare professionals	 SPO: Sociedade Portuguesa de Oncologia- Portuguese society of oncology SPS: Sociedade Portuguesa de Senologia- Portuguese society of breast cancer SPPSM: Sociedade Portuguesa de Psiquiatria e Saúde Mental OM: Ordem dos medicos- College of Physicians SPEO: Sociedade Portuguesa de Enfermagem Oncologica- Portuguese society of oncology nurses SPPC: Sociedade Portuguesa de Psicologia Clínica- Protuguese society of clinical psychology
	Social work professionals	N/A



	Hospitals & clinics, primary health care facilities	 Champalimaud Clincal Center Instituto de Oncologia Francisco Gentil - Porto Instituto de Oncologia Francisco Gentil - Lisboa Instituto de Oncologia Francisco Gentil - Coimbra Centro Hospitalar de São João Centro Hospitalar do Porto HSOG: Hospital da Senhora da Oliveira, Guimaraes, EPE Hospital de Braga Centro Hospitalar Lisboa Norte (Hospital de Santa Maria e o Hospital de Pulido Valente) CHLC: Centro Hospitalar de Lisboa Central (Hospital de S. José, Hospital de S. António dos Capuchos). Centro Hospitalar de Lisboa Ocidental (Hospital de S. Francisco Xavier) Instituto CUF (Porto e Lisboa) Hospital dos Lusíadas (Porto e Lisboa)
	Other service providers, e.g. exercise services, nutritional services, etc.	• Numerous small providers as well as gym chain
Family	Husband/partner	N/A
	Relatives	N/A
Employers	Employers of patient	N/A
ICT service providers	Health-related software and application providers	 Noona Healthcare Oy Virtual Care Glintt
	Telecom service companies	 ALTICE Portugal Delloite
Third sector organizations	NGOs for patients and/or clinicians	 Mamahelp Evita Laço Viva Mulher Viva Europa Donna- Portugal Movimento Vencer e Viver APAMCM: Associação Portuguesa de Apoio à Mulher com Cancro da Mama Amigas do Peito
	Open source platforms/community	 Portal da Saúde PORDATA SPMS: Serviços Partilhados do Ministério da Saúde
	Patient -registry data organizations	N/A
	Charities	 Liga Portuguesa conta o Cancro Terra dos Sonhos



	Foundations of health & social care	 Fundação Gulbenkian Fundação Portugal Telecom Fundação EDP
Education & research organizations	Academic and educational associations	 Champalimaud Clincal Center Instituto de Oncologia Francisco Gentil - Porto Instituto de Oncologia Francisco Gentil - Lisboa Centro Hospitalar de São João Centro Hospitalar do Porto Centro Hospitalar Lisboa Norte (Hospital de Santa Maria)
	Universities and schools	 FMUP: Faculdade de medicina da Universidade do Porto ICBAS: Faculdade de Ciências Médicas Abel Salazar FMUL: Faculdade de Medicina da Universidade de Lisboa FCM-ULN: Faculdade de Ciências Médicas da Universidade Nova
	Research centers	 I3S Instituto de Investigação e Inovação em Saúde IPATIMUP: Instituto de Patologia e Imunologia Molecular da Universidade do Porto IMM: Instituto de Medicina Molecular Champalimaud Clincal Center Instituto de Oncologia Francisco Gentil - Porto Instituto de Oncologia Francisco Gentil - Lisboa Instituto de Oncologia Francisco Gentil - Coimbra Centro Hospitalar de São João Centro Hospitalar do Porto Centro Hospitalar Lisboa Norte (Hospital de Santa Maria)
Authorities	Governments and policy makers	Ministério da Saúde (Health Ministry)
	Authorities	 CEIC: Comissão de Ética para a Investigação Clínica CNPD: Comissão Nacional de Protecção de Dados
Financers of healthcare	Public or private	ASF-APS: Associação portuguesa de Seguradores

A list of global stakeholders

Global/European stakeholders			
Stakeholder class	Stakeholders	European / Global stakeholders	
Third sector organizations	NGOs for patients and/or clinicians	 Europa Donna ECPC: European Cancer Patient Coalition 	
	Open source platforms/community	 Gitlab; Github; Stack Overflow 	
	Patient -registry data organizations	IACR: International Association of Cancer Registries	
	Charities	 pinkribbon.com Breast Cancer Now 	



