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THE ARCTIC
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When Patients Innovate and Share

Implementing Patient Innovation in Norway as a non-profit organization that applies the principles of Responsible Research and Innovation

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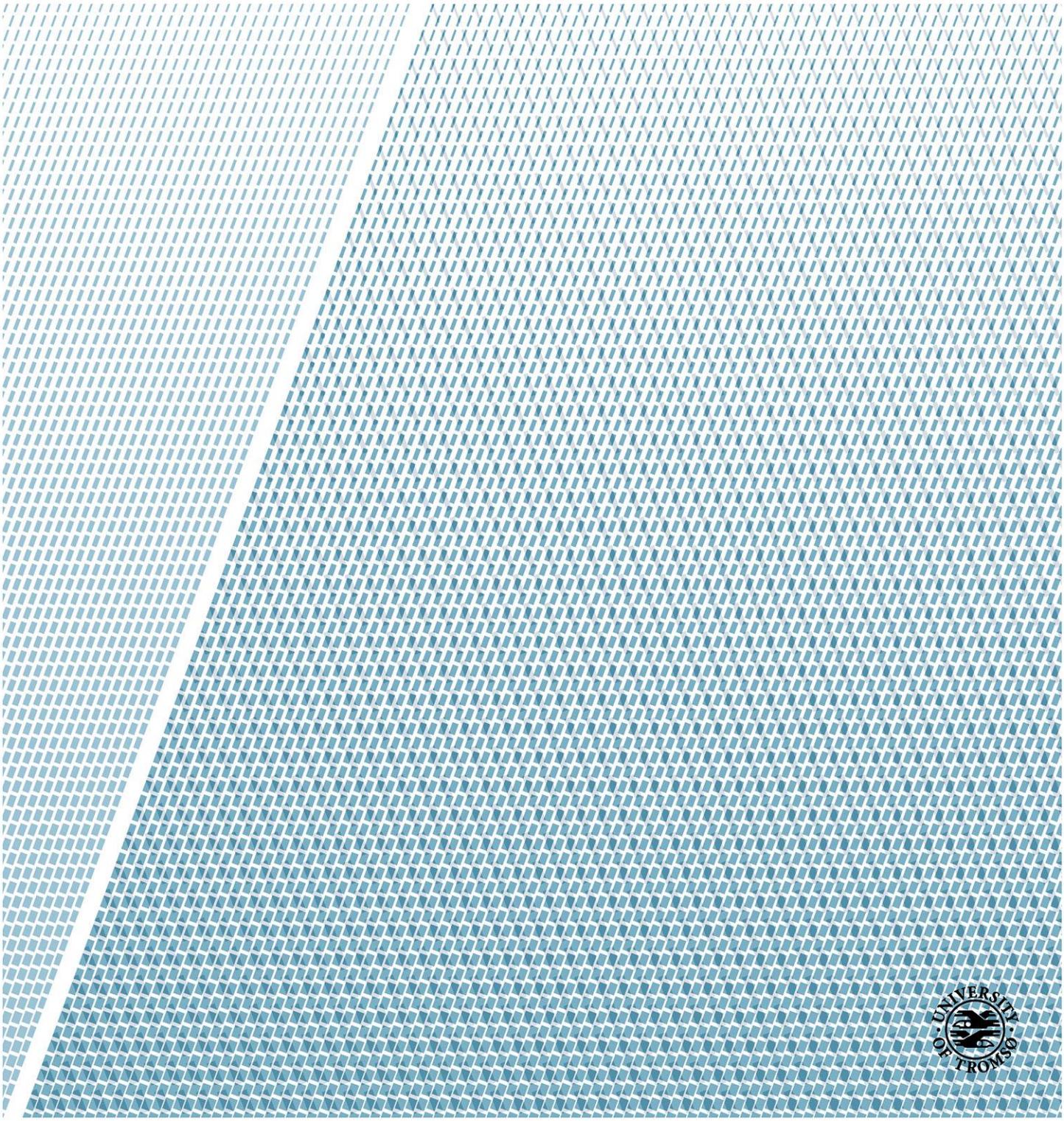
Yati

Master's Thesis in Business Creation and Entrepreneurship - June 2017



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Abstract

Patient Innovation (PI) is a free, safe, and multilingual online platform that facilitates the sharing of innovative solutions developed by patients and their caregivers. This platform is currently available in English, Portuguese, and German. The founders of the platform, originated from Portugal, have a mission to improve the lives of patients around the world through this platform. Thus, they promote PI in different countries and involve in exhibitions. The Local Chapter is one of the efforts of PI in reaching out to patients in other regions of the world. The Local Chapter, which acts as a representative of PI, is also a non-profit organization similar to PI Global Coordination Center (GCC).

The Local Chapter in Norway is the idea of the initiators that met the founders of PI in a dinner meeting. These initiators have a vision of launching PI's Local Chapter in Stavanger. This idea reached the author of this thesis through her supervisor, thus the author decided to write about how to implement the Local Chapter in Norway. This master's thesis aims to answer the research question about how to achieve an effective adaptation of PI's Local Chapter in Norway. In order to answer this main research question, three sub-research questions are generated. These sub-research questions are answered by the innovation study, the market study, and the business plan of this thesis.

This thesis consists of four chapters: introduction, innovation study, market study, and business plan. The introduction presents the research question, the methodology and the theoretical frameworks that are utilized in the following chapters. The innovation study aims to define the innovative position of PI's platform, which is necessary for the market study chapter. The marketing strategy in the market study chapter comprises marketing activities that will ensure the survival and growth of the Local Chapter in Norway. This marketing strategy is also a part of the business plan that is presented in the last chapter. In order to create a sustainable business model, the market strategy that aims to get more users and get more donators (individual and corporate) is formulated as part of the business model. Finally, the business plan, which includes the business model, elaborates comprehensively the decisions that will ensure the successful launch of PI's Local Chapter in Norway.

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List of Abbreviation

4Ps	-	Product, Price, Place, Promotion (of marketing mix)
ALS	-	Amyotrophic Lateral Sclerosis
BCE	-	Business Creation and Entrepreneurship
Bufdir	-	Barne-, ungdoms- og familiedirektoratet
CEO	-	Chief Executive Officer
CSR	-	Corporate Social Responsibility
DALYs	-	Disability Adjusted Life Years
FFO	-	Funksjonshemmedes Fellesorganisasjon
GCC	-	Global Coordination Center
GP	-	General Practitioner
ICT	-	Information and Communication Technology
IPR	-	Intellectual Property Rights
NOK	-	Norwegian Kroner
NSCC	-	Norwegian Smart Care Cluster
PESTLE	-	Political, Economic, Social, Technological, Legal, Environmental
PI	-	Patient Innovation
RRI	-	Responsible Research and Innovation
SWOT	-	Strengths, Weaknesses, Opportunities, Threats
UiT	-	University of Tromsø

1. Introduction

The missions of universities have evolved from the customary teaching and research to playing the role as innovation providers, including commercializing the innovation, thus catalyzing the creation of new firms (Rasmussen et al., 2006). This transformation is due to the fact that universities are expected to contribute to the economy, since they are regarded as the major supplier of new knowledge and skills (Martin and Etzkowitz, 2000). According to Rasmussen et al. (2011), universities provide an impeccable environment for the conception of high technology university spin-off firms. However, the lack of market knowledge and funding has been constantly challenging academic spin-offs (Van Geenhuizen and Soetanto, 2012). Therefore, academic entrepreneurship program, such as Business Creation and Entrepreneurship (BCE) program at UiT – The Arctic University of Norway, Tromsø, is essential for commercializing or acquiring funding for universities spin-off firms.

This thesis presents the case study of implementing Patient Innovation (PI) in Norway, as a case study of academic entrepreneurship, which is conducted by a student in her final semester of Master in BCE at UiT. PI is an innovative electronic health (e-health) platform based in Portugal that brings together patients, their caregivers, and collaborators to share their solutions for the diseases or conditions. As a university spin-off firm, PI also requires a feasible business plan to attract funding, even though it is a non-profit organization. Thus, this thesis provides the feasible strategy for launching a "Local Chapter" or a representative of PI in Norway.

The thesis comprises of four main chapters, starting with this introductory chapter to represent the structure of the thesis. This first chapter starts by discussing the importance of the topic, followed by the history of PI, the research question, the methodology, the limitations of the thesis, and ends with a conclusion. The second chapter focuses on the innovation study of PI, which provides a valuable data for the next chapter. Chapter three concentrates on the market study of PI, including the marketing strategy, which is crucial for the fourth chapter. Lastly, the final chapter illustrates the business plan for launching a Local Chapter of PI in Norway. Overall, the thesis aims to develop a sustainable business strategy in order to attract funding that is necessary for the launching and development of PI in Norway.

1.1 Patient Innovation

Patient Innovation (PI) is a free, multilingual, and open online platform that enables patients and their caregivers to share their innovative solutions in coping with their conditions. Founded in 2014, the Portugal-based non-profit organization has successfully shared more than 650 solutions from more than 40 countries. Besides sharing the solutions, Patient Innovation also connects the patients and their caregivers with collaborators who help them to create the innovative solutions.

Pedro Oliveira, a university professor and researcher from Católica Lisbon School of Business and Economics, initiated the founding of PI while he was conducting the research related to innovative solutions developed by patients to cope with their chronic and rare diseases. Together with his colleagues; Helena Canhão, Eric von Hippel, and Leid Zejnilovic, they discovered that even though 53% of their respondents developed innovative solutions, regardless of the novelty, only 32% of them shared the solutions (Oliveira et al., 2015). Thus, they recognized the importance of sharing the innovative solutions in order to improve the life of patients with rare diseases. For this purpose, Pedro launched the website *www.patient-innovation.com*, with the support of Helena, who also acts as the chief medical officer, to screen the solutions.

To this date, PI has not just "sharing solutions and improving life", which is stated as the tagline on the website, but also giving awards to the innovators. Interestingly, some of the innovators even commercialize their innovations, transforming them into entrepreneurs. Thus, PI as a research spin-off firm also has the potential to catalyze entrepreneurship. However, one of the challenges is to increase the diffusion rate of the innovative solutions.

From the beginning, PI's vision is to reach the global audience, for the purpose of improving the life of patients worldwide. With this intention, PI utilizes three languages on the website: English, Portuguese, and German. In addition, PI also employs automatic online translation to minimize the language barriers between patients, caregivers, and collaborators. Nevertheless, Pedro realizes that online translation might not be sufficient or safe. Therefore, the idea of a Local Chapter as a localized version of PI was conceived. A Local Chapter serves a particular regional community to present PI's content in local languages, promote PI's content in locally organized events, and provide assistance to the users (patients, caregivers, collaborators) in the designated geographical area. Until now, Local Chapters of PI are available in Germany

and Slovenia. However, these Local Chapters have no regular organizational form yet, as they are currently in the development process.

Another yet to come Local Chapter is in Norway, which is initiated by Arild Kristensen, CEO of Norwegian Smart Care Cluster (NSCC), Tatiana Iakovleva (University of Stavanger) and Marit Hagaland from Innovation Lab. The idea of a Local Chapter in Norway is triggered by the conversation at the Digitalize or Die project's kick-off dinner in Stavanger that involved Arild, Tatiana, Marit, Pedro, and Helena. Arild and Marit are enthusiastic in embedding the PI's Local Chapter to NSCC in Stavanger, since they believe that NSCC is able to provide a full support to the Local Chapter. To proceed with this initiative, Arild, Tatiana, and Marit are now eagerly applying for funding of the Local Chapter. Since this thesis elaborates the possible launching process, including the financial requirement, it is also possible to utilize the findings of this thesis to support their effort. Lastly, a detailed information about PI is presented in the Appendices part of this thesis.

1.2 The Importance of the Topic

The topic of this thesis is how to implement PI in Norway as a non-profit organization that applies the principles of Responsible Research and Innovation (RRI). The importance of this topic can be viewed from several aspects, as PI is a university spin-off firm, an e-health firm, and a firm that applies the principles of RRI.

A university spin-off firm is the product of the entrepreneurial activities of the university, which aims to serve the demand of a market or even generate a new market, thus stimulating the economic growth (Berbegal-Mirabent et al., 2015). Policymakers and governments around the world nowadays realize the importance of the university spin-off firms, as they contribute to the regional development, create employment opportunities (Zomer et al., 2010), and they are even viewed as an investment opportunity (Clarysse and Moray, 2004). Therefore, the creation of university spin-offs is highly encouraged by governments, by stimulating academic entrepreneurship (Urbano and Guerrero, 2013). As a university spin-off firm that shares innovative solutions, PI is also expected to catalyze academic entrepreneurship, particularly within the e-health industry.

Eysenbach (2001, p. 1) defines e-health as “an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies”. The development of the e-health industry is essential, especially in Norway, as there is an increasing trend of using the internet for the source of health information, communication, and health-related products (Wangberg et al., 2009). According to Andreassen et al. (2007), patients preferred to use the internet for health purposes, thus they expect doctors to provide e-health services. On the other hand, Wicks et al. (2014) suggest that e-health can help to reduce the cost of healthcare, especially for chronic diseases, by improving healthcare efficiency, increasing the quality of healthcare, and involving patients in the healthcare. Furthermore, an online platform that shares health information transforms the relationship between patients and doctors into a “more equal and collaborative” relationship (Wicks et al., 2014, p. 196). Thus, it is also possible that the existence of PI in Norway will help to minimize the cost of healthcare, as PI shares innovative solutions for chronic diseases.

As an innovative platform that shares solutions posted by the users (patients, caregivers, collaborators), PI is an example of an e-health firm that applies the principles of RRI. Von Schomberg (2013, p.19) defines RRI as “a transparent, interactive process by which societal actors and innovators become mutually responsive to each other with a view to the (ethical) acceptability, sustainability and societal desirability of the innovation process and its marketable products (in order to allow a proper embedding of scientific and technological advances in our society)”. This definition fits PI perfectly, PI involves users (responsiveness), shares innovative solutions posted by users (societal desirability), and also screens the solutions for safety reason (acceptability).

According to Asveld et al. (2015), the purpose of RRI is to assist innovators and producers of innovative products determine and respond to public concerns when designing new technologies by involving a variety of relevant actors. The relevant actors include researchers, civil society organizations, industry, and policy-makers (Owen et al., 2012). In order to reach the intention of RRI, Owen et al. (2013) develop a framework for understanding RRI that includes four dimensions of responsible innovation: anticipation, reflexivity, inclusion and responsiveness. The application of the RRI framework may result in socially acceptable and sustainable new technologies, thus creating new values to the business, society, and the

environment. Nevertheless, as recent literature concentrates on the possible implementation of RRI principles, little is known about the actual application of RRI to firms (Yaghmaei, 2016).

The idea of the Local Chapter is highly related to one dimension of RRI – anticipation. Pedro realized the importance of launching PI in other countries with localized content, since he was concerned about the risk of using an online translator for screening the solutions. As for Norway, a Local Chapter in Norway is necessary in order to promote the existence of PI, which will benefit patients with chronic diseases in Norway. Furthermore, not every Norwegian is comfortable in communicating in English, especially while discussing health conditions. However, launching a Local Chapter has its own challenge, as PI is a non-profit organization that solely depends on funding. Therefore, this thesis provides the possible funding solutions by presenting the innovation study, market study, and business plan to attract funding. In addition, this thesis is the first BCE thesis that discusses the launching process of a non-profit organization.

1.3 Research Question

> "If I had an hour to solve a problem and my life depended on the solution, I would spend the first 55 minutes determining the proper question to ask, for once I know the proper question, I could solve the problem in less than 5 minutes"
>
> – Albert Einstein.

Bryman and Bell (2015) articulate that a research typically starts with a broad research area that needs to be narrowed down in order to generate a small number of specific interrelated research questions. Following this suggestion, the thesis focuses on a main question, followed by three sub-questions. The answers of the sub-questions serve as the basis for answering the main question. As the purpose of this thesis is to present the possible launching process of PI's Local Chapter in Norway, the main question of the thesis is:

How to achieve an effective adaptation of PI's Local Chapter in Norway?

There are three aspects that are necessary for answering the main question: innovation, market, and business plan. In order to present a feasible business plan for the Local Chapter,

an innovation study and a market study need to be carried out. Thus, the first sub-question, which is related to the innovation study is:

What is the innovative position of PI and what value propositions can be generated from the innovation?

By understanding the innovative position of PI and the value propositions that a Local Chapter delivers to its users, the market study can be conducted based on this information. Therefore, the answer for the sub-question related to the innovation study is essential for answering the next sub-question related to the market study, which is:

Who are the stakeholders of PI's Local Chapter in Norway and what is the marketing strategy for each stakeholder?

As PI is a non-profit organization, the stakeholders need to be well defined, since they have different needs to be met. For example, funding providers have different interests with the users of PI's platform. With this in mind, a carefully designed business model and a feasible business plan based on the marketing strategy are necessary in order to satisfy the interests of the stakeholders. Therefore, the last sub-question related to the business plan is:

What is the suitable business model for PI's Local Chapter and the feasible business plan that can effectively attract funding?

The business plan includes the marketing strategy and financial plan that is needed for launching and implementing the Local Chapter, hence answering the main question of this thesis.

1.4 Methodology

According to Dul and Hak (2007, p. 4), "a case study is a study in which (a) one case (single case study) or a small number of cases (comparative case study) in their real life context are selected, and (b) scores obtained from these cases are analyzed in a qualitative manner". The case study method is deemed to be a decent method for exploratory research, thus it has been widely used in social sciences and management (Chetty, 1996). According to Henry and Foss

(2015), research that applies case study method typically achieves more profound and fruitful concept compared to other research that applies other methods.

This thesis aims to explore the possible launching process of PI's Local Chapter. Thus, the most appropriate method is the case study method. In addition, Chad (1998) articulates that the research problem in a case study is normally questioned as "how do", since the aim of the research is to build the theory in solving the problem, instead of testing the theory. Similarly, the main question of this thesis is also a "how do" question, which is then focused down into three sub-questions. Thus, the case study comprises of three parts: the innovation study, the market study, and lastly a business plan that aims to solve the "how do" main research problem.

1.4.1 Case Selection Strategy

A single case study is useful when the research is highly exploratory, whereas multiple-case studies are conducted when the purpose of the research is a description, theory building, or theory testing (Benbasat et al., 1987). As the purpose of this thesis is to explore a specific project, which is PI's Local Chapter, a single case study is appropriate. However, even though it is a single case study, there are different aspects that cover the case study. These different aspects, Responsible Research Innovation (RRI) and the strategic fits, are discussed in the thesis as these frameworks affect the case study. The RRI framework is discussed in the innovation study chapter and the framework of the three fits (technical, cultural, political) is included in the market study.

Seawright and Gerring (2008, p. 299) articulate that "the typical case study focuses on a case that exemplifies a stable, cross-case relationship…Because the typical case is well explained by an existing model, the puzzle of interest to the researcher lies within that case". This description of a typical case study fits the case of PI's Local Chapter in Norway, since it is well explained by the existing PI's model. The research question of this thesis, how to implement and launch PI's Local Chapter, is the cross-case relationship between PI and the Local Chapter in Norway. In addition, the answer to the research question lies within the case of the Local Chapter. Seawright and Gerring (2008) also mention that the researcher of a typical case study may perform a pattern-matching investigation. In the case of the Local

Chapter, it includes pattern-matching investigation from the collected data, which is explained in the next section.

1.4.2 Strategy for Data Collection

It is essential for the case study to use several different sources of data, in order to avoid the effects of single interpretation when using one single source (Runeson and Höst, 2008). Dul and Hak (2007) also suggest that qualitative interviews and the use of various confirmation data are the typical methods of measurements in case studies. Moreover, the conclusion is stronger if it is drawn from a various source of data, such as triangulation, rather than just from a single source (Runeson and Höst, 2008). Yin (2014) suggests that several sources that can be gathered for the case study are: documentation, archival records, interviews, direct observation, and physical artifacts. This thesis utilizes documentation, archival records, direct observation, and interviews.

The interviews conducted for this thesis were unstructured and semi-structured interviews. The focus of the semi-structured interview is how individuals qualitatively and quantitatively experience one phenomenon, whereas unstructured interview is just focusing on qualitative experience (Runeson and Höst, 2008). According to Runeson and Höst (2008), the objective of the unstructured interview is exploratory, whereas semi-structured interview is descriptive and explanatory. Since the purpose of this thesis is exploring the case of PI's Local Chapter, unstructured interviews were conducted with the prospective stakeholders, by utilizing open-ended questions. These unstructured interviews ensure a broader coverage and richer data. On the other hand, semi-structured interviews were conducted with PI's key personnel, as the data needed from them are more descriptive and explanatory. The interviews were conducted in Tromsø, Oslo, Stavanger, through phone calls, and via online video chatting application (Skype). The interviews were recorded by the author by taking notes, but five of the interviews were also recorded using voice recording application. For a full overview over the respondents, see the list of the interviews in Appendix 3. The average duration of the interviews is 45 minutes, with mostly open-ended questions that were limited to the topic (the platform) were asked to the interviewees.

The author strategy in approaching interviewees was by "knocking on doors", which means direct visits to the interviewees without appointments, even though some interviews were

agreed beforehand. This method was executed due to the difficulties that the author experienced when trying to make the appointments. Most of the targeted interviewees rejected to be interviewed probably due to the misunderstanding that the author was asking for financial support. Therefore, the author approached the health-related organizations and private corporations, if possible, without appointments. Besides the key personnel of PI and the initiators of the Local Chapter, the author considered the health-related organizations and private corporations as potential stakeholders. The author chose to approach health-related organizations first, since the author viewed these organizations as the representatives of patients in Norway. Thus, these organizations have more data and experiences regarding the patients. In addition, interviews directly with patients were not the priority of the author, due to the time limit and privacy issue. However, the author did the observation and interview with patients in the Vardesenteret in Tromsø.

Besides the interviews, other data collected are the documentation and archival records, such as documentation of PI and internet publication archives. Therefore, three sets of data were collected: primary data, secondary data, and the triangulation. The primary data consist of the interviews with the founders of PI, initiators of the Local Chapters, potential stakeholders, business advisors, and documentation of PI acquired directly from the founders, including the observation. The secondary data consist of internet publication that is relevant to PI, the market, and the healthcare system in Norway.

Runeson and Höst (2008, p. 146) define triangulation as "taking different angles towards the studied object and thus providing a broader picture". Thus, triangulation is necessary when relying on qualitative data, which is less precise compared to quantitative data (Runeson and Höst, 2008). Stake (1995) suggests that there are four types of triangulation, depending on the purpose of the triangulation: data triangulation, observer triangulation, methodological triangulation, and theory triangulation. The type of triangulation for this thesis is data triangulation, since it was conducted by interviewing the same interviewees for more than once, and also by gathering data from different sources in order to answer the same questions.

1.4.3 Data Analysis

For the data analysis, this thesis follows the inductive process consists of five stages in the framework approach, which is proposed by Pope et al. (2000). The five stages of data analysis

are: familiarization, identifying a thematic framework, indexing, charting, and finally mapping and interpretation (Pope et al., 2000, p. 116). First, the data were read and reread or listened, in order to identify the key issues, concept, and themes. Next, the data were indexed according to the themes, and then rearranged to form a chart. Finally, by mapping and interpreting the associations between themes, the explanations of the findings were provided. The figure below visualizes the five stages suggested by Pope et al. (2000).

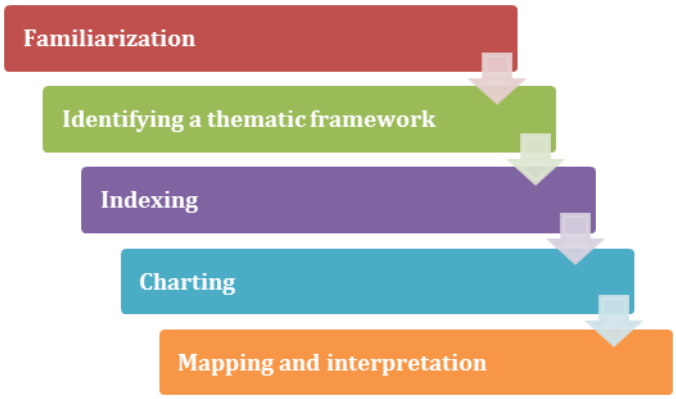

Figure 1: The five stages of data analysis in the framework approach (Pope et al., 2000)

1.5 Choice of Theoretical Frameworks

The case study of this thesis aims to solve the "how do" main research problem, which is divided into three sub-research questions. Therefore, in order to answer each sub-research question, the case study is presented in three parts: the innovation study, the market study, and a business plan. The theoretical frameworks that serve as the foundation of each part of the case study are thus elaborated in the following sections.

1.5.1 Innovation Study

The innovation study is essential in this case study, as the innovation type and the innovative position of PI's Local Chapter determine the marketing strategy, which is presented in the next chapter. The innovation study utilizes three types of frameworks: the idea evaluation framework suggested by Alänge and Lundqvist (2014), the four quadrants of innovation, and also the framework of RRI. The sustainable business development framework proposed by Alänge and Lundqvist (2014) targets innovative university spin-offs that intend to improve the world's condition, by creating not just customer utilities, but also societal utilities and

business utilities. Customer utility can be defined as the reason of why the customers choose a particular product or service, instead of other offerings. This can be the value that the product or service creates, such as the price, the design or the ease of use. On the other hand, societal utility is related to how the product or service can make a better world. The last utility, business utility is related to the feasibility or the economic sustainability of the business idea (Alänge and Lundqvist, 2014).

These three utilities are highly relevant to PI's Local Chapter in Norway, since the users of PI's platform are not the paying customers. On the other hand, the launching and survival of the Local Chapter depends on the funding. Moreover, PI's vision is to create a value for the society, mainly patients with chronic and rare diseases and their caregivers. Therefore, PI's Local Chapter is also expected to generate customer utilities, societal utilities, and business utilities.

The idea evaluation is the first step in generating a sustainable business development and will result in a report consisting of four parts: a summary that briefly illustrates the report, an idea description which includes the novelty and intellectual property protection, value visions (customer, societal, business), and the next steps that are related to market strategy and financial plan (Alänge and Lundqvist, 2014). The novelty of PI's platform is also significant for the next framework – the four quadrants of innovation.

Garcia and Calantone (2002) suggest that by understanding the differences between the types of innovation, the knowledge of innovations can be developed, thus, a consistent typology of innovation is necessary. Schumpeter (1934) classifies innovations into radical innovations and incremental innovations. According to Dewar and Dutton (1986, p. 1422), radical innovation is a groundbreaking technology or a "fundamental change", whereas incremental innovation is a slight upgrade of the existing technology. This typology was transformed into the classical four quadrants of innovations by Abernathy and Clark (1985), which divide the major competitive factors of organizations into two groups; technology/production and market/customer. Using those two groups as "transilience scales", the market as the vertical dimension and technology as the horizontal dimension, they depicted the pattern of competitive factors, or the "transilience map", that resulted in four quadrants of innovative development. These four types of innovation - Architectural, Niche, Regular, and Revolutionary - are illustrated in Figure 2, complete with the examples from the automotive industry (Abernathy and Clark, 1985, p. 7).

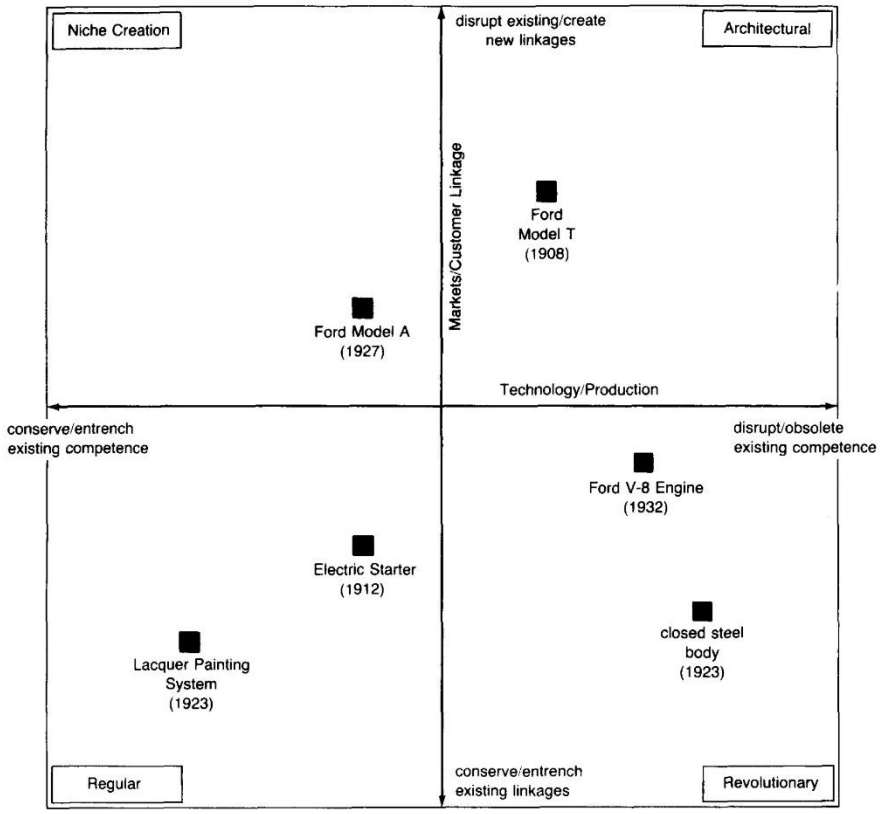

Figure 2: "Transilience map and selected automotive innovations" (Abernathy and Clark, 1985, p. 8)

Abernathy and Clark (1985) define the architectural innovation as the new technology that also creates a new market, whereas the niche innovation is the existing technology that opens a new market. On the other hand, the revolutionary innovation is the technology that disrupts the existing technology but enters the existing market. And lastly, the regular innovation is the changes in the existing technology that apply in the existing market, for the purposes of cost efficiency and better product performance (Abernathy and Clark, 1985). This framework helps organizations to develop their products and identify opportunities.

The classical four quadrants of innovation discussed above are still relevant and referred by recent literature, such as Christensen (1997) and Carpenter (2009). Christensen (1997) suggests that the technology either disrupt or sustain the industry, thus creating a new market or sustaining an existing market. Correspondingly, Carpenter (2009) added the challenges and strategies that can be applied to each quadrant. By combining Christensen (1997) and Carpenter (2009) views, an enhanced version of the classical four quadrants is presented in Figure 3.

Figure 3: The four quadrants of innovation, adapted from Christensen (1997) and Carpenter (2009)

The radical disruptive innovation is a breakthrough in technology, hence it has the opportunity to create its own market. However, this is a high risk but high reward strategy, and if successful, the organization will be the market leader. In contrast, the incremental disruptive innovation is similar with the niche quadrant proposed by Abernathy and Clark (1985), which uses existing technology to create a new market. This quadrant is characterized by low risk but many competitors, therefore, the organization needs to create its own niche. On the other hand, the radical sustaining innovation utilizes radical technology in an existing market, which is actually a defensive strategy in addressing the changing market, but it is also high in risk. The last quadrant, incremental sustaining innovation, resembles the regular quadrant. The organization in this quadrant improves the customer experience while gaining cost efficiency (Christensen, 1997; Carpenter, 2009). This framework helps the organization to identify its own innovation and the circumstance of the market related to the innovation.

Another framework that is discussed in the innovation study is related to Responsible Research and Innovation (RRI), a recently prominent yet still ambiguous topic in Europe. Von Schomberg (2013, p.19) defines RRI as "a transparent, interactive process by which societal actors and innovators become mutually responsive to each other with a view to the (ethical) acceptability, sustainability and societal desirability of the innovation process and its marketable products (in order to allow a proper embedding of scientific and technological advances in our society)". In this case, Patient Innovation can be seen as an example of an e-health technology startup that applies the concept of RRI in their main activities. Owen et al. (2013) propose four dimensions of responsible innovation: anticipation, reflexivity, inclusion,

and responsiveness. Anticipation can be viewed as asking ‘what if?’ questions to the organizations, whereas reflexivity is related to being aware of the organization’s own limits of knowledge. Inclusion means involving and engaging the stakeholders in the activities of the organization, whereas responsiveness is related to adapting the actions of the organizations in response to the limits of knowledge and control (Owen et al., 2013). This framework can be used to analyze the activities of PI, in order to anticipate the possible weaknesses and threats in the operation of the Local Chapter.

1.5.2 Market Study

The market study follows the process of strategic market development suggested by Aaker and McLoughlin (2010), which is a comprehensive structure that is depicted in Figure 4. Aaker and McLoughlin (2010) propose that the process starts with an external and internal analysis of the industry and the company. Consequently, the strategic analysis outputs are derived, which include opportunities, threats, strengths, and weaknesses. Finally, from these outputs, the strategy is created and implemented, with the options of reviewing and adapting the strategy. Overall, this structure enables the utilization of alternative strategy in a dynamic market, thus creating an effective, yet sustainable marketing strategy (Aaker and McLoughlin, 2010). Similar to this, the market study for PI’s Local Chapter in Norway starts with the external analysis (customer, competitor, market, environmental or PESTLE analysis), followed by the SWOT analysis and finally, the marketing strategy is presented.

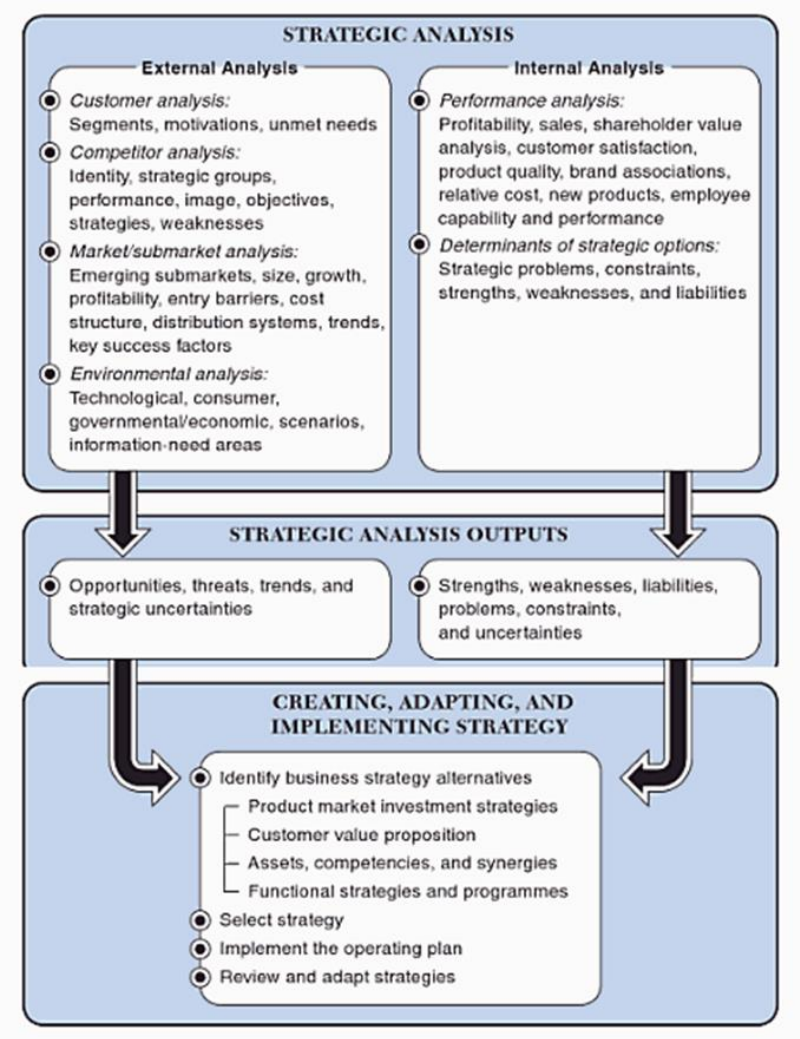

Figure 4: "Overview of Strategic Market Development" (Aaker and McLoughlin, 2010, p. 11)

PESTLE and SWOT analyses are two popular methods for an organization's strategic planning. PESTLE analysis is an external analysis comprises of the components: Political, Economic, Social, Technological, Legal, and Environmental. The purpose of this analysis is to recognize the elements that have the potential to influence the organization. Therefore, the results of the PESTLE analysis contribute to the SWOT analysis. On the other hand, the SWOT (Strengths, Weaknesses, Opportunities, and Threats) analysis determines the factors that the organization needs to consider in formulating their strategy, including the marketing strategy.

Besides PESTLE, the environmental analysis of PI's Local Chapter in Norway also utilizes the strategic fits framework proposed by Ansari et al. (2010). By understanding the diffusion of practices, this framework aims to assist in the decision of whether or not to modify a practice in order to fit in another context. The framework consists of two dimensions of the fit

(or misfit), fidelity and extensiveness, and three forms of fits: technical, cultural, and political fit (Ansari et al., 2010). According to Ansari et al. (2010), "fidelity" relates to how true (accurately) or how distant the practice is implemented, whereas "extensiveness" means the degree of implementation. "Full and true" adaptation means that the practice is adopted accurately by the whole organization, whereas "tailored" adaptation means low fidelity but extensive adaptation. On the other hand, "low-dosage" adaptation occurs when the practice is accurately but not extensively adopted, whereas "distant" adaptation means a loosely and lowly extensive adaptation (Ansari et al., 2010). The framework of the strategic fits is displayed in the figure below. This thesis utilizes the data from the PESTLE analysis for this framework, in order to understand the fits (or misfits) of PI's practices in the Local Chapter in Norway.

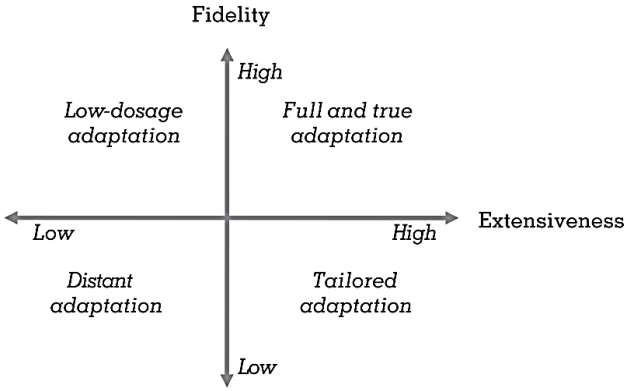

Figure 5: Framework of strategic fits (Ansari et al., 2010)

For the market analysis, Day (1981) classifies the method of market analysis into two approaches: the top-down and bottom-up approach. According to Day (1981, p. 281), the top-down approach, executed by top level management, identifies the market related to the "competitive capability" and "resource transferability". The purpose of this approach is to define the company's competitive advantage in order to secure its competitive position in the market. In contrast, the bottom-up approach focuses on a specific market segment in order to determine the effective marketing mix aimed at that market, thus it is generally performed by marketing managers (Day, 1981). PI's market analysis employs the bottom-up approach, as PI's main purpose is to create a better solution for patients with chronic and rare diseases.

The marketing strategy for the Local Chapter is presented by utilizing the classical 4Ps marketing mix framework. The 4Ps marketing mix is a framework that consists of four levels

of marketing decisions: Product, Price, Place, and Promotion (McCarthy, 1960). This framework is useful for creating a holistic marketing strategy for PI's Local Chapter in Norway. However, as PI is a website of a non-profit organization, the marketing approach suggested by Baker (2001) can also be utilized. Baker (2001, p. 28) proposes four phases of marketing process designed for non-profit organizations' websites that include: "attracting visitors, turning visitor into friends, converting friends into donors, and growing donors into loyal donors". Combined with the traditional 4P's marketing mix (McCarthy, 1960), this approach creates a sustainable marketing strategy for PI's local chapter.

1.5.3 Business Plan

The business plan is viewed as an essential element for a new business venture, particularly for the purpose of gaining financial support in the beginning of a business (Fernández-Guerrero et al., 2012). Massarsky (1987) indicates that the business plan is also considered as a principal instrument of communication between the entrepreneur and the investors, in order to inform the amount of capital funding needed for the new venture. In addition, while the business is running, the business plan can be utilized as a measurement of the performance of the business (Massarsky, 1987).

Fernández-Guerrero et al. (2012, p. 2403) define a business plan as a "a written document that systematically, and in an orderly fashion, details a firm's strategic and operative aspects, and should therefore allow for the assessment of a business project's economic, financial, commercial and legal administrative viability". Moreover, Fernández-Guerrero et al. (2012) articulate that the business plan is a medium for communicating the goals and objectives of the firms to all of the stakeholders.

The definition by Fernández-Guerrero et al. (2012) agrees with the suggestion of Massarsky (1987) regarding the content of a business plan. Massarsky (1987) articulates that most business plans, including for non-profits, consist of six major elements: the executive summary, the description of the idea, the market analysis and marketing plan, the description of the organization, a description of production or service delivery, and lastly, a financial plan.

PI's Local Chapter business plan also follows the suggestion of Massarsky (1987). However, there is one more crucial element – the business model. Dubosson - Torbay et al. (2002, p. 7) articulate that a business model is "the architecture of a firm and its network of partners for creating, marketing and delivering value and relationship capital to one or several segments of customers in order to generate profitable and sustainable revenue streams". The business model serves as a framework that guides the firm to generate its value visions and strategies, discover new opportunities, and conform to the organizational goals that have been communicated to the stakeholders (Persson and Stirna, 2001).

Dubosson - Torbay et al. (2002) propose a business model framework that comprises of four major components: product innovation, customer relationship, infrastructure management, and financial aspects. On the other hand, Alexandros (2016) suggests a more comprehensive framework which is adapted from the business model canvas created by Osterwalder and Pigneur (2010). Alexandros (2016) modified the business model canvas in order to fit nonprofit organizations, thus this thesis utilizes this particular business model. The nonprofit business model canvas consists of nine elements: key partners, key activities, key resources, social value proposition, cost structure, relations, co-creators, and outcome streams.

Key partners are organizations or individuals that help the nonprofit organization to operate. Key activities are the activities conducted in order to operate the organization, including value creation. Key resources are financial, physical, intellectual, and human resources required by the organization in order to create the value proposition. Social value proposition is the mission of the nonprofit organization, whereas cost structure is the cost of key resources and key activities needed for achieving the mission. Relations are the types of bonds that the organization desires to create with the stakeholders. Co-creators are the individuals and other organizations that are involved in the nonprofit organization, including customers, donors, and employees. Channels are defined as the ways to reach the co-creators, whereas outcome streams are the desired outcome of the nonprofit organizations, financially and non-financially. This framework, displayed in Figure 6, will help the Local Chapter in Norway to design a sustainable business model, since it shows the value chain comprehensively, including from and to where the funding comes from. The larger version of this business model canvas is included in Appendix 4.

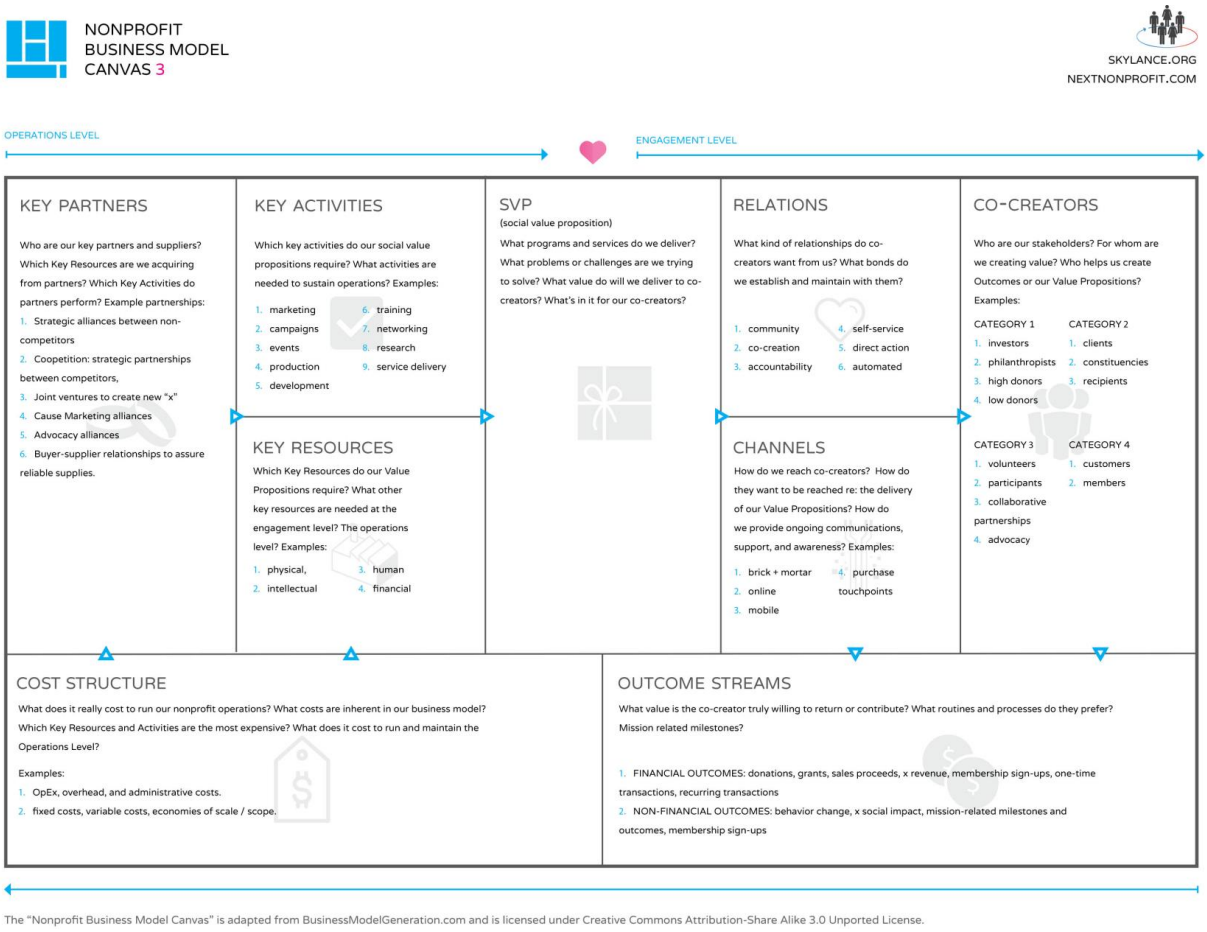

Figure 6: "Nonprofit Business Model Canvas" (Alexandros, 2016)

As for the business model, or funding model, there are ten types of possible funding models that PI's Local Chapter might use or combine. These ten types of funding models, proposed by Foster et al. (2009), are categorized by the dominant type of funders or donators. The funding models are: "Heartfelt Connector", "Beneficiary Builder", "Member Motivator", "Big Bettor", "Public Provider", "Policy Innovator", "Beneficiary Broker", "Resource Recycler", "Market Maker", and "Local Nationalizer" (Foster et al., 2009, p. 37). These ten types of funding models are explained in Table 1.