	Foundations of health & social care	 European Union BCRF: Breast Cancer Research Foundation
Education & research organizations	Academic and educational associations	 EACR: European Association for Cancer Research EHMA: European Health Management Association ICHOM: International Consortium for Health Outcomes Measurement ORAHS: Operational Research Applied to Health Services INFORMS: The Institute for Operations Research and the Management Sciences EURO: Association of European Operational Research Societies ECCO: European CanCer Organisation ESMO European Society for Medical Oncology IPOS EBC Council: European Breast Cancer Council EORTC BCG: European Organisation for Research and Treatment of Cancer Breast Cancer Group ICN: International Council of Nurses EFN: European Federation of Nurses Associations Nordic Nurses Association EFNNMA: European Forum of National Nursing and Midwifery Associations ACENDIO: Association for Common European Nursing Diagnoses, Interventions and Outcomes HORATIO: European Association for Psychiatric Nurses PSSN Nordic Psychiatric Nurses Association EUSOMA: European Society of Breast Cancer Specialists ESO: European Society of Breast Cancer Specialists ESO: European Commission Initiative on Breast Cancer SIOG: International Society of Geriatric Oncology EORC: European Commission Initiative on Breast Cancer SIOG: International Society of Geriatric Oncology
	Universities and schools	most universities in the world are international in their research networks and therefore it does not make sense to start listing them
	Research centers	 IARC: International Agency for Research on Cancer ICRC: International Cancer Research Center IBCSG: International Breast Cancer Study Group The Cochrane Collaboration The Joanna Briggs Collaboration
Authorities	Governments and policy makers	 European Commission ECIBC: European Commission Initiative on Breast Cancer EBCN: European Breast Cancer Network UICC: Union for International Cancer Control
	Authorities	 WHO: World Health Organization WHO Collaborating Center for Nursing (Helsinki, Finland) WHO Collaborating Centre for Women's Health (Manchester, UK) WHO Collaborating Centre for Women's Health (Carlton, Australia)
Financers of healthcare	Public or private	 Freedom insurance services LTD (Breast Cancer Travel Insurance) Insurancewith (Breast Cancer Travel Insurance) Free Spirit Travel Insurance (Travel Insurance for Breast Cancer)



ICT service providers	Health-related software and application providers	 CGI (Information technology and business process outsourcing) Siemens Epic Cerner CareZone Breast Cancer: Beyond the Shock Breast Check Now B4BC My Cancer Coach
	Telecom service companies	N/A

Appendix 2 Interview questions for each stakeholder group

Questions for patients:

Background questions:

- Name:
- Age:
- Marital status / family situation:
- What is your educational background?
- What do you do for living?
- How experienced are you with ICT tools and solutions?

During the treatments/illness:

- Marital status / family situation:
- Employment/studying status
- Age:
- When were you diagnosed with BC?
- What kind of treatment did you receive? (radiotherapy, chemotherapy, surgery)
- Where were you treated?

Questions related to the research project:

Resilience:

- How do you perceive the concept of resilience, especially related to breast cancer?
- How was your resilience assessed during and after the treatments?
- At which stage of care was resilience assessed?
- What kind of challenges did you have in surviving from BC and the treatments? (psychologically)
- Was there any phase during or after the treatments which was particularly challenging?
- When/at which stage of care did you realize that you will survive? How did you notice that?

- What kind of support did you get during your treatments from healthcare? What about from other sources? (E.g. family, friends, patient organizations) *Interventions:*

- What helps you adopt/maintain a positive attitude?

- How willing are/were you to follow interventions to improve your well-being suggested by your oncology group?

- Have you adopted interventions in your daily life to improve your well-being? What type of interventions?

- Were these interventions helpful?

<u>Use cases:</u>

-Would you like to have access to a prediction tool that calculates your potential risk of poor resilience based on your current biomedical and psychosocial status?

- If you would have complete freedom, how would you envision a tool that predicts resilience in BC patients?

<u>Benefits:</u>

- How would the resilience prediction have benefited you?
- What about your family/loved ones, how would they have benefited from it?
- Is there a need for this kind of prediction?