Table 1: Ten types of funding models (Foster et al., 2009, p. 37)

MODEL	CHARACTERISTICS	EXAMPLES	TACTICAL TOOLS
Heartfelt Connector			
Funding source: Individual Funding decision maker: Multitude of individuals Funding motivation: Altruism	The mission has broad appeal The benefits often touch the lives of the funder's family and friends Nonprofit connects donors to the cause through volunteerism or other means	Medical research (Susan G. Komen Foundation) Environment (Natural Resources Defense Council) International (Save the Children)	Special events Direct mail Corporate sponsorship
Beneficiary Builder			
Funding source: Individual Funding decision maker: Multitude of individuals Funding motivation: Self-interest followed by altruism	The mission initially attracts individuals pursuing, and paying for, specific individual benefits Mission creates a strong individual connection through the delivery of the benefit (for example, spending four years on campus or having one's life saved) Benefits created viewed as having important societal benefits	Universities (Princeton University) Hospitals (Cleveland Clinic)	Fees Major gifts
Member Motivator			
Funding source: Individual Funding decision maker: Multitude of individuals Funding motivation: Collective interest	Most of the benefits have a group orientation (for example, religious services or hiking), creating an inherent collective community to tap into for fundraising Uses richest mixture of tactical tools to raise money	Religious congregations (Saddleback Church) Arts and culture (National Public Radio) Environment and conservation (National Wild Turkey Federation)	Membership Fees Special events Major gifts Direct mail
Big Bettor			
Funding source: Individual or foundation Funding decision maker: Few individuals Funding motivation: Altruism	Builds majority of support from small number of individuals or family foundations Mission may be fulfilled within limited number of decades (for example, finding cure to a certain disease)	Medical research (The Stanley Medical Research Institute) Environment (Conservation International)	Major gifts
Public Provider			
Funding source: Government Funding decision maker: Administrators Funding motivation: Collective interest	Provides services that are perceived as core government responsibility (for example, foster care) Clear definitions exist of the services and processes that nonprofits must provide (for example, RFPs)	Human services (TMC) Education (Success for All Foundation) International (Family Health International)	Government contracts
Policy Innovator			
Funding source: Government Funding decision maker: Policymakers Funding motivation: Collective interest	Secures government funds for a significant new approach to problem or to address a problem not currently viewed as a core government responsibility Requires a high-level government "champion" Generally succeeds when significant pressures exist on government as a result of a fiscal or media crisis	Human Services (Youth Villages) Education (Communities in Schools) International (International AIDS Vaccine Initiative)	Legislative appropriation or earmark Executive earmark Government pilot project
Beneficiary Broker			
Funding source: Government Funding decision maker: Multitude of individuals Funding motivation: Self-interest	Individual beneficiaries decide how to spend the government benefit Must navigate and influence government decision makers for eligibility and compliance with reimbursement requirements Requires individual marketing capability to reach and service end beneficiary	Health (East Boston Neighborhood Health Center) Housing (Metropolitan Boston Housing Partnership) Employment (Peckham Vocational Industries) Public and societal benefit (Iowa Student Loan Liquidity Corporation)	Government reimbursement
Resource Recycler			
Funding source: Corporate Funding decision maker: Few individuals Funding motivation: Self-interest	The nonprofit uses goods that are created in the market economy where there are inefficiencies that create a surplus (for example, food) or where the marginal costs to produce the product are low (for example, pharmaceuticals)	Food (Oregon Food Bank) International (AmeriCares Foundation)	In-kind giving
Market Maker			
Funding source: Mixed Funding decision maker: Mass of individuals (one side), few individuals (other side) Funding motivation: Altruism (one side), self-interest (other side)	A funder with some degree of self-interest and the ability to pay exists (for example, a health system buying blood) Often, one of the parties involved in the transaction is motivated largely by altruism (for example, a blood donor or land donor)	Health (American Kidney Fund) Environment or conservation (The Trust for Public Land)	Fees Major gifts (corporate or individual)
Local Nationalizer			
Funding source: Mixed Funding decision maker: Few individuals Funding motivation: Altruism	The issue is one of a few top priorities for improvement or success in a locality (for example, creating a quality city school system) The issue is common enough to exist in many localities nationwide The level of funding available in any single geographic area is usually limited	Education (Teach for America) Youth development (Big Brothers Big Sisters of America)	Major gifts Special events

1.6 Findings

The innovation study shows that PI's innovative position is incremental disruptive, thus the strategy that can be employed by PI's Local Chapter in Norway should aim to create its own market. In this case, the initial mission of PI, which is to improve the lives of the patients with chronic and rare diseases, fits perfectly with the innovative position. In other words, PI's own market is the group of patients with chronic and rare diseases, including their caregivers. On the other hand, PI's innovation, which is empowering patients, creates values to its customers. The customers can be defined as the users and the benefactors. For the users, PI's values are: to improve their lives, empowering them, and also potentially transforming them into entrepreneurs. For the benefactors, PI gives them the opportunity to create a good impact on the society (do good, feel good). However, regarding the Responsible Research and Innovation (RRI) framework, PI needs to anticipate the possible misuse of the content, which is also related to the validity of the posted solutions. There are also minor improvements, such as the platform search-ability, that needs to be taken into consideration, in order to reach the market effectively.

The market study reveals that the Local Chapter's stakeholders are the customers (users and benefactors), the partners, and the employees of the Local Chapter including PI GCC (Global Coordination Centre). The benefactors can be defined as individual and corporate donators, whereas the partners are other health-related organizations in Norway. Public organizations are not emphasized as the main donators, since the existing business model analysis shows that depending on this type of donators is not sustainable. Interestingly, this is also supported by the pattern found in the qualitative data analysis, which indicates a suggestion that the Local Chapter in Norway should approach individual and corporate donators, instead of public organizations. Moreover, the results of the strategic fits analysis also suggest that the political fit, which includes the business model, should be "tailored adaptation" in order to fit in Norway. Thus, this suggestion is integrated into the marketing strategy, which has two basic goals: getting more users and getting more donators. These two basic goals create the values to the stakeholders, which lead to the creation of a sustainable business model.

The results of the market study, which are the foundation of the business model, indicate that the most suitable business model for the Local Chapter in Norway matches the characteristics of the 'Heartfelt Connector' funding model. However, the marketing strategy of the Local Chapter does not only aim for individual donators, but also corporate donators, in order to

ensure financial sustainability. The complete business model, which is visualized by utilizing the nonprofit business model canvas suggested by Alexandros (2016), is presented in the last chapter.

1.7 Limitations

This thesis was prepared within a short period of less than six months, thus the limited time lowered the number of interviews. Moreover, due to the financial limit, the interviews with PI's key personnel were carried out by utilizing online video call application (Skype), thus there was no possibility of observing PI GCC in Portugal. Even though some of the interviews were conducted in Oslo and Stavanger, the geographical and financial limitations lower the number of the on-site interviews. The initiators of the Local Chapter are located in Stavanger, whereas the prospective stakeholders are in Oslo. Therefore, it was a challenge for the author of this thesis to conduct more interviews with them.

Another limitation to this thesis is the educational background of the author. As the author has no background in healthcare or ICT (Information and Communication Technology) education, there might be technical and/or medical inaccuracies in this thesis. However, the attached appendices will be supportive in clarifying information regarding the technical and medical related content of this thesis.

1.8 Conclusion

This thesis answers the main research question: "*How to achieve an effective adaptation of PI's Local Chapter in Norway?"* This main research question is answered by first answering the three sub-research questions related to the innovation, the market, and the business plan. The findings from the innovation study, market study, and the business plan are the foundations for answering the main research question.

The innovation study indicates that PI's innovative position is in the incremental disruptive quadrant, thus the strategy that fits the organization is the market niche creation. The market study reveals that the niche is the group of patients with chronic and rare diseases, which agrees with PI's initial goal. In addition, the environmental analysis in the market study

suggests the need for “tailored adaptation” for the political fit, as the existing business model does not fit to the Local Chapter in Norway. Thus, in order to create a sustainable business model, the market strategy that aims to get more users and get more donators (individual and corporate) is formulated as part of the business model. Finally, the business plan, which includes the business model, elaborates comprehensively the decisions that will ensure the successful launch of PI’s Local Chapter in Norway.

2 Innovation Study

This chapter aims to answer the sub-research question: *"What is the innovative position of Patient Innovation (PI) and what value propositions can be generated from the innovation?"* In order to answer this question, the innovation study follows the framework suggested by Alänge and Lundqvist (2014), which includes an explanation of the platform, the Intellectual Property (IP) protection, current status, next steps, value visions, and competitive landscape of PI. In addition, an explanation about the healthcare system in Norway and the expected impact of PI on it are also presented in this chapter. However, the market quantification and financial plan are presented in the business plan part of this thesis.

Next, the innovative position of PI is determined by utilizing the classic four quadrants of innovations (Abernathy and Clark, 1985). However, this thesis employs the enhanced version of the four quadrants framework, which is proposed and adapted by Christensen (1997) and Carpenter (2009). Furthermore, PI's activities related to the framework of Responsible Research and Innovation (RRI) is also discussed in this chapter.

2.1 The Patient Innovation Platform

The Patient Innovation platform exhibits a simple menu and a few featured solutions on its front page. This starting page emphasizes the search and post of a solution, thus it displays the search and post buttons on the top of the page. Further down, this page also encourages visitors to join the platform and register as users. As a registered user, a patient or caregiver can search and post a solution that is suitable for the patient's health condition. Furthermore, the user can also join the forum specific to the health category. The front page also enables visitors and users to explore the solutions by categories: disease, symptom, location, activity, device, and therapy. The screenshot of this front page is displayed in Figure 7.

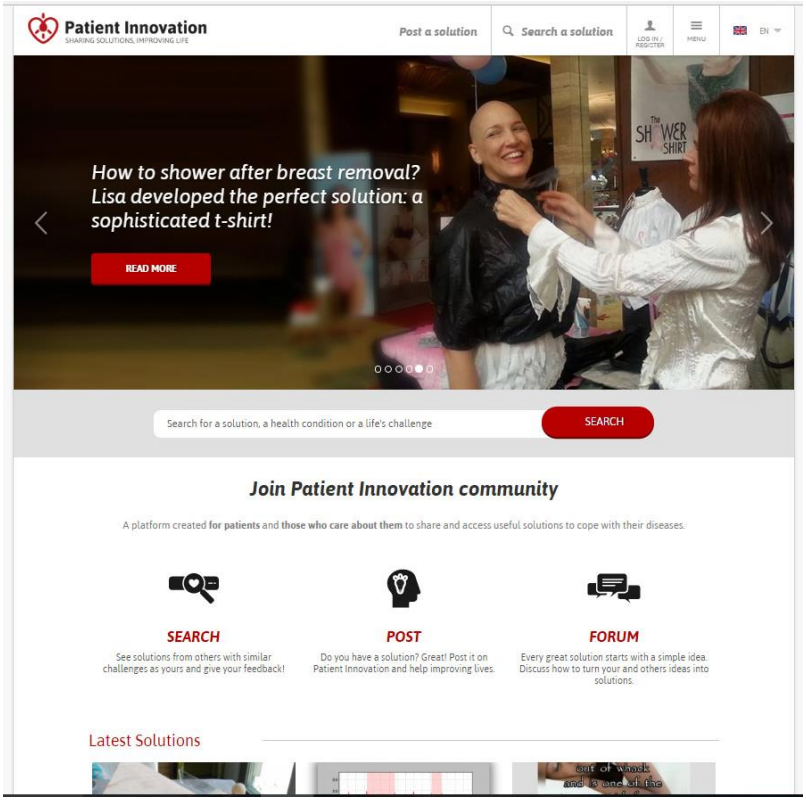

Figure 7: Screenshot of PI's front page (source https://patient-innovation.com)

The platform is easy to use with simple instructions under the 'How It Works' menu that also describes the user features. It is also mentioned under the 'User Features' section that as a registered user, the patient or caregiver can share the solution through Facebook, change the language of the platform, contribute in the patient group and also post media files such as photos and videos. Registered users also receive notifications when there is a new solution posted that is related to their health condition. This feature is crucial provided that patients with chronic diseases and their caregivers struggle daily to cope with their condition. Therefore, their lives will be improved if they are aware of the solution in a timely manner. The screenshot of PI's 'How It Works' page is displayed in Figure 8.

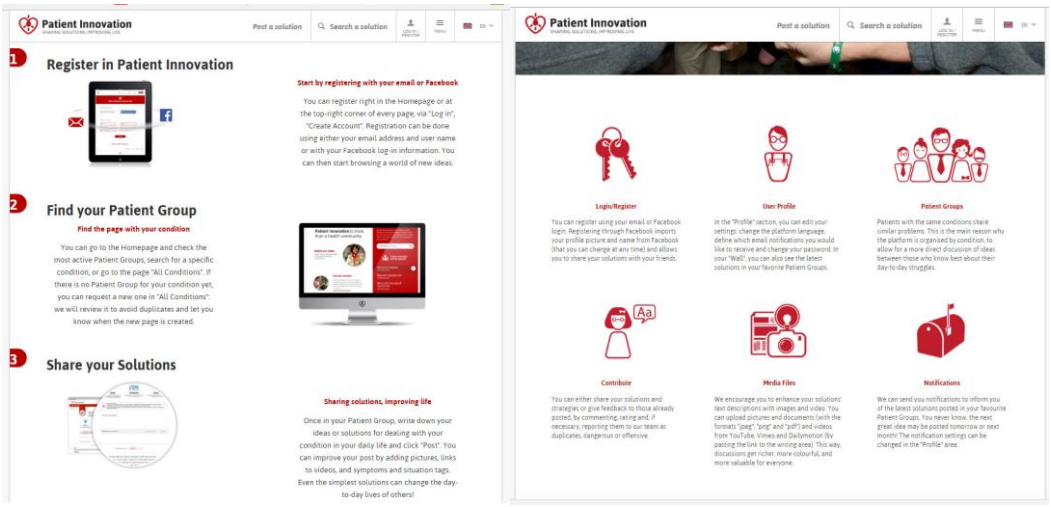

Figure 8: Screenshot of 'How It Works' page and the 'User Features' section (source: https://patient-innovation.com/how-it-works)

The 'How It Works' page also includes the 'Technology' section that describes the platform's technological features. These features, displayed in the figure below, are employed by PI in order to reach its goals, such as the compatibility with social media, easy and intuitive interface, smart algorithm, intelligent language system, secure data, and anti-spam.

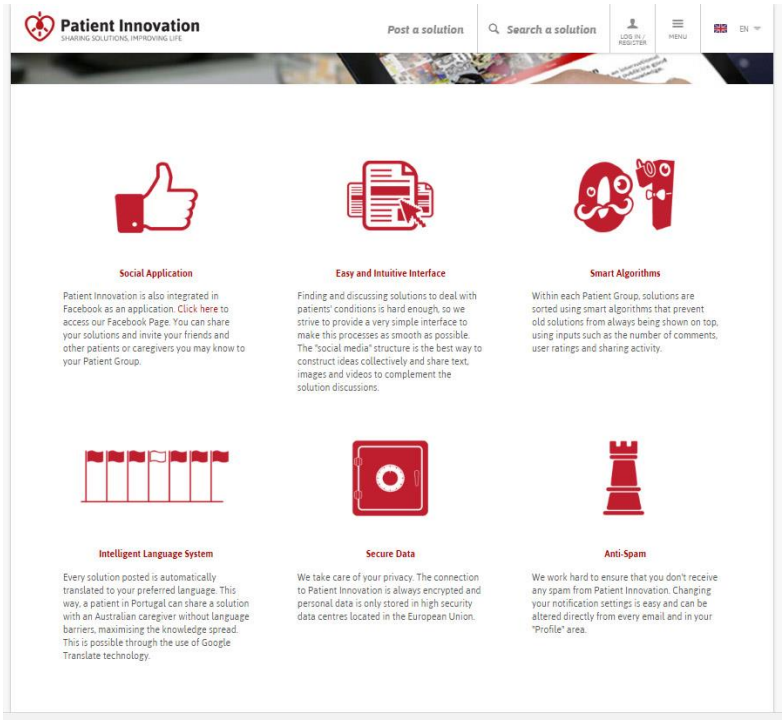

Figure 9: Screenshot of the 'Technology' section (source: https://patient-innovation.com/how-it-works)

Besides posting innovative solutions, PI's platform also exhibits the promotion activities under the 'Beyond the Lab' menu. This page shows the tour that PI is executing, including the schedule. Finally, below every posted solution, there is a cautionary message that ensures the

safety of the content and the avoidance of any medications or product commercialization. This message, as depicted below, also differentiates PI from other health-related platforms, thus it also serves as a competitive advantage of the platform.

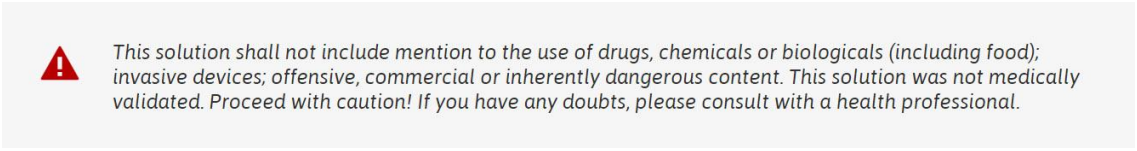

Figure 10: Cautionary message below each posted solution (source: https://patient-innovation.com/post/1642)

2.2 Limitations of the Platform

Even though the platform employs easy and intuitive interface, it is still difficult to navigate the solutions without putting in the right keywords, since there is no list or menu for each category, as displayed in the figure below. Therefore, if a user has a specific symptom which can only be described with more than one word, there is a high possibility that the search will end up with no results. In other words, there is a need for better display or grouping of the solutions, for easier navigation.

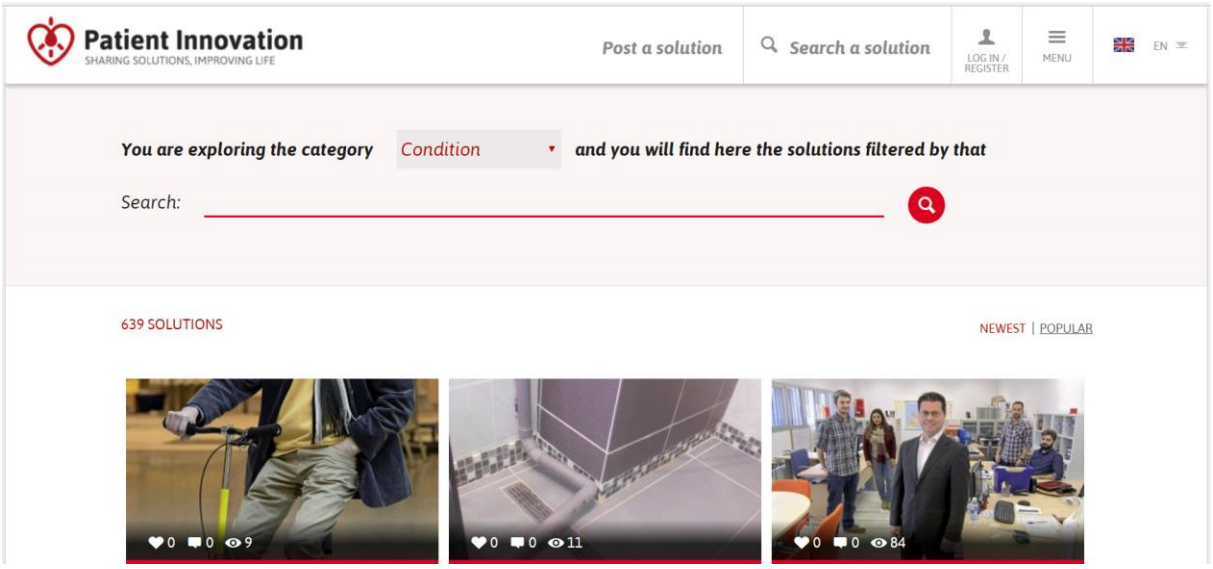

Figure 11: Search bar in one of the categories (source: https://patient-innovation.com/browse?vid=2)

Another limitation is related to the search-ability of the platform itself, which will affect public awareness of the platform and the number of users. If a patient or caregiver, who is not aware of PI, search for the solution of a condition in a search engine such as Google, PI's name is not included in the top list of the search results. Thus, the patients or caregivers

usually visit the most popular platform, such as www.webmd.com, or www.lommelegen.no, if the search keywords are in Norwegian. In other words, PI needs to improve its ability to be discovered by more patients and caregivers, in order to achieve more users.

2.3 The Healthcare System in Norway

The healthcare system in Norway can be considered as semi-decentralize. The state is responsible for the specialist care by delegating it to four Regional Health Authorities, whereas the primary care is managed by the municipalities (Ringard et al., 2012). The Minister of Health appoints an executive board to lead all hospitals in each region, and these hospitals are supervised by the Regional Health Authorities. Thus, as illustrated in the figure below, there are two separate tiers that base the provision of health services: state-owned health authorities and municipalities (Mørland et al., 2010). The figure below also shows the flow of the patients and the flow of financing in the Norwegian healthcare system.

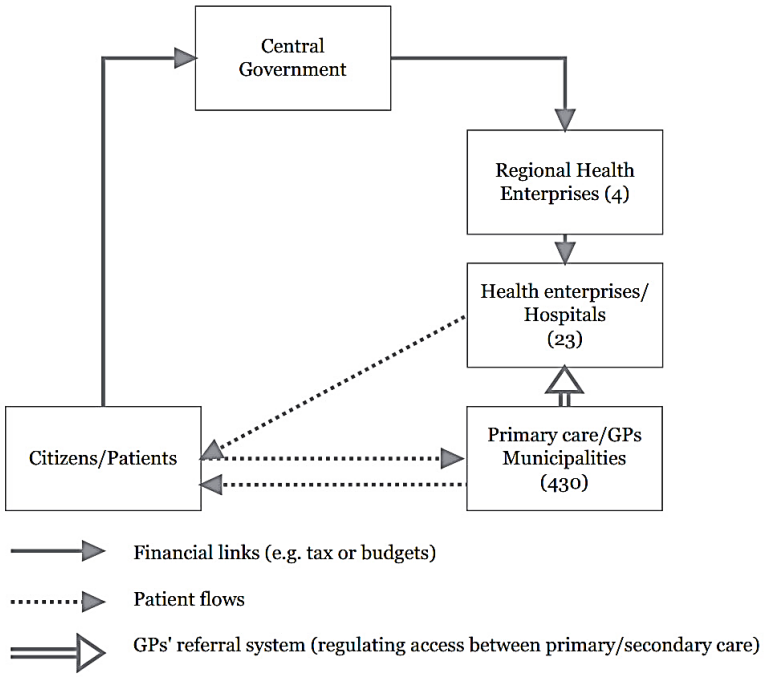

Figure 12: 'Overview of the Norwegian healthcare system' (Mørland et al., 2010, p. 399)

Norwegian healthcare is publicly financed, with public sources account for over 85% of total health expenditure, while the private health financing is majorly funded from households' out-of-pocket payments (Ringard et al., 2012). Even though Norwegian healthcare is funded publicly, the service provision is a mixed solution of public and private actors. In addition, the

patients' individual purchasing power does not influence the access to the services (Neby, 2016). Furthermore, according to Melby and Hellesø (2014), the collaboration between healthcare actors in Norway, as in anywhere else, always has to face challenges such as organizational borders and financial structures.

From the patients' point of view, they visit the General Practitioners (GPs) that are appointed by the municipalities for checking their illness, and these GPs assign them to the hospitals for necessary treatment. Even though the government funds the necessary treatment and equipment, the patients have no influence in the government's decision-making process for buying the services and equipment or tools from the healthcare actors. Therefore, the existence of PI in Norway will help the patients to show to the government what they actually need from the healthcare services. Thus, the patients will be involved in the government's decision-making process for providing healthcare services/tools.

2.4 The Expected Impact of PI on the Healthcare System

PI enables patients to share their innovative solutions in coping with their conditions, thus PI empowers patients to show what they actually need. By empowering the patients, PI is novel and disruptive because it might create better communication flows among stakeholders in the healthcare system. Therefore, PI platform itself is an innovation, since it empowers the patients to strengthen their influence in the healthcare system. Figure 13 shows the expected impact of PI on the healthcare system, by portraying how PI enhances the influence of patients in the healthcare system. By serving as a communication hub between patients and other healthcare actors, PI empowers patients to involve in the decision for providing healthcare services.

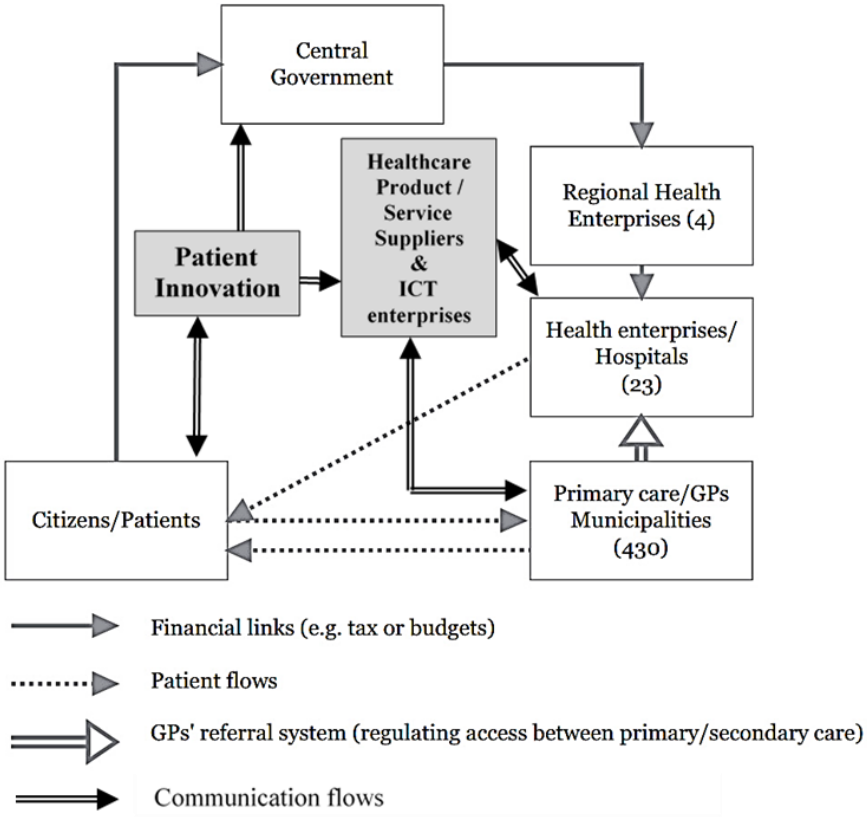

Figure 13: The expected impact of PI on the healthcare system

2.5 Novelty and Intellectual Property Protection

At present, numerous healthcare-related platforms that share treatment and solutions are available to patients. The most popular in the world is www.webmd.com, which is famous for checking symptoms and treatments. However, the website that has the similarity with PI to this day is only www.patientslikeme.com, which also shares solutions posted by patients, instead of opinions written by medical doctors. The difference between PatientsLikeMe and PI is that the latter focuses on innovative solutions, not medication. Thus, the service offered by PI is novel, compared to the content of other healthcare-related platforms.

As a website, the choices of intellectual property protections are copyright and trademark. The text, data, and layout of the website are protected by copyright, which is owned by PI, whereas the logo and branding can be protected by registered trademark. However, the innovative solutions that are shared on PI's platform have a possibility of infringing intellectual property rights owned by the innovators. Therefore, PI always asks for permission from the idea owners before posting the videos, images, and stories about the innovation. In

addition, some of the solutions are posted by the idea owners themselves, as they are eager to share their innovation with other patients and caregivers.

Another concern about intellectual property protection within PI's platform is related to the innovative solutions shared by the users or the idea owners themselves. Even though the innovators might have the intention to help other patients and caregivers, they have to consider about protecting their own intellectual property, especially if they plan to commercialize their innovation. For this reason, PI's team normally encourages users not to disclose their innovation in details, if they want to commercialize or further develop their innovation.

2.6 Current Status and Next Steps

Until now, PI's platform has already shared more than 650 solutions gathered from more than 40 countries. These solutions are not only shared by the users, but also posted by the platform manager. Moreover, the website is currently available in three languages: English, Portuguese, and German. The recently added language, German, is translated by the Local Chapter in Germany. Therefore, the next step for the Local Chapter in Norway is to translate the content of PI's platform into Norwegian. This is an important step for reaching the audience in Norway and thus gaining more users from Norway.

There are also steps to be taken for the improvement of the website. First, the posted solutions need to be organized in a list under each category for better navigation. Secondly, PI needs to be searchable by popular search engines, such as Google, when the potential users search with keywords that are related to symptoms and health conditions. Lastly, it is essential to increase the number and variety of the posted solutions, in order to cover a wider range of patients and caregivers. These improvements aim to create greater awareness of PI's existence, and also to help existing users navigate easier, thus increasing the number of users in the long run.

2.7 Value Visions

As Alänge and Lundqvist (2014) propose, an innovative idea has different values, depending on the situations of use. Thus, the idea generates values not only to the customers or the users,

but also to the society and to the business itself. Furthermore, by generating the value visions, the overall potential of the idea, including the market potential, can be discovered (Alänge and Lundqvist, 2014). PI's values for its customers, society, and business affect the choice of its business model.

2.7.1 Customer Utility

PI's customers can be divided into two groups: the users of the platform and the benefactors that fund PI's activities. Both these customer groups are crucial to the survival of PI, since the users are contributing to the content of PI, and the benefactors provide the funding for maintaining the platform. Thus, it is impossible for PI to focus on just one of the customer group. This situation results in two value propositions and a specific business model that is discussed in the last chapter.

The main value for the users, which are mostly patients and their caregivers, is that PI improves their lives by sharing the innovative solutions that the patients can use for coping with their conditions. Besides improving their lives, PI also has the potential to transform them into entrepreneurs, if the users that own the innovative solutions want to commercialize the idea. As for the benefactors, which can be private or government organizations, funding PI's activities is a form of Corporate Social Responsibility (CSR) that enhances the image of the organizations, especially private organizations. In other words, PI gives the benefactors the opportunity to create a good impact on the society (do good, feel good).

2.7.2 Societal Utility

As PI enables patients to share their own innovative solutions, PI has the potential to change the role of patients. Thus, by facilitating the patients to search and share innovative solutions, PI also empowers the patients. Moreover, the innovative solutions posted on PI's platform are usually the results of patients and caregivers innovating for improving their lives and saving the cost of their own healthcare. However, in Norway, the cost of healthcare is mainly the burden of the government, and the government covers this cost with the tax from the citizen of Norway. Therefore, PI's Local Chapter in Norway has the potential to lower the cost of healthcare, or the burden to the society, by utilizing the successful innovation. For example,

one of the solutions shared on the platform is the 3D prosthetic hand, which has a lower cost and is easier to be customized and produced compared to a conventional prosthetic hand. In Norway, the government provides for such need, and if it is applied in Norway, it can lower the cost of healthcare, especially for children, who require the replacement of the prosthetics periodically as they grow.

In addition, there is also a possibility that PI's Local Chapter can benefit the research of healthcare in Norway. For example, by analyzing the Norwegian content in PI's website, it's possible to identify the trend of a disease in Norway and how patients cope with it. This practice has been done by PatientsLikeMe, which also benefits the platform.

Another societal value that PI creates is the potential to contribute to the improvement of the economy, as PI also catalyzes entrepreneurship. Several users of the platform has already commercialized their innovation and thus transformed themselves into entrepreneurs. Therefore, by sharing the success stories of these users, PI encourages other patients and caregivers to become entrepreneurial, which also helps the society economically.

2.7.3 Business Utility

PI generates business utility indirectly for its customers, as PI is a non-profit organization and does not commercialize any products or services. However, PI generates business opportunities for its users if they plan to commercialize their innovative solutions. In addition, the benefactors that donate to PI's Local Chapter will acquire better image and publication, which is considered as an investment.

Even though it's a non-profit, PI's Local Chapter has to be financially sustainable in order to survive in the long run. Therefore, PI needs a sustainable business model, which determines the source of funding, the potential partners, the anticipated costs, and also the possible marketing strategy. The sustainable business model of PI's Local Chapter in Norway is displayed in the last chapter.

2.8 Competing Platforms

Generally, when searching for a solution or treatment of a health condition, popular platforms such as WebMD appear on top of the search results. Similarly, if the keywords are Norwegian, the search results usually consist of popular names in Norway, such as NHI, Helsenorge, Lommelegen, and Nettdoktor. However, these platforms emphasize on health information services, instead of connecting patients and facilitating them to share their experiences. Thus, regardless of the popularity in search engines, PI's potential competitors are online health support groups or online health communities.

Internationally, there are several online health support groups and communities that resemble PI. Popular examples of these platforms are PatientsLikeMe, MDJunction, Healthboards, and Inspire. On the contrary, in Norway, online health support groups and communities are scattered through different websites and blogs based on the focus of the health conditions. As described in the following table, all of the international websites shares opinions, experiences, and treatment options posted by patients or users. Nevertheless, none of them focus on sharing innovative solutions developed by patients and caregivers. In addition, all of them allow the posts that mention the use of medication, which is avoided by PI. These distinctions serve as the competitive advantage and uniqueness of PI, which are focusing on sharing only innovative solutions developed by patients and caregivers and prohibiting the posts that mention the use of medication. In other words, PI's content is safe and credible, as it is screened by a team of medical doctors.

Table 2: Comparing PI with its potential competitors

Name of platform	Focus	Number of members /visitors	Source of funding	Competitive advantage	Remarks
www.patient-innovation.com	Sharing innovative solutions developed by patients	50K visitors until now since 2014	Research grants	Screening of the content, prohibit the posts that mention the use of drugs	Screening by medical doctors
www.patientslikeme.com	Options for treatments, open source research data	500K members	Selling research services, partnership with pharmaceutical companies	Covers more than 2,500 conditions, largest ALS members in the world	Allows posts with the use of medication

www.mdjunction.com	Bringing together 800 other online groups	16M visitors/year	Private funding, ad on site, and affiliation fees	Directory of support groups that cover 800 groups	No screening of the material posted by users
www.healthboards.com	The opinion and experience of patients only, not health professional	850K members, 10M visitors/month	On site advertisement, direct or through google	A unique one-stop support group community offering over 200 message boards on various diseases, conditions, and health topics	Prohibits posts from health professional and research articles
www.inspire.com	Health community for patients with chronic, rare diseases, cancer, and their caregivers	1M members	Clinical trial recruitment, consumer health research, advertising	More than 100 partners, covers more than 200 conditions	No screening of the content, customers include pharmaceutical companies

2.9 Patient Innovation in the Frameworks of Innovation

The innovative position of PI determines the choice of the marketing strategy that is presented in the next chapter. Furthermore, the framework of Responsible Research of Innovation (RRI) can be utilized to analyze the activities of PI, in order to anticipate the possible weaknesses and threats, which are related to the SWOT analysis in the market study chapter.

2.9.1 The Position of PI in the Four Quadrants of Innovation

PI's platform can be viewed as an innovation, as it is the first platform in the world that focuses on sharing patient-driven innovation. In addition, the platform has the potential to stimulate more innovation by sharing the existing innovation. However, even though PI's platform is a breakthrough, it is the content, or the service, that is innovative. Therefore, it is necessary to determine the innovative position of PI's platform, as it influences the marketing strategy for PI's Local Chapter, which is required for the launching and survival of the Local Chapter.

In order to determine the innovative position of PI, it is necessary to understand the service that PI offers and its method of delivering the service. PI's service is connecting and sharing innovative solutions from patients to other patients and their caregivers. As displayed in the competitor analysis, there are no other online health support groups or communities that offer the same service or content. Thus, PI's service can be determined as disruptive, since it creates its own group of users, or in other words, its own market niche.

On the other hand, PI delivers its specialized content by utilizing a website, which is an existing technology, or incremental innovation. Therefore, PI's innovative position is incremental disruptive, as it uses existing technology to create a new market or niche. PI's innovative position is depicted in the figure below. As an incremental disruptive innovation, PI's innovative position is described as a low risk market with high competition. The strategy that can be utilized for this particular innovative position is discussed in the market study chapter of this thesis.

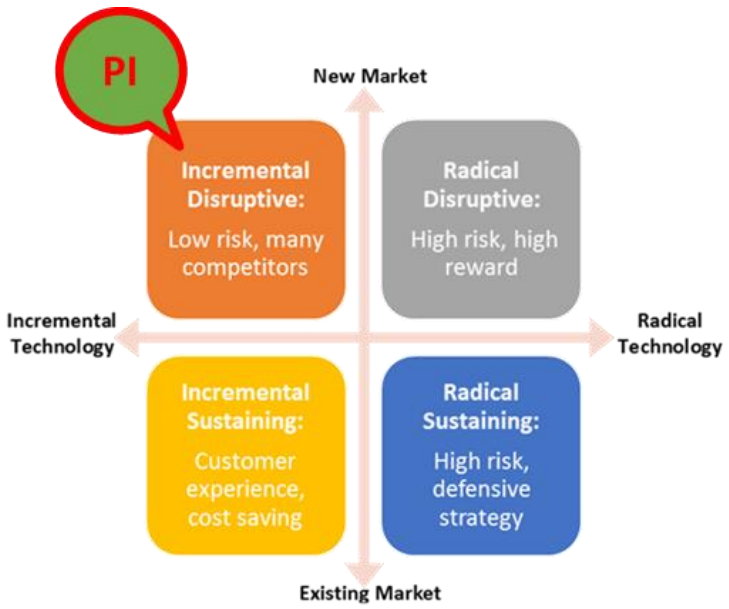

Figure 14: The position of Patient Innovation in the four quadrants of innovation

2.9.2 PI in the framework of Responsible Research and Innovation

As Stilgoe et al. (2013) propose, there are four dimensions of Responsible Research and Innovation (RRI): anticipation, reflexivity, inclusion, and responsiveness. As a research-based spin-off and an innovative platform, PI has in fact applied the four dimensions of RRI. Starting from the first dimension, PI has anticipated that its content should be translated into

other languages, in order to reach patients that use other languages than English and to overcome the limitations of the automatic online translator. Thus, the idea of the Local Chapter was conceptualized, with the additional goal to cover the specific interest of the particular region. Another practice of anticipation within PI is that PI prohibits the content that mentions the use of drugs and harmful methods, in order to prevent misleading information that is dangerous for the users. However, there are two aspects of anticipation that PI has to consider: the validity of the posted solutions and the potential misuse of PI's content. For example, if a solution posted on PI's platform is not proven effective, but people assume it is effective, it can be misused or even commercialized by other people. Even though it would be challenging to validate every solution from different countries with different languages, this sort of anticipation is crucial for PI's credibility.

For the second dimension, PI has at least two ways in applying reflexivity in its activities. First, PI's initial goal is to improve the lives of patients and caregivers by providing a platform for sharing innovative solutions. This goal is indeed a reflection of PI's impact on the society, which is creating social value. Secondly, PI also has reflected upon the impact of its content on the users, thus PI practices screening of every innovative solution before it is published on the platform, in order to ensure the safety of the content.

Next, related to inclusiveness, PI involves its users, which is also the public, to create the content by posting their own innovative solutions. PI also provides a forum for discussion, which enables the users to discuss the content of PI. Lastly, PI encourages its users to join PI's community, in order to be able to give feedback to PI, thus enabling PI to practice the last dimension, which is responsiveness.

2.10 Conclusion

This chapter answers the sub-research question: *"What is the innovative position of Patient Innovation (PI) and what value propositions can be generated from the innovation?"* PI is innovative and novel, since it is the first platform that shares innovative solutions developed by patients. In addition, PI empowers patients to strengthen their influence in the healthcare system, by connecting patients and healthcare actors. Nevertheless, PI's platform is not considered as a breakthrough, since a website is not a new technology. However, the service offered by the platform, or the content, is the breakthrough, since there are no other platforms

that focus on sharing innovative solutions for patients and caregivers. Therefore, PI's position in the four quadrants of innovation is in the incremental disruptive quadrant.

PI's activities generate values for its customers and the society. However, PI generates indirect business utility, since it is a non-profit organization. The customers of PI are categorized as the users and the benefactors. For the users, PI improves their lives and potentially transforms them into entrepreneurs, which also generates the values for the society, as it also improves the economy. The benefactors are private and government organizations, and PI provides them the opportunity of practicing CSR as the value for them.

Even though PI has its own uniqueness that also serves as its competitive advantage, there are improvements that are necessary for the better future of PI and particularly for the Local Chapter in Norway. The quality and quantity of the content need to be improved, such as the grouping of the solutions, search-ability of the platform, and also the variety and quantity of the solutions. Nevertheless, there is currently no health support group or community that is identical to PI, both internationally and in Norway. In addition, as an innovative healthcare platform, PI has in fact applied the four dimensions of responsible innovation on its activities.

3 Market Study

The purpose of this chapter is to answer the sub-research question: ”*Who are the stakeholders of PI’s Local Chapter in Norway and what is the marketing strategy for each stakeholder?*” In order to answer the question, this chapter follows the framework for strategic market development proposed by Aaker and McLoughlin (2010). The market study starts with the customer analysis, in order to identify the customers of PI’s Local Chapter. Next, the competitor analysis presents the potential competitors of PI’s Local Chapter in Norway, followed by the market analysis that estimates the size of the market.

The existing business model analysis shows the current condition of PI, which is useful for the next sub-chapter, the environmental analysis. Next, the PESTLE (Political, Economic, Sociological, Technological, Legal, and Environmental) analysis is presented in the environmental analysis. By using the data from the PESTLE analysis, the framework of technical, cultural, and political fit is also presented in the environmental analysis sub-chapter. Following the environmental analysis, the SWOT (Strengths, Weaknesses, Opportunities, and Threats) analysis helps to determine the next section, the marketing strategy section. The marketing strategy employs the classical 4Ps marketing mix (McCarthy, 1960), supplemented with the marketing strategy process (Baker, 2001). The marketing strategy aims to achieve sustainable funding that is vital for the survival of PI’s Local Chapter in Norway. Lastly, this chapter ends with a conclusion of the market study, which is also presented in the last chapter, the business plan chapter.

3.1 Customer Analysis

Although the use of the internet for health services does not replace other health services, a research by Andreassen et al. (2007) shows that 44% of the total sample in Europe, 71% of the internet users had utilized the internet for health services. Moreover, a study by Wangberg et al. (2009) estimated that in 2010, 84% of the Norwegian population used the internet for health purposes. Therefore, as one of the healthcare related platforms that specialize in posting innovative patient-driven solutions, PI will create its own customer base.

As a non-profit organization, PI’s customers can be divided into 2 groups, the users of the platform and the paying customers, or the benefactors. These groups of customers are

identified by the different values delivered by PI. PI's main goal is to provide a platform for sharing innovative solutions developed by patients, thus creating the value of improving the lives of the users. These users are patients or caregivers who actively search for solutions in coping with their health condition. However, these users can also be patients who have already found innovative solutions and they are searching for a place to share the solutions to other patients. Therefore, the users can be defined as patients with chronic and rare diseases, disabled people and their caregivers. There is also a possibility that the users are people that discovered innovative solutions for patients, which are not patients themselves. This group of users is defined as collaborators. In conclusion, the users of PI's Local Chapter in Norway are patients with chronic and rare diseases, disabled patients, their caregivers, and the collaborators in Norway.

Another value created by PI is the opportunity to make a good impact on the society (do good, feel good) by supporting PI's activities. This value is relevant to public and private organizations, or corporations that aim to enhance their image as a part of their Corporate Social Responsibility (CSR) program. However, there are more drivers of CSR in Norwegian companies than just enhancing their image or reputation. The other factors that drive Norwegian companies to engage in CSR activities are: the desire to support the local community, the pressure of competition, the obligation to comply with government regulation, and also the tendency to follow the leading companies that have already engaged in CSR activities (Laudal, 2011). Besides public organizations and private companies, there is also a possibility that individuals are willing to donate, if they perceive that PI's value fits their own personal value. To sum up, the possible paying customers or benefactors of PI's Local Chapter are public organizations, private companies, and private individuals (donators).

3.2 Competitor Analysis

The competitors of PI's Local Chapter in Norway can be viewed in three ways. The first approach is from the users' point of view. If a patient or a caregiver is searching for a solution to cope with his or her condition, the patient or the caregiver usually searches by using certain keywords related to the health condition or the disease. Thus, in this category, the competitors are popular healthcare platforms that appear on top of the results of a search engine, since the users usually choose to access the websites on top of the list. Normally, if the keywords are in English, popular websites such as WebMD.com and Mayoclinic.com appear on top of the list.