<u>Activities:</u>

- How would the prediction have affected your way of being / daily life?

- Did you answer any questionnaires during your treatment? How (in paper format, in digital format, face to face)? How often?

- Would you have been able/willing to answer any questionnaires during the treatments? (e.g. online, with mobile application)? How often?

Information flow:

- What information would you have needed about the tool, if it had been in use during your treatments?

<u>Costs:</u>

- What kind of challenges you see in predicting resilience?
- What kind of inconvenience do you think it would cause for the patient?
- What kind of costs do you think it would cause for the patient?

Connections:

- Which stakeholders should the patient be in contact with regarding resilience prediction? <u>*Closing:*</u>

- Would you like to share something else related to this topic, which we did not cover in this interview?

- Do you wish to be informed about the progress of the project?
- Can I be in contact with you after this interview if needed?

Questions for health care and social service providers (e.g. doctors and nurses):

Background questions:

- Name, title, organization
- What is your educational background?
- What do you do for living and how is your job related to breast cancer patients?
- How long have you taken care of this kind of patients?
- How familiar are you with clinal information technology?
- How experienced are you with using clinical decision support systems (CDSS)?
- Is your experience with CDSS good?

Questions related to the research project:

<u>Resilience:</u>

- How do you perceive the concept of resilience, especially related to breast cancer?

- How do you currently assess resilience / how is resilience currently being assessed in breast cancer?

- At which stage of care is resilience assessed?
- How are the challenges in breast cancer patients' resilience currently assessed or detected?
- How does bad resilience manifest itself? When does it manifest itself?
- How does good resilience manifest itself? At which stage of care does it manifest itself?
- How are the patients in need of support currently supported? How is that support different from the support of patients with good resilience?
- From your experience describe the profile of patients that are more prone to bad resilience.
- From your experience describe the profile of patients that are more prone to good resilience.
- From your experience what type of resilience interventions seem to help breast cancer patients?

<u>Benefits:</u>



- How could you make a use of resilience predictions of (e.g. resilience level) in patient care?

- How would this information benefit 1) you/the hospital/the society/health service provider, 2) patients?

- Could you name other stakeholders, who would benefit from this information and how would they benefit from it?

- What kind of need is there for predicting resilience / a resilience prediction tool in your work?

- Is there a need for this kind of tool?

<u>Use cases:</u>

- If you would have complete freedom, how would you envision this kind of resilience prediction tool?

- How would you actually use the tool in your work?

- What kind of functionalities would you wish for from the tool?

- How should the tool be in order to be easy for you to use in your work?

- In which way would you like to receive the information about the patient's risk level? (e.g. as one number, colour coding of risks (red, amber and green), risk categories, or in some other way? In which view?)

- At which stage would you want to receive the information about the patient's risk level? (e.g. before the reception or at the reception? Information about the changes in risk level?)

-How could clinicians be convinced to use this kind of resilience prediction tool?

-Should the patient's risk level be shared with the patient?

-Should the resilience prediction module be accessible by the patient?

Activities:

- How would you have to change your way of working / current practice, if the tool would be in use?

Information flow:

- What information would you need in the installation phase of the tool?

- What information would you need to use the tool?

<u>Costs:</u>

- What kind of challenges you see in the tool and in its use?

- What kind of inconvenience would the installation of the tool/using the tool cause?

- What kind of costs would there be in the installation phase of the tool/in using the tool? <u>Connections:</u>

- Which stakeholders would you be in contact with in the installation phase of the tool?

- Which stakeholders would you be in contact with when using the tool?

- Would you like to share something else related to this topic, which we did not cover in this interview?

<u>Closinq:</u>

- Do you want to be informed about the progress of the project?

- Can I be in contact with you after this interview if needed?

Questions for the family

Background questions:

- Name:
- Age:
- Marital status / family situation:
- How experienced are you with ICT tools and solutions?



During the treatments/illness:

- Relationship to your loved one:
- How and how often were you in contact to your loved one during the illness?
- Marital status / family situation:
- Employment/studying status

- Age:

Questions related to the research project:

Please answer the questions from your perspective

Resilience:

- How do you perceive the concept of resilience, especially related to breast cancer?
- How was your loved one's resilience assessed during and after the treatments?
- At which stage of care was resilience assessed?
- What kind of challenges did she/you have in surviving from BC and the treatments? (psychologically)
- Was there any phase during or after the treatments which was particularly challenging?
- When/at which stage of care did you realize that your loved one will survive? How did you notice that?
- What kind of support did she/you get during the treatments from healthcare? What about from other sources? (E.g. family, friends, patient organizations)
- What kind of support you would have needed during the illness?
- What kind of support she would have needed during the illness?

<u>Benefits:</u>

- How would the resilience prediction have benefited her/you?
- What about other loved ones, how would they have benefited from it?
- Is there a need for this kind of prediction?

<u>Use cases:</u>

- If you would have complete freedom, how would you envision a tool that predicts resilience in BC patients?

<u>Activities:</u>

- How would the prediction have affected her way of being / daily life?

- How would the prediction have affected your way of being / daily life?

- Did you answer any questionnaires during your treatment? How (in paper format, in digital format, face to face)? How often?

- Would you have been able/willing to answer any questionnaires during the treatments? (e.g. online, with mobile application)? How often?

Information flow:

- What information would you have needed about the tool, if it had been in use during the treatments?

<u>Costs:</u>

- What kind of challenges you see in predicting resilience?

- What kind of inconvenience do you think it would cause for the patient/the patients' loved one?

- What kind of costs do you think it would cause for the patient/the patients' loved one? <u>Connections:</u>

- Which stakeholders should the patient's loved one be in contact with regarding resilience prediction?

<u>Closing:</u>



- Would you like to share something else related to this topic, which we did not cover in this interview?

- Do you wish to be informed about the progress of the project?
- Can I be in contact with you after this interview if needed?

Questions for the ICT service providers

Background questions:

- Name, title, organization
- What is your educational background?
- What do you do for living and how is your job related to breast cancer patients?

- How long have you been working with BC patients (incl. product development etc. before the actual business started)?

- How long have you been offering services for BC patients?

Questions related to the research project:

Resilience:

- How do you perceive the concept of resilience, especially related to breast cancer?
- How do you currently assess BC patients' resilience?
- At which stage of care is resilience assessed?
- How are the challenges in breast cancer patients' resilience currently assessed or detected?
- How does bad resilience manifest itself? When does it manifest itself?
- How does good resilience manifest itself? At which stage of care does it manifest itself?
- How are the patients in need of support currently supported? How is that support different

from the support of patients with good resilience?

<u>Benefits:</u>

- How could you make a use of resilience predictions of (e.g. resilience level) in your business?
- How would this information benefit your business/the patients?

- Could you name other stakeholders, who would benefit from this information and how would they benefit from it?

- What kind of need is there for predicting resilience / a resilience prediction tool in your work?
- Is there a need for this kind of tool?

<u>Use cases/user requirements:</u>

- If you would have complete freedom, how would you envision this kind of resilience prediction tool?

- What kind of functionalities would you wish for from the tool?

<u>Activities:</u>

How would you have to change your way of working/the service, if the tool would be in use?How could you connect/integrate the tool in your service?

Information flow:

- What information would you need in the installation phase of the tool?

- What information would you need to use the tool?

<u>Costs:</u>

- What kind of challenges you see in the tool and in its use?
- What kind of inconvenience would the installation of the tool/using the tool cause?

- What kind of costs would there be in the installation phase of the tool/in using the tool? <u>Connections:</u>

- Which stakeholders would you be in contact with in the installation phase of the tool?





- Which stakeholders would you be in contact with when using the tool?

<u>Closinq</u>

- Would you like to share something else related to this topic, which we did not cover in this interview?

- Do you wish to be informed about the progress of the project?

- Can I be in contact with you after this interview if needed?

Questions for the third sector organizations (e.g. patient organization):

Background questions:

- Name, title, organization
- What is your educational background?
- What do you do for living and how is your job related to breast cancer patients?
- How long have you taken care of this kind of patients?
- How familiar are you with clinal information technology?
- How experienced are you with using clinical decision support systems (CDSS)?
- Is your experience with CDSS good?