However, since the Local Chapter focuses on the Norwegian users, the competitors in this category are popular Norwegian healthcare websites, including Helsenorge.no, NHI.no, Lommelegen.no, and also Nettdoktor.no. All of these platforms offer general health information and symptom checker that are written and edited by medical doctors. The goal of these websites is to provide free health information and treatment information, with a massive range of health conditions and diseases. These platforms are very different from PI, as none of them share innovative solutions developed by patients. Nevertheless, since they are the choices of patients, they can be defined as PI's competitors. The next approach explains the competitors that are more similar to PI's platform.

The second approach is from the service point of view. In this case, PI's competitors can be identified as websites that offer the same service, which is connecting patients and facilitating them to share their experiences. In other words, PI's competitors are online health support groups or online health communities. In Norway, online health support groups and communities are scattered through different websites and blogs based on the focus of the health conditions. Therefore, PI's competitors are international online health support groups, since patients in Norway also have the possibility to access these websites, and most Norwegians understand English. Popular examples of these platforms are PatientsLikeMe, MDJunction, Healthboards, and Inspire. Even though these websites enable patients to share their experience and solutions, none of them focus on innovative solutions. In addition, all of the health support groups mention the use of medication, which is prohibited on PI's platform.

The last approach in identifying PI's competitors is from the benefactors' or donators' point of view. In this case, the competitors are the non-profit organizations that donators in Norway choose to donate. Some of the popular health organizations in Norway are Kreftforeningen, FFO, and Pasientforeningen. These organizations' main goal is to connect and assist patients. Similarly, PI's goal is also to connect patients and to improve their lives. Even though PI and these organizations have different focuses, they are currently receiving funding from donators. FFO and Pasientforeningen are publicly funded, whereas Kreftforeningen is funded by both public and private donators. Therefore, as PI is also searching for funding, these organizations can be viewed as potential competitors.

The table below summarizes the three ways of viewing PI's potential competitors. In the end, these approaches also reveal the distinctiveness of PI, which also serves as the competitive

advantages of PI. PI's competitive advantages are: PI screens the content to ensure safety, PI prohibits the posts that mention the use of medications, PI shares innovative solutions developed by patients, which also creates the possibility of transforming the patients into entrepreneurs if they decide to commercialize their innovative solutions. However, PI also has a competitive disadvantage, since PI is not on top of the search results of the search engine when patients search for health-related solutions.

Even though the platforms and organizations listed in the table below are considered as competitors, they can be better viewed as indirect competitors, since PI is the only platform that focuses on sharing innovative solutions developed by patients. Moreover, these indirect competitors can even be viewed as potential partners of PI's Local Chapter, especially the other non-profit organizations. These health organizations connect and assist patients in Norway, thus they have the capability to reach patients with chronic and rare diseases in Norway, or the potential users of PI's Local Chapter. Since these health organizations are capable of spreading the awareness of PI's existence in Norway, it is crucial for PI's Local Chapter to establish a partnership with them.

Table 3: Comparing PI's Local Chapter with the potential competitors (or partners) from different points of view

Name of platform	Focus	Screen the content	Share innovative solutions	Mention the use of medication
Patient-innovation.com	Enabling users to share innovative solutions developed by patients and their caregivers	Yes	Yes	No
Popular Norwegian healthcare platforms				
Helsenorge.no	General health information	Yes	No	Yes
NHI.no	General health information	Yes	No	Yes
Lommelegen.no	General health information	Yes	No	Yes
Nettdoktor.no	General health information	Yes	No	Yes
Popular online health support groups				
Patientslikeme.com	Options for treatments, open source research data	No	No	Yes
Mdjunction.com	Bringing together 800 other online groups	No	No	Yes

Healthboards.com	The opinion and experience of patients only, not health professional	No	No	Yes
Inspire.com	Health community for patients with chronic, rare diseases, cancer, and their caregivers	No	No	Yes
Other health organizations in Norway				
Kreftforeningen	Increasing the awareness of cancer, helping cancer patients, and funding cancer research in Norway			
FFO	An umbrella organization of 82 member organizations for people with chronic diseases and disabilities			
Pasientforeningen	Assisting patients and their families that experience difficulties in receiving healthcare			

3.3 Market Analysis

As defined in the customer analysis section in this chapter, the users of PI's Local Chapter are patients with chronic and rare diseases, and their caregivers. Since patients with chronic diseases are actively searching for solutions to cope with their lifelong condition, they have the highest probability of being the users or visitors of PI's platform. In order to define the size of the market in Norway, it is crucial to be aware of the number of patients living with chronic and rare diseases in Norway. However, the statistics showing the population of people with chronic diseases usually display the Disability Adjusted Life Years (DALYs) instead of the number of the population. One of the examples of the statistics is presented in Figure 15.

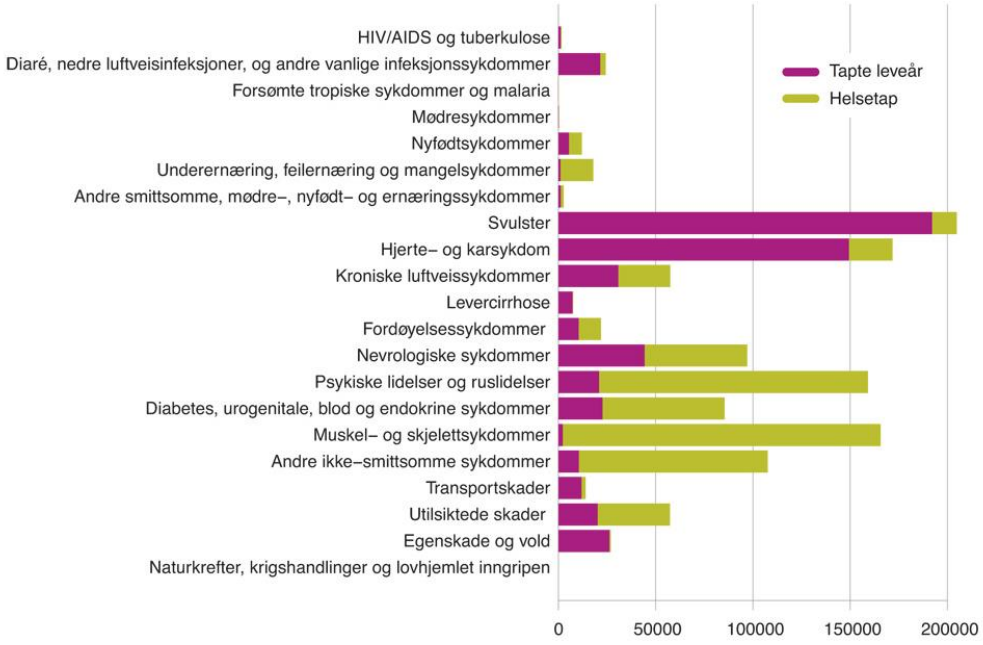

Figure 15: Number of DALY by disease group in Norway 2013 (source: Regjeringen.no (2016))

DALYs is defined as “the sum of years of potential life lost due to premature mortality and the years of productive life lost due to disability” (WHO, 2005). As illustrated in Figure 15, the numbers displayed are DALYs of the disease group, and the purple bars are the lost years of life, whereas the green bars represent the years of productive life lost due to disability. Therefore, since patients with chronic diseases might also be people with disabilities, Figure 16 can be utilized to define the number of possible users of PI’s Local Chapter in Norway. Figure 16 shows that in 2016, 18% of the population in Norway between the ages of 16 - 66, or about 636,000 people, are disabled. Nevertheless, this number does not cover the population under the age of 16 and above the age of 66. Thus, the number of PI’s Local Chapter potential users are at least 600,000. This number will increase as the trend of using the internet for searching healthcare solutions in Norway is increasing (Wangberg et al., 2009). Therefore, the Local Chapter in Norway aims to reach 600,000 visitors per year, and 200,000 registered users or subscribers by the fifth year. The growth of the visitors per year means that more visitors access the platform more than once (recurrence), which also means that the possibility of improving the lives of patients is higher.

Even though the Local Chapter is in Norway, PI’s platform can be accessed globally. Therefore, even if the potential users in Norway are 600,000 people or less, but since a website coupled with social media has the potential to create the “snowball” effect, there is a possibility that the number will exceed 1 million visitors globally per year in the long run. In addition, people that have innovative solutions, who are not patients, but want to share, can also be the possible users of the platform. This group of people is defined as the collaborators. Therefore, if the content of the platform is managed carefully together with the social media, PI’s platform will automatically attract more visitors or users. The strategy to attract more users is included in the market strategy part.

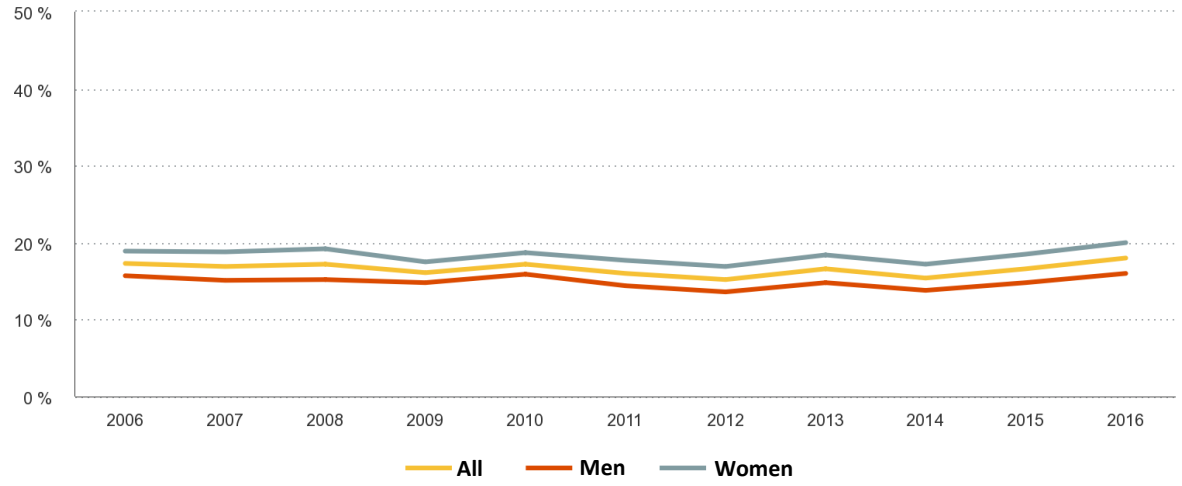

Figure 16: Proportion of the population in Norway with disabilities, according to the Labor Force Survey, 16-66 years old (source: Bufdir.no (2017))

The number of users might create the value for the benefactors, which in the end will ensure the survival of PI's Local Chapter. However, there is a more important aspect of the market, which is the number of patients that can be helped by PI. As the mission of PI is to empower patients and improve their lives, it is crucial that PI has the ability to show the benefactors that the donated funds effectively help the patients. This might be challenging, but examples can be presented, such as the 3D printed prosthetic hand that is posted as one of the innovative solutions. Until this thesis is written, the design of the prosthetic hand has been viewed by more than 13,000 viewers on another website, Thingiverse.com. Moreover, as the design is available to be downloaded for free, it has been downloaded by more than 8,000 times (Robohand, 2014). Even though this might not be accurate, the number shows that one innovation has the potential to improve the lives of 8,000 people that need it.

3.4 Existing Business Model Analysis

As indicated by one of the founders, PI is a project instead of a business, thus there was no business plan or business model from the start of the project. Currently, PI is a non-profit organization that relies on research grants for its operations. This mode of survival is deemed to be unsustainable, especially in Norway, where even one of the largest non-profit organizations, the Norwegian Cancer Society (Kreftforeningen) grows by utilizing mostly private sponsors and donations. The reason behind this is that the amount of public funding in Norway is usually very limited and thus hinder the ability of the organizations to survive and grow in the long run.

Interestingly, a website, Changemakers.com, published a page of information written by Ramalho (2014) that supports this matter. On this website, it is stated that PI faces challenges such as high staff turnover and limited marketing activities due to the dependency on the research grants. This difficulty also occurs in other Local Chapters, Germany and Slovenia, as PI Global Coordination Center (GCC) in Portugal provides no financial support to all Local Chapters (Appendix 2). In Germany, the Local Chapter is run by students that volunteer to campaign for PI, thus the volunteer turnover is also high, as the students graduate and leave. In Slovenia, the Local Chapter is not launched yet due to funding challenges. Therefore, in order to avoid this problem, PI's Local Chapter in Norway has to implement a sustainable business model, which aims to ensure financial sustainability in order to survive and grow. The business model describes how PI's local chapter will acquire both public and private funding, including the market strategy for achieving more users in order to increase the marketability of the platform. The strategy is presented in the Market Strategy section of this chapter, whereas the business model is displayed in the Business Plan chapter.

3.5 Environmental Analysis

The environmental analysis helps to define the opportunities and threats for PI's Local Chapter in Norway, thus facilitating the next analysis, the SWOT (Strengths, Weaknesses, Opportunities, and Threats) analysis. In the end, these analyses enables PI's Local Chapter to formulate the market strategy. Therefore, the environmental analysis is a crucial preliminary step before the launching of PI's Local Chapter. In order to analyze the environment, the PESTLE (Political, Economic, Sociological, Technological, Legal, and Environmental) analysis is utilized.

The first aspect of the analysis is the political aspect, and regarding PI's Local Chapter, the healthcare system in Norway is considered as an important factor. Van den Noord et al. (1998, p. 16) state that "the health service in Norway appears to be unable to always ensure speedy access to hospital care, and there is also scope for improved efficiency through a better regional coordination and planning of health care services…long waiting lists and reduced freedom of choice of hospitals by patients is widely considered to be unacceptable". The long waiting lists might trigger patient to seek for solutions by themselves. Thus, in order to search for the solutions, patients usually turn to the internet. The research conducted by Wangberg et al. (2009) also shows the significant increase of people using the internet for health purposes

for the last 10 years. As PI empowers patients by enabling them to share their own innovative solutions on the internet, this situation is considered as an opportunity for PI.

For the economic aspect, the high labor costs in Norway can be viewed as a threat for PI's Local Chapter in Norway. The high labor costs mean that a large proportion of the funding acquired by PI will be only used for financing the salary of the staffs. Therefore, it will pose a danger to the Local Chapter if the funding is insufficient for covering the salary. On the other hand, the sociological aspect can be considered as favorable to PI's Local Chapter in Norway. The increasing trend of using the internet for health-related information is an opportunity for PI to reach more users. Similarly, the technological aspect, such as the increasing use of social media and the availability of high-speed internet connection in Norway, is beneficial to the Local Chapter. By using the social media as a low-cost marketing channel, PI's Local Chapter will be able to create the "snowball" effect in reaching its audience. Moreover, the easily and readily accessible high-speed internet connection is necessary for PI, as PI posts most of its solutions in video format, which requires high-speed internet connection.

The last two aspects of this environment analysis are the legal and environmental aspects. For the legal aspect, intellectual property rights (IPR) is the most important issue that should be taken into careful consideration. Even though some of the innovative solutions are protected, there is still a possibility of infringement by the other users that view the solutions in the platform. For example, a user might be able to commercialize an innovative solution from the platform by copying and modifying the original solution. Lastly, the environmental aspect has no significant impact to PI's Local Chapter, since PI is an online service and has no physical production facility. The table below summarizes the PESTLE analysis of PI's Local Chapter in Norway.

Table 4: PESTLE Analysis of PI's Local Chapter in Norway

Element	Factor	Impact on PI's Local Chapter
Political	• Norwegian healthcare system, patients' long waiting lists	• Patients turn to the internet for solutions; opportunity for PI, as PI empowers the patients
Economic	• High labor costs	• Threat for PI, if the raised funding is insufficient
Sociological	• Increasing trend of using the internet for health-related information	• Opportunity for PI to acquire more users
Technological	• The rise of social media, a low-cost mean of marketing • High-speed internet connection is available and easily accessible	• Opportunity for low-cost marketing campaign • Opportunity for PI, as PI posts solutions in video format

Legal	• IPR of the innovative solutions posted	• Threat for PI, as there is always a possibility of IPR infringement
Environmental	• PI's activities have very little environmental impact, since PI is an online service	• No significant impact

Beside the PESTLE analysis, the framework suggested by Ansari et al. (2010) can be utilized to supplement the environmental analysis. The information from the PESTLE analysis can be applied to this framework, which consists of three elements: technical, cultural, and political fits. By applying the information from PESTLE on the framework, the extent of adaptation of PI GCC practices by the Local Chapter in Norway can be identified, based on the technical, cultural, and political fits. In the end, this framework reveals whether the Local Chapter in Norway needs to modify the practices of PI GCC or fully adopt the practices.

For the first element, the technical fit, the Local Chapter in Norway is considered to be a fit to the PI GCC technical practices. This is due to the availability of the technical infrastructure: the already available platform, social media, and the high-speed internet connectivity in Norway. The use of social media enables the Local Chapter to reach more users without having to modify the existing platform. Thus, the Local Chapter practices high fidelity and high extensiveness for the technological adaptation. In conclusion, for the technical fit, the Local Chapter can be characterized as a full and true adaptation. The position of the Local Chapter's technical fit in the framework is presented in the image below.

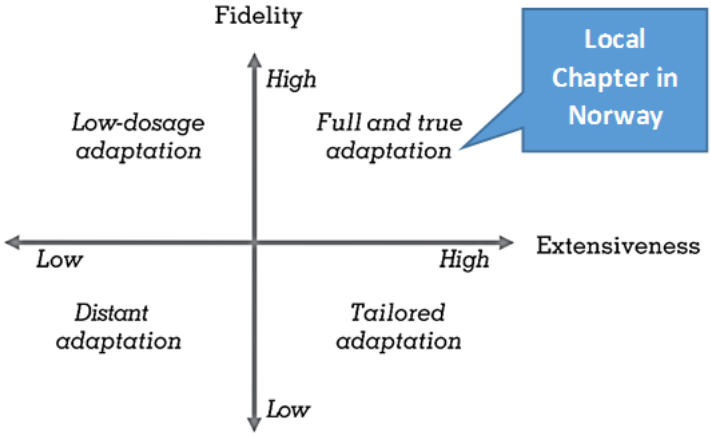

Figure 17: The technical fit of PI's Local Chapter in Norway

As for the cultural fit, it is also possible for the Local Chapter to practice the full and true adaptation, since the Local Chapter shares the same values and beliefs, including the vision of

improving the lives of patients with chronic and rare diseases. Therefore, the cultural fit of the Local Chapter is also considered as high fidelity and high extensiveness. The cultural fit of the Local Chapter in the framework is displayed below.

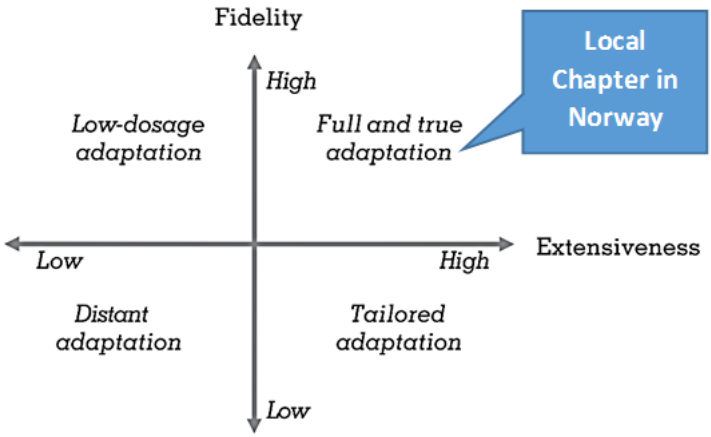

Figure 18: The cultural fit of PI's Local Chapter in Norway

The last element, the political fit of the Local Chapter, which is depicted in the figure below, is different from the technical and cultural fit. This is due to the difference in organization's agenda, regarding the business model. The PI GCC currently only depends on research grants, whereas the Local Chapter in Norway will employ a different business model in order to be sustainable. Therefore, for the political adaptation, the Local Chapter can be considered as adapting with low fidelity, but with high extensiveness, since the business model covers the whole organization of the Local Chapter. In conclusion, the Local Chapter will implement a tailored adaptation for the political fit.

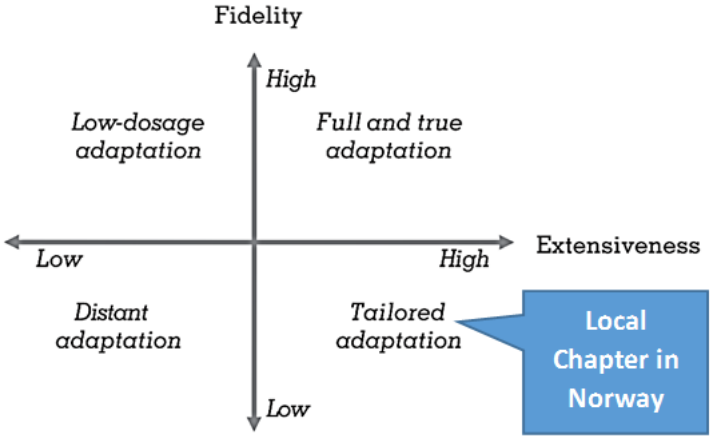

Figure 19: The political fit of PI's Local Chapter in Norway

3.6 SWOT Analysis

The SWOT (Strengths, Weaknesses, Opportunities, and Threats) analysis describes the current status of PI's Local Chapter in Norway, which is the result of environmental analysis and internal analysis of the current situation. This analysis is essential as the foundation of the marketing strategy which is presented in the next section. The Local Chapter's marketing strategy can be formulated by utilizing the strengths and taking the available opportunities, as well as by eliminating the weaknesses and minimizing the threats.

The core strength of the Local Chapter, or PI, is the fact that PI is the only platform that facilitates the sharing of innovative solutions developed by patients. This unique content is one of PI's competitive advantage that also creates its own group of users or market niche. Besides the unique service, PI also screens its content before publishing it, thus creating higher credibility. In addition, by using the platform, either for sharing or searching for innovative solutions, patients are empowered to show their needs and choices to the healthcare actors. As for the Local Chapter, this existing platform provided by PI GCC is free to use, thus enables the Local Chapter to utilize the available opportunities without having to compensate PI GCC. Moreover, PI GCC even supports its Local Chapters by executing the second-level content screening and assisting the promotion of the Local Chapters.

One of the opportunities for the Local Chapter in Norway is the increase of the internet usage for health purposes. Therefore, the increase of the internet users will also create more potential users for PI. Besides the increase of the internet usage for healthcare purposes, the increased usage of social media will also catalyze the number of PI's users. If the Local Chapter utilizes the social media aptly, it will create the "snowball" effect. The use of social media for sharing the videos of innovative solutions will be effective with the available high speed-internet connection in Norway.