Questions related to the research project:

<u>Resilience:</u>

- How do you perceive the concept of resilience, especially related to breast cancer?
- How do you currently assess resilience / how is resilience currently being assessed in breast cancer?
- At which stage of care is resilience assessed?
- How are the challenges in breast cancer patients' resilience currently assessed or detected?
- How does bad resilience manifest itself? When does it manifest itself?
- How does good resilience manifest itself? At which stage of care does it manifest itself?
- How are the patients in need of support currently supported? How is that support different from the support of patients with good resilience?
- From your experience describe the profile of patients that are more prone to bad resilience.
- From your experience describe the profile of patients that are more prone to good resilience.
- From your experience what type of resilience interventions seem to help breast cancer patients?

<u>Benefits:</u>

- How could you make a use of resilience predictions of (e.g. resilience level) in patient care?

- How would this information benefit 1) you/the hospital/the society/health service provider,

patients?

- Could you name other stakeholders, who would benefit from this information and how would they benefit from it?

- What kind of need is there for predicting resilience / a resilience prediction tool in your work?
- Is there a need for this kind of tool?

<u>Use cases:</u>

- If you would have complete freedom, how would you envision this kind of resilience prediction tool?

- How would you actually use the tool in your work?
- What kind of functionalities would you wish for from the tool?
- How should the tool be in order to be easy for you to use in your work?
- In which way would you like to receive the information about the patient's risk level? (e.g. as



one number, colour coding of risks (red, amber and green), risk categories, or in some other way? In which view?)

- At which stage would you want to receive the information about the patient's risk level? (e.g. before the reception or at the reception? Information about the changes in risk level?)

-How could clinicians be convinced to use this kind of resilience prediction tool?

-Should the patient's risk level be shared with the patient?

-Should the resilience prediction module be accessible by the patient?

<u>Activities:</u>

- How would you have to change your way of working / current practice, if the tool would be in use?

Information flow:

- What information would you need in the installation phase of the tool?

- What information would you need to use the tool?

<u>Costs:</u>

- What kind of challenges you see in the tool and in its use?

- What kind of inconvenience would the installation of the tool/using the tool cause?

- What kind of costs would there be in the installation phase of the tool/in using the tool? <u>Connections:</u>
- Which stakeholders would you be in contact with in the installation phase of the tool?
- Which stakeholders would you be in contact with when using the tool?
- Would you like to share something else related to this topic, which we did not cover in this interview?

Closinq:

- Do you want to be informed about the progress of the project?
- Can I be in contact with you after this interview if needed?

Questions for the healthcare financers

Background questions:

- Name, title, organization
- What is your educational background?
- What do you do for living and how is your job related to breast cancer patients?

- How long have you been working with BC patients (incl. product development etc. before the actual business started)?

- How long have you been offering services for BC patients?

Questions related to the research project:

Resilience:

- How do you perceive the concept of resilience, especially related to breast cancer?

- How do you currently assess BC patients' resilience?
- At which stage of care is resilience assessed?
- How are the challenges in breast cancer patients' resilience currently assessed or detected?
- How does bad resilience manifest itself? When does it manifest itself?
- How does good resilience manifest itself? At which stage of care does it manifest itself?
- How are the patients in need of support currently supported? How is that support different

from the support of patients with good resilience?

<u>Benefits:</u>



- How could you make a use of resilience predictions of (e.g. resilience level) in your business?

- How would this information benefit your business/the patients?

- Could you name other stakeholders, who would benefit from this information and how would they benefit from it?

What kind of need is there for predicting resilience / a resilience prediction tool in your work?Is there a need for this kind of tool?

Use cases/user requirements:

- If you would have complete freedom, how would you envision this kind of resilience prediction tool?

Activities:

How would you have to change your way of working/the service, if the tool would be in use?How could you connect/integrate the tool in your service?

Information flow:

- What information would you need in the installation phase of the tool?

- What information would you need to use the tool?

<u>Costs:</u>

- What kind of challenges you see in the tool and in its use?

- What kind of inconvenience would the installation of the tool/using the tool cause?

- What kind of costs would there be in the installation phase of the tool/in using the tool? <u>Connections:</u>

- Which stakeholders would you be in contact with in the installation phase of the tool?

- Which stakeholders would you be in contact with when using the tool?

Closing:

- Would you like to share something else related to this topic, which we did not cover in this interview?

- Do you wish to be informed about the progress of the project?

- Can I be in contact with you after this interview if needed?