There are also weaknesses that PI's Local Chapter has to eliminate. The existing business model of PI GCC is one of the weaknesses that the Local Chapter needs to consider. It is imperative that the Local Chapter in Norway utilizes a new business model that ensure the survival and sustainability of the Local Chapter. Other minor weaknesses are the search-ability and the website navigation of the existing PI platform. Currently, the platform is not on the top of the search engine results of diseases or symptoms, thus hinder the opportunity to

reach more users. Therefore, PI needs to increase its search-ability and design a better navigation list for easier search of solutions on its platform.

The greatest threats for PI's Local Chapter are the high labor costs in Norway and the possibility of discontinued funding, since the consequence is the extermination of the Local Chapter. These threats can be minimized by employing a sustainable business model and by implementing the marketing strategy that ensures continuous funding. In addition, the Local Chapter has to anticipate the issues regarding IPR while posting the solutions originated from Norway. Lastly, the summary of the SWOT analysis of PI's Local Chapter in Norway is displayed in the image below.

Strengths • Unique content/service • Screening of the content (safety) • Empowering patients • Free existing platform • Free support from PI GCC	**Weaknesses** • Existing business model • Search-ability • Website navigation
Opportunities • Increasing use of the internet for health purposes • Increasing use of social media • Easily accessible high-speed internet connection	**Threats** • High labor costs • IPR issues • Discontinued funding

Figure 20: SWOT analysis of PI's Local Chapter in Norway

3.7 Marketing Strategy

The environmental analysis and the SWOT analysis reveal what marketing strategy is needed for the Local Chapter in Norway. In order to formulate the marketing strategy, it is necessary to sum up the main objective of the marketing strategy, based on the environmental and SWOT analysis. From these analyses, it is identified that the most significant threat is the discontinued funding, thus the main objective of the marketing strategy will be acquiring more donators. However, in order to achieve more donators, PI has to be well known, thus the platform needs to reach more users. The popularity of PI is the main value to the donators, especially for the corporate donators, as it means that their CSR program is functioning. In addition, by reaching more users, PI's vision to empower more patients will also be accomplished. Therefore, the marketing strategy is formulated to achieve two different but interrelated objectives: to get more users and to get more donators/benefactors (Figure 21).

In order to reach these goals, the strengths, such as the unique content, will be utilized with the opportunities, such as social media, to reach more users and more donators. In addition, the effort to eliminate the weaknesses, such as the improvement of the platform, has to be executed in order to attract more users. The overall marketing strategy is presented in the 4Ps of marketing mix framework. In addition, since the users can also be donators and vice versa, the marketing process proposed by Baker (2001) is also presented.

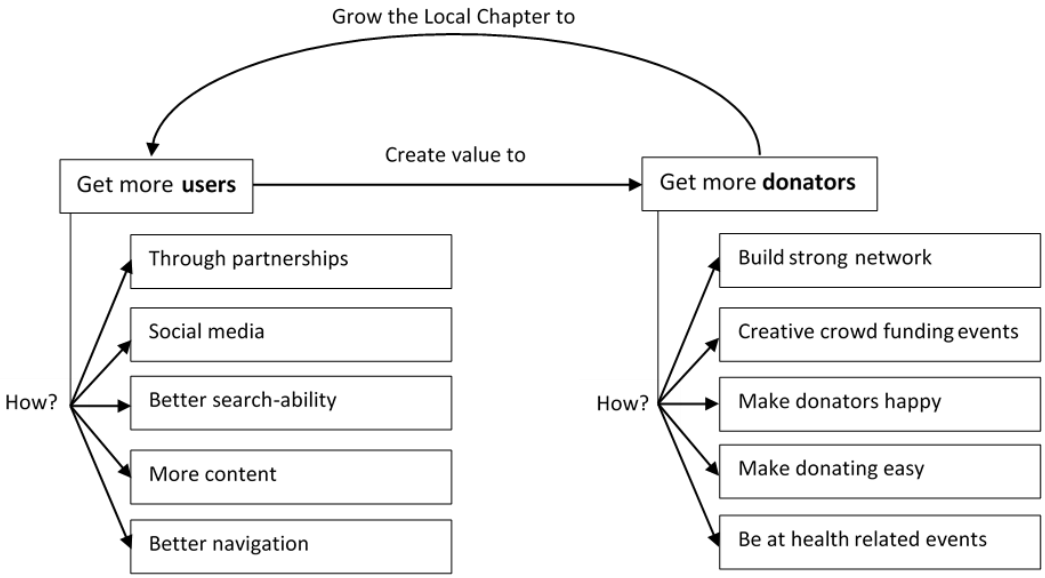

Figure 21: The objectives of the marketing strategy for the Local Chapter

3.7.1 Marketing Mix Strategy

The marketing mix strategy for the Local Chapter consists of marketing tools that are categorized according to the four elements of the 4Ps: Product, Price, Place, and Promotion. The marketing strategy related to the Product aims to eliminate the weaknesses of the existing platform, thus attracting more users. In order to reach this goal, the search-ability of the platform has to be improved. If the search-ability is improved, patients that search for solutions or symptoms can be directed to PI's platform. For the Local Chapter in Norway, this means that by adding Norwegian keywords to the platform, besides translating the content into Norwegian, will attract more Norwegian audiences. In addition, by increasing the number and the variety of the solutions posted on the platform, the chance of getting more users will be higher, even though the initial target audiences are patients with chronic and rare diseases and their caregivers. In addition, an information about how many patients actually use the

posted solutions should be presented, even though it might be challenging to get the exact numbers. However, this information is crucial for the benefactors, as they might want to ensure that the donation is utilized effectively according to PI's mission. Lastly, a minor improvement for better navigation in the platform, such as by adding a list of symptoms category, might be helpful for a better user experience.

The second element, the Price, for PI's case is unavailable, since the product or service offered by the platform is completely free. However, this is more relevant to the funding, as it is the foundation of PI's existence. In order to ensure sustainable funding, it is crucial to acquire donations from every possible source through every possible way, as long as it is not harming PI's credibility. Thus, providing a direct donation button on the platform and the social media is one of the ways of making it easier for the benefactors to donate. Moreover, users or benefactors will be more encouraged to donate if the amount of donation is not specified or voluntarily.

The Place element of the Local Chapter can be defined as the channel where PI delivers its service to the users and the benefactors. One of the most effective channels is the social media, since it has the potential to grow the number of viewers exponentially. Therefore, by packaging the videos with PI's logo and sharing the videos on a daily basis through the social media, it will create a legion of subscribers and catapult PI's popularity. An example of successful similar practice is the American based internet media company, BuzzFeed. However, this practice has to be executed carefully, particularly regarding the IPR of the solutions. Another way of delivering PI's content is through the platforms and social media that belong to other non-profit organizations, such as Kreftforeningen, FFO, and Pasientforeningen. As PI's initial market niche is the patients with chronic diseases, partnerships with these organizations will be tremendously beneficial in reaching the patients and improving their lives. Lastly, for the Place component, physical presence is also necessary in order to deliver better service to the benefactors. In this case, the strategic location of the Local Chapter's physical presence will be in Stavanger, as the initiators of the Local Chapter and the potential benefactors are situated there.

The last element of the marketing mix, Promotion, is the most crucial activity for the Local Chapter. The promotion activities of the Local Chapter will include creative crowd funding events, which can be done either online or through real-life events. Competitions, auctions, or charity concerts are some of the examples of the possible activities that can support the crowd

funding efforts. In order to cover the costs of such events, building a network of prospective benefactors is necessary, as the benefactors might also be able to support these efforts. For example, hotel chains as benefactors will offer a special price for the events hosted in their premises. In fact, network building is essential for reaching the potential individual and corporate donators that are willing to support PI's Local Chapter financially on a regular basis. Network building can also be done by participating in healthcare related events, especially the ones that are related to chronic and rare diseases.

The benefactors that donate on a regular basis are individuals and corporations that might have the same vision with PI or have a well-matched CSR program. For this type of corporate benefactors, supporting PI's Local Chapter might be viewed as indirect marketing for them, as PI will have to put their logos on the platform or on the social media. However, currently PI also posts solutions that might be mistaken by visitors as the marketing of the solutions. Therefore, allowing the logos of the companies on the platform or social media will be the first step in building a strong relationship with the benefactors. In addition, the increasing number of users is one of the factors that make these benefactors happy, as it will be a good publication for them. Lastly, the summary of the marketing mix is presented in the figure below.

Product • Increase search-ability • Varied solutions (more content) • Better navigation • Show the efficacy of the platform (number of patients helped)	**Price** • Non-specified amount of donation • Enable donation through social media and platform
Place • Social media (daily video feed) • Partnership with other non-profit organizations • Physical presence in Stavanger	**Promotion** • Creative crowd funding events • Build strong relationship with benefactors • Network building • Healthcare related events

Figure 22: Marketing mix of the Local Chapter

3.7.2 Marketing Strategy Process

As a non-profit platform, PI's Local Chapter can also apply the marketing strategy process designed for the websites of non-profit organizations, which is proposed by Baker (2001). The purpose of this strategy is to transform the platform's visitors into loyal donors. The marketing strategy process consists of four phases: attracting visitors, turning visitors into friends, converting friends into donors, and growing donors into loyal donors.

To begin with the first phase (attracting visitors), PI's Local Chapter can perform online and offline marketing. Similar to the 4Ps of the marketing mix, online marketing includes the use of social media and improving the search-ability of the platform. On the other hand, promotion through crowd funding events and participation in health-related events are some of the offline marketing efforts. After that, the next phase is to the visitors into friends, by engaging and involving them. For this phase, newsletter and event calendars can be sent to the users. Besides, sending personal messages and asking for feedback from the users will be useful in this phase. Furthermore, asking the users for their own testimonials and encouraging them to be a volunteer will create a sense of involvement, thus turning them into friends. In this case, these friends are considered as registered users or members of the platform.

Next, in order to convert the friends into donors, communicating the mission of PI to the users is important. It is also necessary to inform these friends about the amount of funding needed and how it can help the mission of PI. This can be accomplished by telling the story of PI's users or patients that have experienced the benefit of the platform. At this point, the users might already have the desire to donate, thus a direction to the donate button in the mail, platform or social media should be present, so that it is easy to donate. If they donate, PI should send the confirmation through on-screen and separate thank you mail, followed by the report of the progress periodically. It is also necessary to ensure the security and the privacy for the donation process. Moreover, providing a special section or page for the donors on the platform can be beneficial for them, especially when they want to manage their donation.

Lastly, the most challenging phase is to grow the donors into loyal donors. Song et al. (2015) even articulate that most donors of crowd funding platforms only donate once or a few times and never come back. Thus, by creating online and offline donor loyalty program, this challenge can be overcome. Keeping the donors updated about the status of funding and the impact of the funding is one of the examples of online donor loyalty program that will make

them happy. Moreover, the Local Chapter can even invite the loyal donors to be involved in their activities, in order to create a sense of belonging. All in all, the entire marketing strategy process is displayed in the figure below.

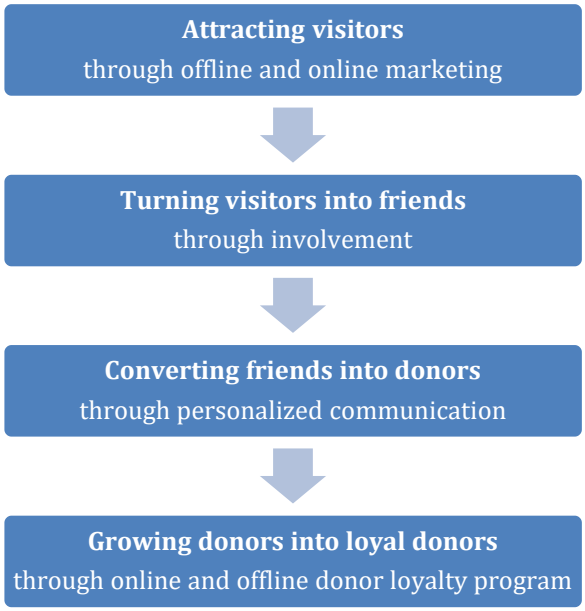

Figure 23: The marketing strategy process of PI's Local Chapter, as suggested by Baker (2001)

3.8 Conclusion

This chapter answers the sub-research question: "*Who are the stakeholders of PI's Local Chapter in Norway and what is the marketing strategy for each stakeholder?*" The result of the customer analysis suggests that the customers of the Local Chapter in Norway can be defined as the people who use the platform (users) and the people or organizations who are willing to pay for the service (benefactors). The target users are patients with chronic and rare diseases, their caregivers, and collaborators. On the other hand, the potential benefactors are not only public and private organizations, but also possibly individual donators. These groups of customers are defined according to the value created by PI's platform.

The possible competitors are popular Norwegian health information platforms, popular international online health support groups, and other health-related non-profit organizations in Norway. However, since PI's platform is the only platform that shares innovative solutions developed by patients, the competitors can be viewed as indirect competitors and even as potential partners, especially the other non-profit organizations. Thus, the stakeholders of the

Local Chapter can be defined as the customers, the partners, and the employees of the Local Chapter including PI GCC (Global Coordination Centre). The roles of the stakeholders are best represented by the business model in the business plan chapter.

The environmental analysis suggested that the most significant threat that the Local Chapter has to anticipate is regarding the funding. Insufficient funding or unsustainable business model, together with the high labor costs in Norway, will threaten the existence of the Local Chapter. In addition, the framework of the three fits (technical, cultural, and political) also suggests that the Local Chapter should have tailored adaptation regarding the organization's agenda. Therefore, by utilizing the SWOT analysis, the marketing strategy is formulated, which aims for the survival of the Local Chapter. The goals of the marketing strategy are to get more users and at the same time to get more donators to ensure sustainable funding. The marketing strategy consists of a marketing agenda that is presented in two ways: the marketing mix and the marketing process. This marketing strategy is an essential part of the business plan chapter, which is presented in the following chapter.

4 Business Plan

4.1 Executive Summary

OUR OPPORTUNITY	
THE PROBLEM	OUR SOLUTION
Many patients with chronic diseases and their caregivers develop innovative solutions to cope with their conditions, but there is no "one-for-all" place to share the solutions to other patients.	Patient Innovation (PI) is a **free**, safe, and multilingual platform that promotes the posting and sharing of innovative solutions developed by patients and caregivers to cope with the challenge imposed by any kind of disease or health condition.

OUR MISSION
To empower patients, improve their lives, and inspire them to become entrepreneurs

WHY IN NORWAY?
A representative of PI, or a "Local Chapter", is essential in Norway: • In order to reach the Norwegian patients and caregivers • Not all Norwegians are confident in communicating in English while discussing about their health conditions • Online translator might be inaccurate in translating medical terms and conditions, thus unsafe

VALUE PROPOSITION
PI connects patients with chronic and rare diseases, their caregivers, and collaborators to share their innovative solutions to other patients in order to improve their lives, lower the cost of healthcare, and catalyze entrepreneurship. PI also provides other organizations an opportunity to create a good impact on the society.

THE COMPETITIVE LANDSCAPE	
OUR COMPETITORS / POSSIBLE PARTNERS	OUR ADVANTAGES
www.helsenorge.no www.lommelegen.no www.nettdoktor.no	• PI shares innovative solutions, not just symptoms • PI catalyzes entrepreneurship • PI screens the content to ensure safety

TARGET MARKET AND MARKETING STRATEGY	
TARGET MARKET (USERS)	MARKETING STRATEGY
Patients with chronic and rare diseases, and their caregivers in Norway	• Creative crowd funding events • Partnership with other organizations • Promotion through benefactors • Social media marketing

FUNDING / DONATION NEEDED AND THE TEAM	
FUNDING / DONATION NEEDED	NECESSARY TEAM
1M NOK for the first year	• Local Chapter leader – Full time • Platform manager – Part time • Medical officer – Part time / Volunteer

POSSIBLE RESOURCES AND MILESTONES	
POSSIBLE FUNDING / DONATION FROM	MILESTONES
• Norwegian Smart Care Cluster (NSCC) • University of Stavanger (UiS) • Lyse • UnIKT • Esso	• 2017 – Apply for funding • 2018 – Launching, Reach 50K visitors • 2019 – Reach 100K visitors, 50% private donations • 2020 – Reach 300K visitors, 75% private donations • 2021 – Reach 600K visitors, 99% private donations

4.2 The Problem

The research conducted by the founders of Patient Innovation (PI) shows that many patients with chronic and rare diseases or their caregivers often find innovative solutions for coping with their conditions. However, only a fraction of these patients and caregivers shared the solutions to other patients (Oliveira et al., 2015). This was due to the fact that, before PI's platform was launched, there was no place or media that facilitate the sharing of innovative solutions developed by patients and caregivers. The founders realized that there was a need to share the innovative solutions in order to improve the lives of the other patients and caregivers, particularly the ones with chronic and rare diseases. The image below depicts the result of the research and the problem.

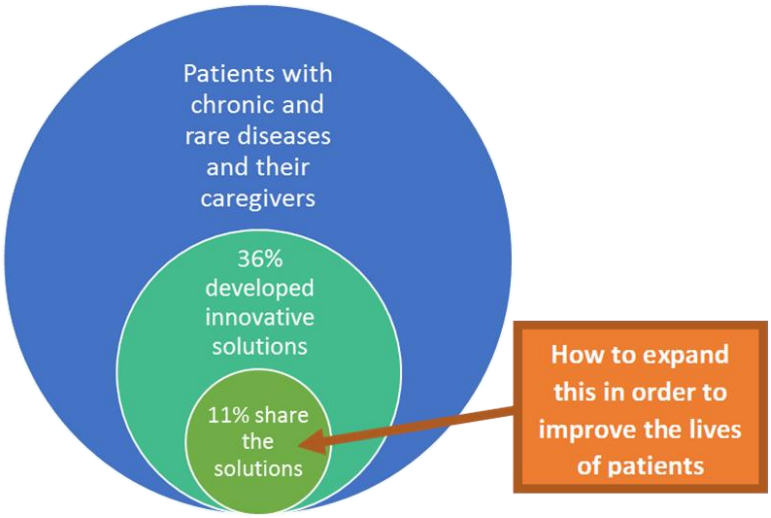

Figure 24: Illustration based on the result of the research (Oliveira et al., 2015) and the problem

4.3 The Solution

Patient Innovation (PI) is a free, safe, and multilingual online platform that promotes the posting and sharing of innovative solutions developed by patients and caregivers to cope with the challenge imposed by any kind of disease or health condition. It is free to search and view all the posted innovative solution as well as to post innovative solutions. The content of the website is also screened by a team of medical doctors in order to ensure that the posted solutions mention no use of medication or other dangerous methods. Besides posting and sharing, users of the platform can also join the forum. A screenshot of PI's platform is displayed below.

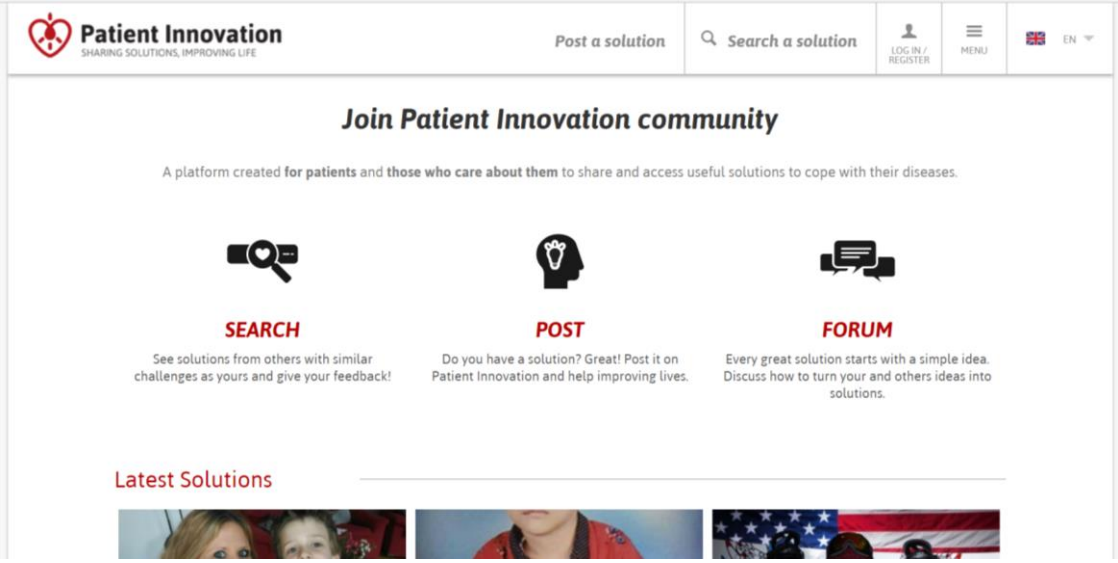

Figure 25: PI's platform

4.4 Value Proposition

PI's Local Chapter customers can be divided into two groups: the users of the platform and the benefactors. The users of the platform are the visitors and the registered members. PI's target viewers are patient with chronic and rare diseases, including their caregivers, as PI's mission is to empower them and improve their lives. These users can either search for solutions in order to cope with their conditions, or share the solutions that they developed. However, the users can also be healthy people that want to share innovative solutions that they discovered. This group of users is defined as collaborators. On the other hand, the benefactors are the paying customers, which can be corporate or individual donators. There is also a possibility that the donators are publicly funded organizations. However, PI's Local Chapter focuses more on the private donators for the reason of financial sustainability, which is elaborated in the business model section. Lastly, there is a possibility that the users are also the donators, or vice versa.

4.4.1 The Users

The value proposition for the users is that PI connects patients with chronic and rare diseases, their caregivers, and collaborators to share their innovative solutions to other patients in order to improve their lives, empower them, and inspire them to become entrepreneurs.

4.4.2 The Benefactors

The value proposition for the benefactors is that PI provides the donators an opportunity to give back to the society, by helping patients and their caregivers improve their lives. For corporate donators, this value includes the opportunity to enhance their image, or even indirect marketing.

4.5 The Local Chapter

As written on the Local Chapter Guidelines (Appendix 2), "Local chapter (LC) of Patient Innovation (PI) is an associated, formal or informal, organization that is attributed a dedicated area of the Patient Innovation Platform". The Local Chapter Guidelines also state that the Local Chapter is established to serve a geographical region in order to cover the subjects and interests relevant to the region. Therefore, the objectives of the Local Chapter are:

- To present PI's content in the local language
- To promote PI's content in the locally organized events
- To search and facilitate the content from the region according to the terms and services of PI's platform
- To assist the local users (patients, caregivers, and collaborators) in using PI's platform.

As PI is a non-profit organization, it is stated in the Local Chapter Guidelines that the Local Chapter shall also be a non-profit formal or informal organization, thus the Local Chapter is prohibited to take any commercial or financial advantages from PI's content. Moreover, PI Global Coordination Center (GCC) neither requires any payment from the Local Chapter nor provides any financial support to the Local Chapter. Therefore, all Local Chapters must search for their own funding.

4.6 The benefits of the Local Chapter in Norway

The Local Chapter is needed in Norway in order to promote PI in Norway, thus helping patients and caregivers in Norway. In addition, not every Norwegian is comfortable in communicating in English, especially regarding health problems. Furthermore, even though it

is possible to use online translator on the platform, it might be inaccurate and unsafe for translating medical terms. The benefits of the Local Chapter in Norway are:

- Improving the lives of patients and caregivers in Norway
- Empowering the patients
- Enabling them to share their own innovative solutions
- Lowering the cost of healthcare, for example: 3D printed prosthetic hand is cheaper than the usual prosthetic hand
- Stimulating entrepreneurship in the healthcare sector in Norway

All of the benefits mentioned above can be acquired by the Local Chapter in Norway without having to compensate PI GCC, even though PI GCC provides the assistance in using and promoting the platform.

4.7 Competitive Landscape

The potential competitors of the Local Chapter in Norway can be identified by using three different points of view. The first point of view is from the patients' point of view in Norway. If patients want to search for health information in Norwegian, usually the most popular platforms appear on top of the search engine are Helsenorge.no, NHI.no, Lommelegen.no, and Nettdoktor.no. These platforms are managed by medical doctors, thus the content of each platform is screened. Another way of identifying the potential competitors is to compare PI's platform with other health support groups, which are platforms that share patients' experience. These platforms are international platforms like Patientslikeme.com, Mdjunction.com, Healthboards.com, and Inspire.com. Similar to PI's platform, these platforms facilitate the posting and sharing of solutions by patients. In Norway, this kind of platforms is scattered and usually focuses on one specific disease.

The last point of view is from the benefactors' point of view in Norway. Public and private donations usually go to popular health-related nonprofit organizations such as Kreftforeningen, Pasientforeningen, and FFO. However, instead of being competitors, these organizations have more potential to be the partners of PI's Local Chapter, as they already have the patients' network. Even though the other platforms also have the potential to be the partners, the possibility is lower than that of the healthcare organizations, since the other

platforms might want to require payment for advertising PI's platform. Therefore, the competitive landscape presented in the table below only compares PI with other platforms. Nevertheless, until this thesis is written, PI is the only platform that focuses on sharing innovative solutions developed by patients, internationally and in Norway. Thus, the competitive advantages of PI's platform and Local Chapter in Norway are:

- PI is the only platform that shares innovative solutions developed by patients
- PI screens the content to ensure safety
- PI has the potential to catalyze entrepreneurship, if the idea owners want to commercialize their innovative solutions
- Free support from PI GCC (except financial support), thus eliminating the cost of web development for the Local Chapter

Table 5: The competitive landscape for PI's Local Chapter in Norway

Name of platform	Focus of content	Screen the content	Share innovative solutions	Prohibit mentioning the use of drugs
Patient-innovation.com	Innovative solutions	Yes	Yes	Yes
Popular Norwegian healthcare platforms				
Helsenorge.no	General information	Yes	No	No
NHI.no	General information	Yes	No	No
Lommelegen.no	General information	Yes	No	No
Nettdoktor.no	General information	Yes	No	No
Popular online health support groups				
Patientslikeme.com	Patients' experience	No	No	No
Mdjunction.com	List of 800 groups	No	No	No
Healthboards.com	Patients' experience	No	No	No
Inspire.com	Patients' experience	No	No	No

4.8 Market Quantification

In order to define the number of potential users in Norway, the relevant statistics can be utilized. The available statistics of patients with chronic and rare diseases in Norway display the years of life instead of the number of population. Thus, the most relevant available data is the statistics of the disabled people in Norway. The data show that in 2016, 18% of the population in Norway between the ages of 16 - 66, or about 636,000 people, are disabled (Bufdir.no, 2017). Since this number only covers a part of the target users, it can be considered that the potential users are at least 600,000 visitors in Norway alone. Therefore,

the Local Chapter aims for 600,000 visitors per year, with 200,000 registered members or subscribers by the 5th year. This goal is achievable if the social media marketing is done effectively, as the social media has the potential to create the "snowball" effect. The marketing strategy and the yearly goals are elaborated in the market strategy section and the milestones section of this chapter.

Another quantification that is essential for the benefactors is related to the impact of PI's Local Chapter. Besides the numbers of visitors, benefactors also need to know that their donations are utilized effectively by the Local Chapter, aligned with its mission. Therefore, by presenting the number of the patients that are helped by the platform is one of the factors that will satisfy the benefactors. This might be challenging, but not impossible. For example, the 3D printed prosthetic hand, which is posted on PI's platform, has been viewed more than 13,000 times and downloaded for more than 8,000 times by the time this thesis is written (Robohand, 2014). This data can be found on Thingiverse.com, where the design of the prosthetic hand, Robohand, can be downloaded for free. Thus, this innovative solution has helped thousands of patients, even though it might be less than 8,000 patients.

Lastly, the number of the innovative solutions that are posted on the platform is also crucial. One of the factors that attracts visitors of a health information platform is the variety and quantity of the posted solutions. Therefore, the Local Chapter in Norway aims to collect and share 1,000 solutions from Norway by the 5th year of the operation. If it is assumed that averagely one solution has the potential to help 500 patients, 500,000 patients in Norway will be helped by PI's platform by the 5th year. The illustration of the market quantification is presented in Figure 26.

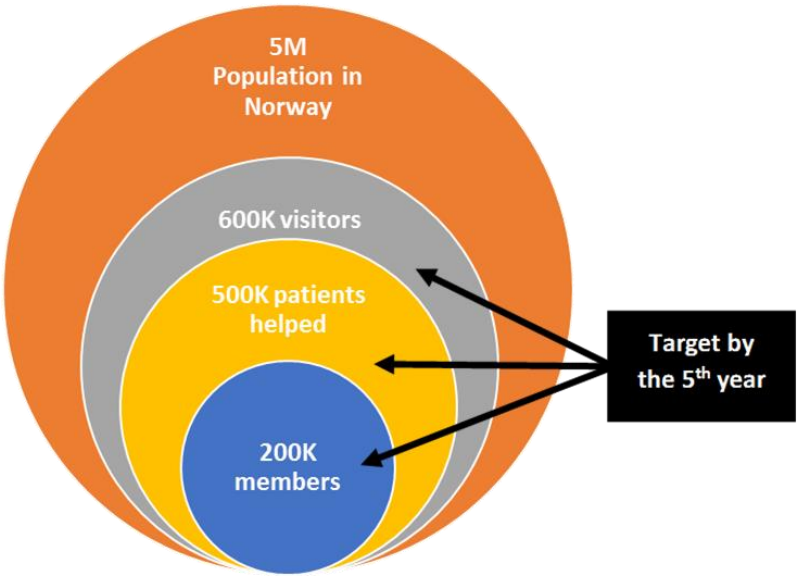

Figure 26: Market Quantification of the Local Chapter in Norway

4.9 Market Strategy

The market strategy, pictured below, consists of marketing activities that are categorized according to the goals of the strategy: to get more users and to get more donators. This strategy is formulated to ensure that the Local Chapter is financially sustainable.

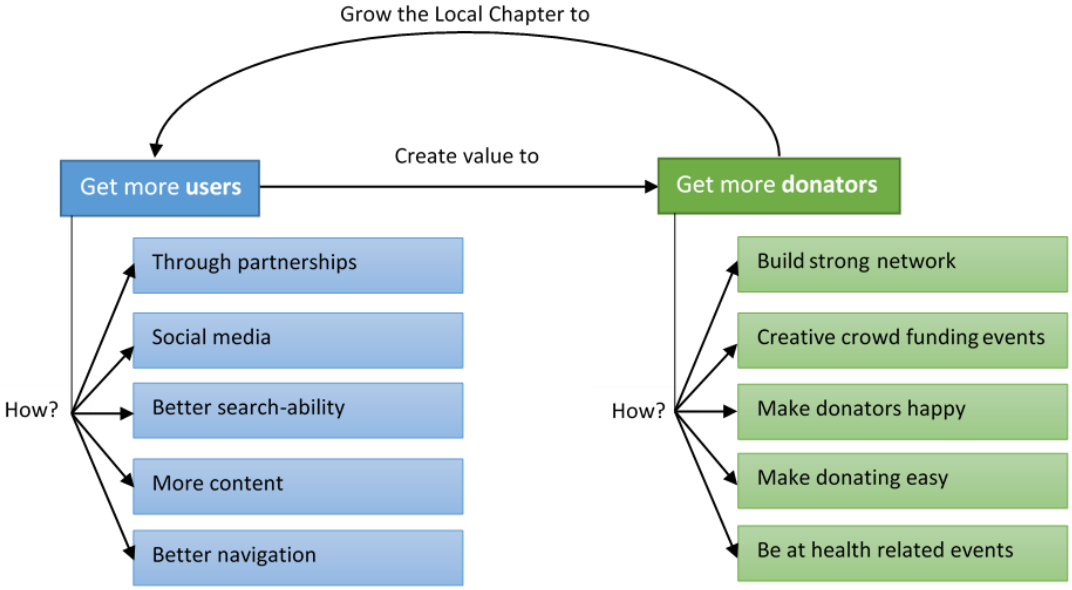

Figure 27: Market strategy of the Local Chapter in Norway

By getting more users, PI will create value to the benefactors or donators, as PI will also create indirect marketing for them. On the other hand, more donators mean more source of

funding, which will result in the survival and growth of the Local Chapter. The detailed strategy is presented in the table below.

Table 6: Marketing activities of the Local Chapter

How to get more users	
Through partnerships	Approach organizations such as Pasientforeningen, FFO, and Kreftforeningen, and promote for free through their social media.
Social media	Post one customized video (with PI's logo) about innovative solutions per day through social media, in order to create the viral effect, just like BuzzFeed or Unilad.
Better search-ability	Add keywords about symptoms and diseases, in order to get the platform on the top of the search engine's list.
More content	Collect more innovative solutions, especially from Norway, in order to get more varied content, so that visitors are attracted to come back.
Better navigation	Add a list under each search categories, such as the symptoms and diseases category, in order to make it easier for visitors to navigate even without keywords.
How to get more donators	
Build strong network	Approach private corporations for possible funding. Ask for references of who might be interested in donating. Find the individual donators through partners. Keep good relationship with existing donators.
Creative crowd funding events	Organize creative activities for crowd funding, such as competitions (online or offline), charity concerts, and auctions. An example of a successful effort is the "ice bucket challenge".
Make donators happy	Keep existing donators update with the activities of the Local Chapter, including the financial report. Involve them in activities, and show them the result of the activities, such as how many patients are helped.
Make donating easy	Enable direct donation through the platform and social media. Provide a donation box when holding crowd funding events.
Be at health-related events	Always present at health-related events, in order to create the awareness of PI's existence. This is also useful for network building.

Another market strategy that is relevant to the Local Chapter is the marketing strategy process that aims to transform the users of the platform into loyal donors (Baker, 2001). The marketing strategy process consists of four phases: attracting visitors, turning visitors into friends, converting friends into donors, and growing donors into loyal donors. The detailed activities of this process can be found in the market study chapter of this thesis.

4.10 Business Model

The appropriate business model for the Local Chapter in Norway is the "Heartfelt Connector" funding model suggested by Foster et al. (2009, p. 37). As presented in the table below, the characteristic of the funding model is very similar to PI's Local Chapter, such as the mission and the tactical tools. However, this business model for nonprofit organizations has the funding source from individual donators, whereas for the Local Chapter, the source will also include corporate donators. This is due to the fact that the Local Chapter needs to ensure financial stability by attracting donations from all possible sources. For the first year of the operation, the funding sources might even include public funding. However, this source of funding might not be continuous, therefore, the Local Chapter must have backup sources.

Table 7: "Healtfelt connector" funding model (Foster et al., 2009, p. 37)

MODEL	CHARACTERISTICS	EXAMPLES	TACTICAL TOOLS
Heartfelt Connector			
Funding source: Individual Funding decision maker: Multitude of individuals Funding motivation: Altruism	The mission has broad appeal The benefits often touch the lives of the funder's family and friends Nonprofit connects donors to the cause through volunteerism or other means	Medical research (Susan G. Komen Foundation) Environment (Natural Resources Defense Council) International (Save the Children)	Special events Direct mail Corporate sponsorship

The business model for the Local Chapter is presented using the modified version of Osterwalder's business model canvas (Alexandros, 2016). This business model, displayed in Figure 28, shows the stakeholders of the Local Chapter and their roles in the activities of the Local Chapter. The core of the business model is the social value proposition (SVP) created by the Local Chapter, which is divided into two: the value for the users and the value for the benefactors. The users and the benefactors are the co-creators of PI's Local Chapter, which form a community with the Local Chapter. The users are also co-creating the platform, by posting their own innovative solutions or participating in the forum. The Local Chapter reaches these co-creators by utilizing the platform, social media, and through the partners. The expected outcome of the Local Chapter's business model is divided into two categories: financial outcome and non-financial outcome. Sustainable funding from individual and corporate donators is the financial outcome, whereas the non-financial outcome includes the expected numbers of visitors, members, and the impact of the Local Chapter.

Organizations, such as Kreftforeningen, Pasientforening, FFO, Bufdir, are the Local Chapter's most potential partners, as they have the network of patients in Norway. Moreover,

the support of PI GCC is crucial for the Local Chapter, thus PI GCC is the main partner. These partners are involved in the Local Chapter key activities, such as the marketing strategy. In order to execute the key activities, key resources such as funding and human resources are essential. Lastly, costs, such as wages and marketing costs, are the compensations that the Local Chapter has to pay, in order to get the key resources.

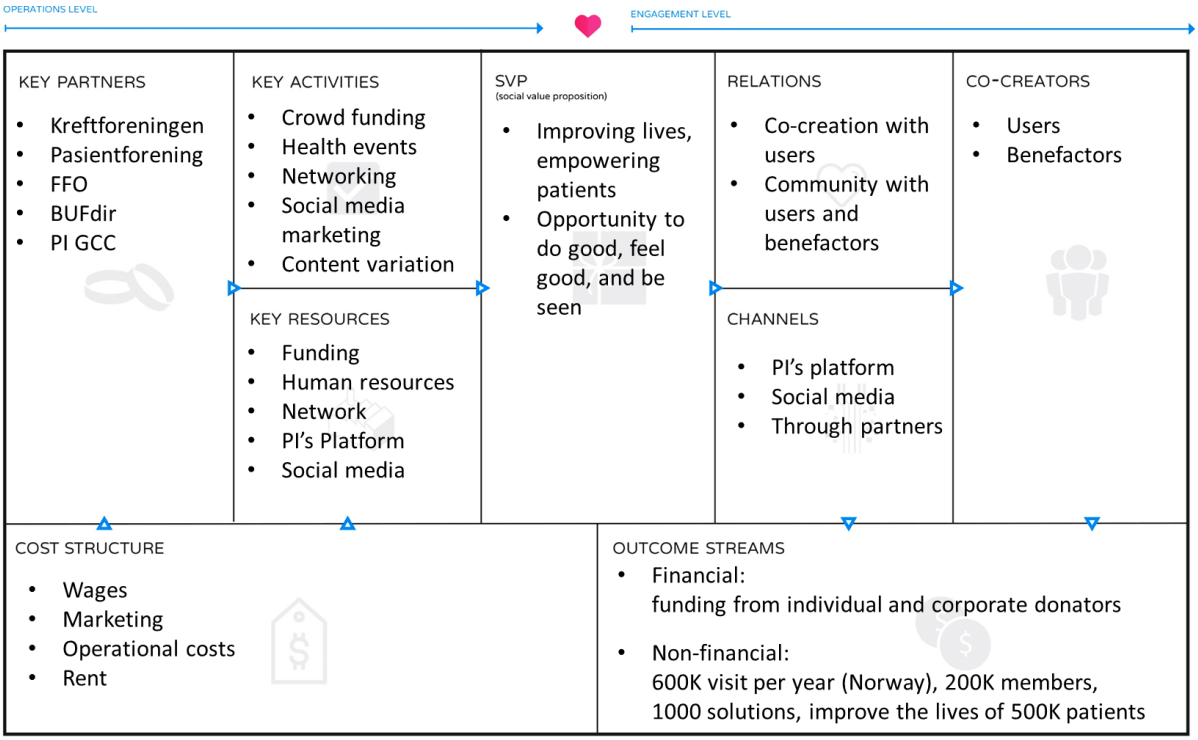

Figure 28: The Local Chapter's business model canvas

4.11 Milestones

The milestones of PI's Local Chapter in Norway are presented in Figure 29. These milestones describe the expected achievements of the Local Chapter in five years. These achievements include the expected funding per year, numbers of visitors per year, and numbers of expected registered members. The launching of the Local Chapter, which is planned for 2018, will be in Stavanger, as the first and possibly long term donators are located in Stavanger. Lastly, the milestones also present the expected impact of the Local Chapter, such as the number of the posted innovative solutions and the number of patients helped by the solutions.

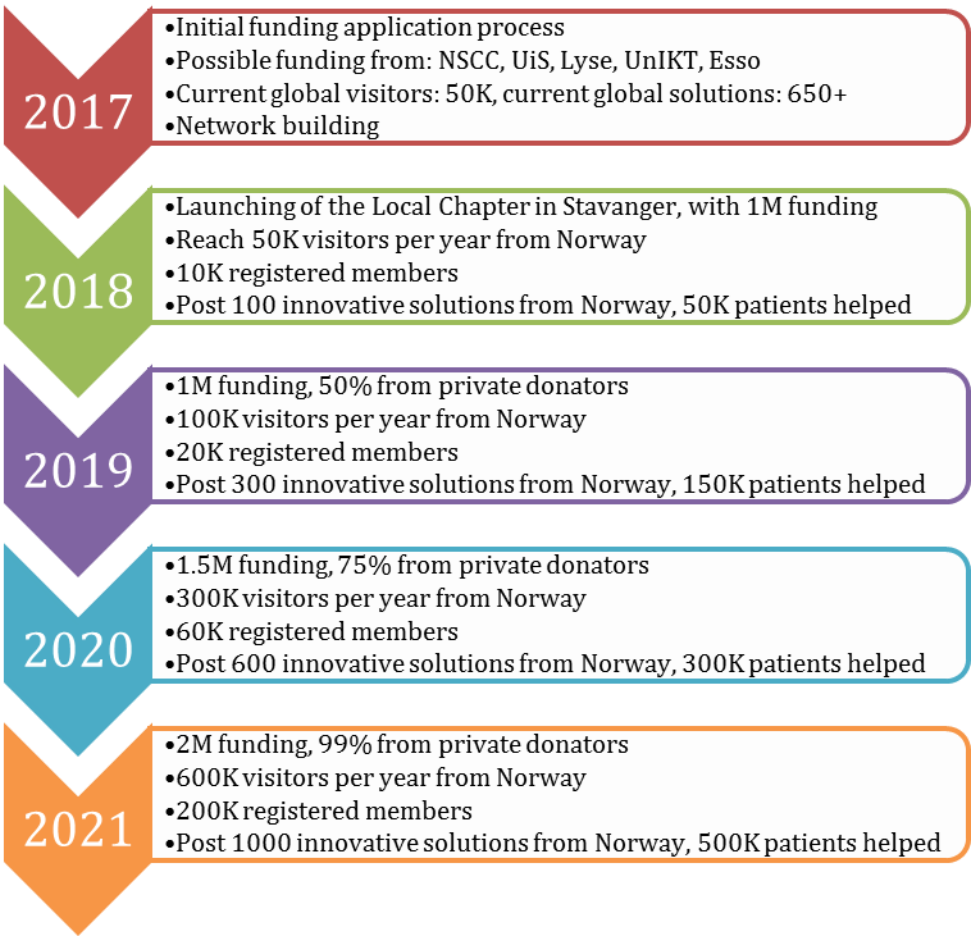

Figure 29: Milestones of the Local Chapter in Norway

4.12 Financial Plan

The financial projection of PI's Local Chapter in Norway is presented for the year 2018 until 2022, since the funding is estimated to be acquired at the beginning of 2018. Until this thesis is written, the effort in searching for funding is done voluntarily by the initiators of the Local Chapter. As PI GCC provides no financial support to the Local Chapters, the initiators of the Local Chapter have to search for sustainable funding in order to launch and to ensure the financial sustainability of the Local Chapter.

The estimated required funding for the first year is 1 million NOK, which will cover the wages of employees and the operational costs. For the first year of operation (2018), the Local Chapter will employ only one full time staff, the Local Chapter leader, and one part time staff, the platform manager. There is also a possibility to invite volunteers for the pre-screening of the content, which can be done by medical students. By the second year (2019), the Local Chapter is expected to achieve the same amount of funding (1 million NOK), in order to

sustain the operation. However, the wages and operational costs will increase, thus the marketing cost will be reduced. In the third year (2020), the amount of funding is expected to be increased (1.5 million NOK), in order to grow the Local Chapter. By employing another part time staff, it is expected that the content of the platform will be more varied and attractive to the visitors. In this year, more marketing effort should be done, thus the marketing costs will be increased.

Statement of Financial Activities
PI's Local Chapter in Norway

Year	2018 NOK	2019 NOK	2020 NOK	2021 NOK	2022 NOK
Funding	1,000,000	1,000,000	1,500,000	2,000,000	2,000,000
Operating expenses (per. year):					
Wages - employees, monthly salary x 11	495,000	506,000	836,000	1,199,000	1,222,100
Wages - owner, monthly salaryx 11					
Employers' national insurance contributions (not including vacation pay)	69,795	71,346	117,876	169,059	172,316
Vacation pay	50,490	51,612	85,272	122,298	124,654
Employers' national insurance contributions (vacation pay)	7119	7277	12023	17244	17576
Rent	72,000	73,200	84,000	86,400	87,600
Electricity	3,600	3,660	4,200	4,320	4,380
Telephone, mobile, fax, internet	6,000	6,000	7,200	9,600	9,600
Car expences, leasing, gas, etc.	24,000	24,000	25,200	30,000	30,000
Other travel costs / other unforeseen expenses	24,000	24,000	24,000	26,400	26,400
Office supplies	2,400	2,400	3,600	4,800	4,800
Marketing (advertising, etc.)	245,000	230,000	300,000	330,000	300,000
Accounting	0	0	0	0	0
Depreciation	0	0	0	0	0
Sum operating costs	999,404	999,495	1,499,371	1,999,121	1,999,427
Surplus / Deficit	596	505	629	879	573

Figure 30: Statement of financial activities

By 2021, the Local Chapter aims to achieve 2 million NOK funding in order to grow the numbers of both users and donators. Thus, the Local Chapter will hire 3 full time employees, so that the marketing efforts will be more effective. In this fourth year, it is assumed that the number of visitors has reached 600,000 per year and the number of posted solutions have reached 1,000. Therefore, in order to maintain the content and users, 2 full time employees will take the responsibilities. By the 5th year, the Local Chapter should be able to maintain the amount of funding, but some costs must be reduced in order to avoid a deficit. Therefore, careful budgeting is needed for every year. The details of the costs per year can be viewed in the statement of financial activities in the figure above. A cash flow projection is also presented in Appendix 5. The cash flow chart for every quarter year is displayed in Figure 31. For a non-profit organization, the goal is not to increase the cash flow, but to maintain a healthy cash flow. Thus, for the Local Chapter in Norway, careful spending and sustainable funding will result in the cash flow displayed in Figure 31.

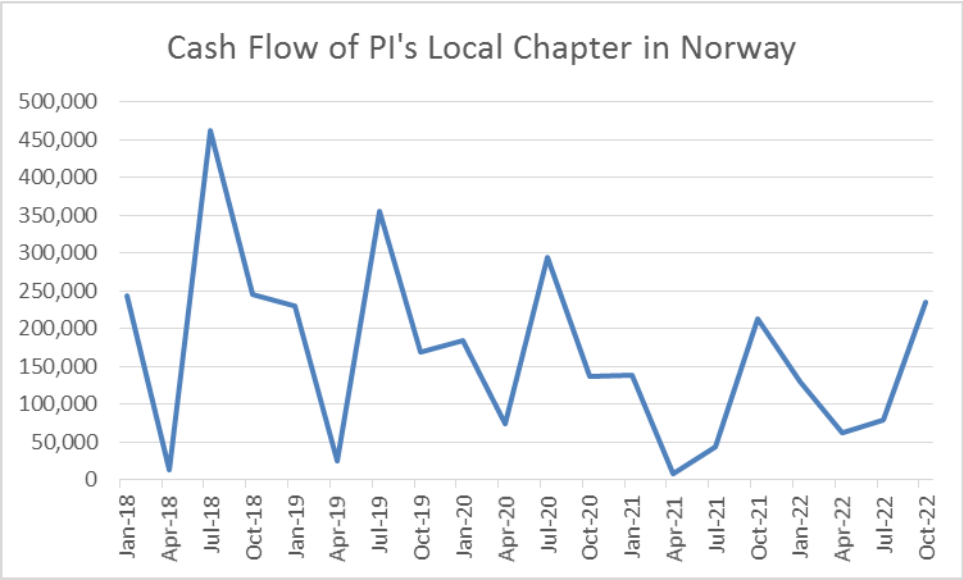

Figure 31: The cash flow chart of PI's Local Chapter in Norway

4.13 Necessary Team

There are three main roles needed in order to manage the Local Chapter in Norway. Thus, the Local Chapter needs to hire three employees: the Local Chapter leader, the platform manager, and the medical leader. The Local Chapter leader will be responsible for the whole operation of the Local Chapter, therefore, it is more suitable for a full time employment. On the other hand, the platform manager will be responsible for the whole content of the platform, whereas the medical leader will be responsible for the pre-screening process of the content. For the first two years, a part time employee can be hired for the platform manager position. However, as the pre-screening will not be a daily task at the beginning of the operation, volunteers from medical faculty can be invited for the role. As the organization and the platform grow, which is expected in the fourth year (2021), full time platform manager and medical leader will be hired.

The Local Chapter leader should be a person that has a business education background and preferably non-profit experience. The tasks of the Local Chapter leader are:

- Building and maintaining good relationship with stakeholders, mainly partners and benefactors (networking)
- Searching for funding or “knocking on doors”
- Promoting PI (spreading the awareness)
- Planning and implementing crowd funding events (organizing)

- Responsible for the finances
- Recruiting platform manager, medical manager, and volunteers
- Checking the content: permission, IPR, validation (pre-screening)
- Reporting and collaborating closely with PI Global Coordination Center (GCC)

A person with IT background and preferably social media marketing experience will fit in the position of the platform manager. The tasks of the platform manager include:

- Translating the content into Norwegian
- Gathering innovative solutions from the media in Norway
- Maintaining relationship with the users, respond to questions from users
- Adjusting the content to meet the Norwegians' need and culture
- Promoting PI through social media
- Pre-screening
- Collaborating closely with PI GCC in maintaining, adjusting and proactively improving the platform
- Creating and maintaining PI social media channel in Norwegian
- Collaborating with partners to share the content in their social media channel

Lastly, the tasks of the medical manager might be suitable for medical students as volunteers. These tasks include

- Medical pre-screening of the content, including the forum postings
- Promoting PI

4.14 Critical Risks

The following table shows the risks that the Local Chapter in Norway must take into consideration. The list of the risks also includes the level of probability and impact, as well as the preventive measures for each risk.

Table 8: List of critical risks

Risks	Probability	Impact	Preventive measures
Disagreement with PI GCC regarding the business model, as currently PI GCC relies on research grants and does not allow the display of corporate logos on the platform.	High	Extremely high	Discussion with PI GCC and asking for permission before implementing the business model.
Discontinued funding from public or private donators.	High	High	Build a strong relationship with benefactors, aim for multiple funding sources, especially from corporate and individual donators.
Staff turnover, especially for the first two years, as the platform manager and the medical leader are not full time employees.	Moderate	Moderate	Employ people that have volunteering experience. Aim for permanent employment by the 2nd year, if possible.
Losing credibility because of the business model, by displaying corporate logos.	Moderate	High	Choose the right corporate donators. For example, not pharmaceutical companies.
The validity of the posted solutions, which can cause the inappropriate use of the content. For example, users take commercial advantage of the posted solutions that are not proven effective.	Moderate	Moderate	Always ask for permission when posting a solution, and check whether it is effective or not, even though it might be challenging, especially if it is in other foreign languages.
Possible IPR infringement by viewers of the platform, especially if the posted solutions have not been protected. Other people might take the advantage of copying an innovative solution and commercialize it.	High	Moderate	Display a warning message on each posted solution, if possible. For example, a “patent pending” message can be displayed for an unprotected innovation, if the innovator agrees.

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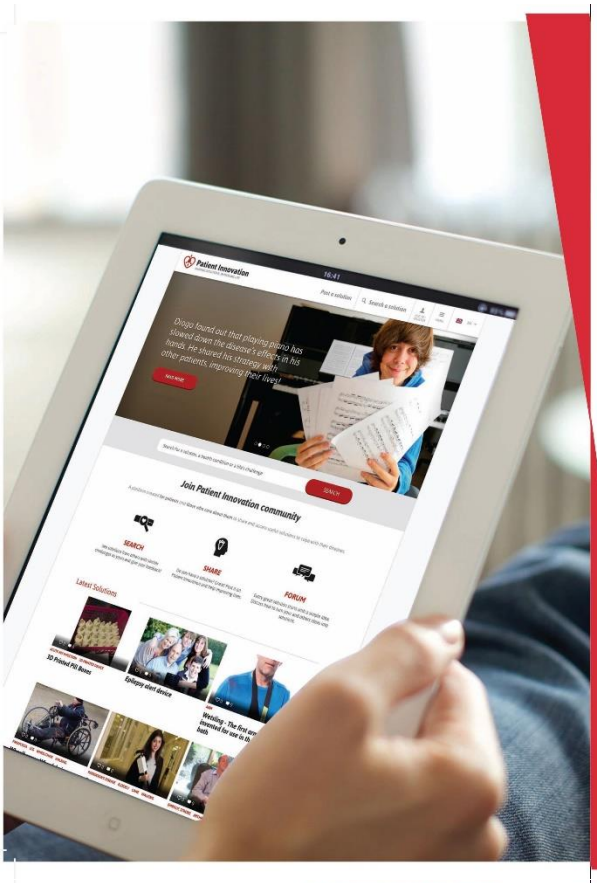
Appendices

Appendix 1: PI's brochure



Patients of chronic diseases have to deal with long-lasting conditions and everyday challenges. They frequently develop valuable solutions to improve their quality of life and even treat their own disease, sometimes saving their own lives! **What if they could end up saving the lives of others?**

These innovations usually occur behind closed doors and might never be known or used by anyone else. However, if successful innovations and knowledge were shared with other patients and caregivers with similar needs, it could improve the lives of many others.

Potentially a game changer in the healthcare industry

Potential benefits

Diffusing innovative solutions and devices developed by patients to help them cope with their disease or condition.

Sharing ideas between patients in order to develop or enhance innovative solutions.

Collaboration between patients and specialists from different areas in the development of ideas or improvement of existing solutions.

Each patient, caregiver or collaborator is a potential innovator.

We are driven to, everyday, work on a non-profit platform that connects patients, caregivers and collaborators and enables the sharing of solutions, devices and knowledge, otherwise unknown to others.

"Doctors make the worst patients. Maybe in the future patients will make the best doctors."

Carlos Moedas
European Comissioner for Research, Science and Innovation
in 1st Patient Innovation Awards Ceremony, Lisbon, 2015

Doron Somer (Israel)

Doron's son, Itamar, is autistic and suffered mis-treatment at the hands of a professional caregiver. So Doron invented **ANGELSENSE**, a personal GPS device designed specifically to keep special needs children monitored.

CAREGIVER

Kenneth Shinozuka (USA)

To prevent his grandfather, who suffers from Alzheimer's disease, from wandering alone at night, Kenneth created **SAFEWANDER**. A wearable sensor designed to send an alert to a caregiver whenever a patient gets out of bed.

CAREGIVER

Pavel Kurbatsky (Russia)

Having worked with disabled children, Pavel wanted to invent something to make their lives better. So he created a **WALKING TALKING STICK** to help blind people move around. The cane contains sensors that can trace obstacles at three levels: the head, waist and feet.

COLLABORATOR

Duncan Fitzsimons (UK)

Having created **FOLDABLE WHEELS** for his bicycle, a man in a wheelchair made him realize disabled people would also benefit from his innovation, if Duncan adapted that concept to wheelchairs. So he did, and now wheelchair users can fold their wheelchairs.

COLLABORATOR

WINNERS OF THE 2ND PATIENT INNOVATION AWARD

Michael Seres (UK)

PATIENT

Michael was diagnosed with Crohn's disease. That is why he invented the **OSTOM-I ALERT**: a sensor-based device that can be attached to any ostomy bag and is able to send messages via Bluetooth to a mobile app to warn the patient when his bag is close to being full.

Giesbert Nijhuis (Netherlands)

SERIAL PATIENT INNOVATOR

Giesbert is a tetraplegic who created his own website, **LAESIEWORKS**, where he shares several solutions he created that help him coping with challenges he faces daily due to his condition.

David Day (UK)

CAREGIVER

David Day's daughter, Alicia, suffers from Cystic Fibrosis. David developed **COMPUTER GAMES** which are played by using a device that connects breathing tubes to the computer, controlling characters and shapes on screen by exhaling at a certain pressure.

THE PLATFORM PATIENT INNOVATION HAS MORE THAN **600 SOLUTIONS** ONLINE.

How does it work?

The Patient Innovation Platform is an international, multilingual, totally free-of-charge venue for patients, caregivers and collaborators of any disease to share their innovations within the community.

The platform allows searches by disease, symptom, location, type of activity, device, and therapy. It is available online at www.patient-innovation.com

www.patient-innovation.com

Research and management team

The Patient Innovation Platform has resulted from the joint research and international cooperation of scholars (in the health sciences, management, engineering and law), healthcare practitioners and institutions that are committed to help promote knowledge and solutions that can improve patients' well being.

Advisory Board

Aaron Ciechanover
Professor, Technion-Israel Institute of Technology
Nobel Laureate in Chemistry

Lee Fleming
Professor, University of California, Berkeley

Eric von Hippel
Professor, MIT Sloan School of Management

Robert Langer
Professor, MIT

Richard Roberts
Chief Scientist, New England Biolabs
Nobel Laureate in Physiology or Medicine

Katherine Strandburg
Professor, New York University School of Law

Debby Elnatan (Israel)

Debby Elnatan's youngest son was born with cerebral palsy, so he couldn't stand and walk. Debby tried different ways to "link him" to her through straps, leading to **UPSEE.** With Upsee, her son is now able to "walk" like other children and participate in family activities.

CAREGIVER

Joaquina Teixeira (Portugal)

Joaquina Teixeira's son, Gonçalo, has Angelman Syndrome, which is characterized by psychomotor problems. Although Gonçalo was six years old and able to walk, he refused to stand. One day Joaquina placed **HELIUM BALLOONS** all over her house and watched Gonçalo jump and walk to reach the balloons. Today he walks.

CAREGIVER

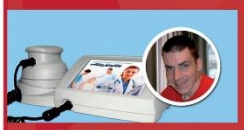
Ivan Owen (USA)

Ivan Owen is an artist who posted one of the "mechanical hands" he created on YouTube. A carpenter from South Africa that had lost fingers in a sawing accident contacted Ivan and asked him for help in designing and building a **LOW-COST PROSTHETIC HAND**. Ivan accepted the challenge and also developed low-cost 3D printed prosthetic hands for children. He later shared the digital files used to produce the parts in a 3D printer.

COLLABORATOR

WINNERS OF THE 1ST PATIENT INNOVATION AWARD

Louis Plante (Canada)



PATIENT

Louis Plante suffers from Cystic Fibrosis. Louis developed the **FREQUENCER**™, a device that uses sound waves to help clearing the lungs. The Frequencer™ is the first device to deliver low-energy resonant (acoustic) vibrations, reducing mucus viscosity and promoting mucus flow in patients with Cystic Fibrosis.

Lisa Crites (USA)

PATIENT

Lisa Crites was diagnosed with breast cancer. Following a mastectomy, she was advised to avoid showering in order to prevent infection through the drain sites. She then created a water-resistant garment, the **SHOWER SHIRT**™, to enable patients to shower without risking infection.

Tal Golesworthy (UK)

PATIENT

Tal Golesworthy suffers from Marfan Syndrome. He applied his engineering background and worked with his doctor and addressed his own aortic problem with the **PERSONALIZED EXTERNAL AORTIC ROOT SUPPORT (PEARS)**. Since PEARS was first installed on Tal's heart in 2004, the device has been implemented several patients to prevent aorta rupture.

Sir Richard Roberts

CHIEF SCIENTIST, NEW ENGLAND BIOLABS
NOBEL LAUREATE IN PHYSIOLOGY OR MEDICINE 1993

"I think this is a very creative and useful idea, because when people are faced with a difficult situation they often come up with quite innovative solutions all by themselves, but not everybody comes up with the same one. If there's a forum whereby they can share their solutions, then that can be very helpful to others in the same situation, who didn't find any solution. Even better, some people will look and realize they could combine some of these ideas, or add a new wrinkle of their own, and come up with an even more innovative and useful solution. ***THIS IS AN OUTSTANDING USE OF SOCIAL MEDIA THAT SHOULD HELP MANY DISADVANTAGED PEOPLE*** who desperately seek ways to improve their quality of life!"

Prof. Eric von Hippel

PROFESSOR, MIT SLOAN SCHOOL OF MANAGEMENT

"Research in the field of User Innovation has shown that millions of individuals create products and services they need for their own use. Many of these have great value to others as well. Research by Professor Oliveira documents that medical patients are also innovators, developing innovations to help them manage and maybe even cure the diseases that afflict them. In my view, ***THE PATIENT INNOVATION PLATFORM IS A PROJECT WITH POTENTIALLY VERY GREAT SOCIAL VALUE***. It will facilitate sharing of solutions developed by patients that would otherwise be lost. It will also contain tools to enable low-cost statistical evaluation of solution effectiveness by patients themselves. I support this project with great enthusiasm."

Prof. Katherine J. Strandburg

PROFESSOR, NEW YORK UNIVERSITY SCHOOL OF LAW

"This platform has enormous potential to improve the lives of rare disease sufferers. Patient and caregiver communities already work proactively to educate patients and physicians, organize support networks, pursue regulatory reform, and confront providers about treatment availability and cost. They advocate increased research funding and maintain patient registries. Policymakers have begun to recognize that rare disease patients are indispensable research collaborators and to design research strategies accordingly. This initiative goes further, recognizing that ***PATIENTS AND CAREGIVERS ARE INNOVATORS IN THEIR OWN RIGHT*** and using IT to facilitate the sharing, improvement, and evaluation of their innovations."

Prof. Francisco Veloso

DEAN, CATÓLICA LISBON SCHOOL OF BUSINESS & ECONOMICS

"Católica-Lisbon is proudly committed to supporting this international research project and solution sharing platform. ***I FIRMLY BELIEVE IT IS AN INITIATIVE AT THE CUTTING EDGE OF RESEARCH AND INNOVATION, AND A PROJECT WITH THE POTENTIAL TO IMPROVE THE LIVES OF MANY AROUND THE WORLD.*** Patient Innovation is also the result of joint interdisciplinary research collaboration with a variety of leading scholars at MIT, Carnegie Mellon and others, to whom we are grateful for their deep involvement and support."

Supporters


Carliss Baldwin
Professor, Harvard Business School
Harvard University


James Boyle
Professor, School of Law
Duke University


António Câmara
CEO, YDreams


Maria Carmo-Fonseca
President, Instituto de Medicina Molecular
Professor, FMUL


Alexandre Castro Caldas
Professor and Director, Instituto de Ciências da Saúde, Universidade Católica Portuguesa


António Coutinho
Coordinator, Conselho Nacional de Ciência e Tecnologia


Joi Ito
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Lawrence Lessig
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Kathrin Möslein
Professor, Universität Erlangen-Nürnberg
& HHL Leipzig


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Director, Carnegie Mellon Portugal Program
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Erich R. Reinhardt
Chairman, Executive Managing Board
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Aleda Roth
Professor, Clemson University


Francisco Veloso
Dean, Católica Lisbon School of
Business & Economics


Artur Santos Silva
President of the Board of Trustees of the
Calouste Gulbenkian Foundation

Appendix 2: PI's Local Chapter Guidelines

Local Chapter Guidelines

PATIENT INNOVATION

SHARING SOLUTIONS, IMPROVING LIFE

Local Chapter Guidelines

Contents

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2. **Local Chapter organization (structure, functions, and finances)** 3

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1. What is a Local chapter of Patient Innovation

Local chapter (LC) of Patient Innovation (PI) is an associated, formal or informal, organization that is attributed a dedicated area of the Patient Innovation Platform. The LC is established to specifically address topics and covers subjects more relevant for a domain of interest or a geographical region, and it is acting in compliance with PI values and goals.
Local chapters may be organized by an individual or a group of individuals with an aim to serve the needs of a regional community of interest, in terms of:

- presentation of PI content in local languages;
- promotion of the content in locally organized events;
- search and facilitation of content originating in the geographical region or the domain of interest, according to the terms and services of the PI platform;
- provision of help to patients, caregivers, and collaborators in the domain or geographical region of interest, in terms of usage of PI platform.

Local chapter is a Non-profit (as is Patient Innovation) formal or informal organization, and shall not take any commercial financial advantage from unauthorized distribution of the platform's content.

2. Local Chapter organization (structure, functions, and finances)

A Local Chapter is organized to effectively fulfill the following operations within the region of interest:

- Pre-screening of the content (originating from the region of interest) to filter for the posts that do not comply with the terms of service. After each pre-screening, the content is sent to PI GCC for the second-level screening;
- Provision of help to patients, caregivers, and collaborators, situated in the geographical region or the domain of interest, and in terms of usage of the PI platform;
- Promotion of PI, adjusted to local needs and context;
- Planning and execution of locally organized activities;
- Recruitment and management of volunteers/staff to grow the local chapter;
- Search for financial funds (grants and donations) to sustain the activities of the local chapter; PI GCC may provide help in this process, which shall be decided on a case by case basis;
- Periodic assessments of the quality of service and meaningfulness of the local chapter in collaboration with PI GCC;
- Adequately planning all the activities with the PI global coordination center.

To make sure these operations are executed properly, the suggested organizational form for the Local Chapter is presented next.

Suggested roles in the Local Chapter are:

- Local Chapter leader
- Platform manager
- Local Chapter communications manager
- All reporting to the central PI's structure.

Below you can find the mapping of descriptions of these roles.

Responsibility of / role	Operation/Function
Platform manager	Pre-screening of the content (originating from the region of interest) to filter for the posts that do not comply with the terms of service. After the pre-screening all the potential posts are forwarded to the second-level screening by PI GCC
Platform Manager	Provision of help to patients, caregivers, and collaborators, situated in the region of interest, and in terms of usage of the PI platform
Platform Manager	Proactive improvements of the PI platform, in coordination with the PI GCC
Local Chapter Leader, Local Chapter communications manager,	Promotion of PI, adjusted to local needs and context
ALL	Planning and execution of all locally organized activities
All	Search for financial funds (grants and donations) to sustain the activities of the local chapter
All, with PI GCC	Periodic assessments of the quality of service and meaningfulness of the local chapter.
Local Chapter Leader	Recruitment and management of volunteers/staff to grow the local chapter
Local Chapter Leader	Adequately planning all the activities with the PI global coordination center.

While internal management is not a subject of interest for the PI Global Coordination Center (PI GCC), the Local Chapter Leader is obliged to attend regular meetings with the PI GCC team, and coordinate all activities that shape the public image and bring any responsibility to the PI platform in general and in the region of interest.

Financing of a Local Chapter
PI GCC cannot ex-ante promise any financial support for any activity of the Local Chapter. All the work in the PI GCC is either a pro-bono basis, or is partially funded by the Research Grants. Local Chapter can expect organizational support in the process of search for grants and sponsorships, in the limits of availability at the time of a request.

3. Description of the pre-screening process

PI GCC and PI does not assume any responsibility for the content on the platform, in terms of its medical or scientific validity. However, in order to prevent, where humanly possible, malicious content, and ensure compliance with our Terms of Service, we have developed a two-phase procedure to control the main content published on the PI platform.
The two phases of this procedure are:

- Phase 1: pre-screening
- Phase 2: medical content validation.

Pre-screening of solutions that originate in the geographical region or domain of interest is the responsibility of the Local Chapter. Medical content validation is a responsibility of the PI GCC. Next, we explain the pre-screening process.

Pre-screening is a four-stage process.
Stage 1: identify and remove posts that are considered offensive or inappropriate, of commercial intent, that does not qualify as a solution/forum topic proposal, or that are visibly and intrinsically dangerous.
Stage 2: classify the post as a solution or a forum topic:

- A **solution** is a product, combination of products, services, or a mix of products and services that a patient, caregiver or collaborator develops to address a specific need. Solutions that involve drugs, chemicals or biologics that consist of invasive devices are not accepted.
- A **forum topic** is a type of post through which users can start their discussions about any topic related to health. The forum topic needs to be approved by the medical team before it becomes visible.

Stage 3: identify and classify the author of the post. The premise of this platform is to collect and diffuse solutions developed by patients, caregivers and collaborators. The classification is made on the basis of the innovator's "need"; the innovator can be classified as a Patient, Caregiver or Collaborator:

- **Patient** – The innovator is a person who is under health care, treatment, has a disability (impairment, activity limitation, and/or participation restriction) and he/she developed a solution in order to overcome his/her own health need
- **Caregiver** – The innovator is a caregiver who must not be a professional or paid caregiver and he/she developed a solution in order to overcome a health problem of a relative (spouse, partner, or a friend).
- **Collaborator** – The innovator is a collaborator who helped or was asked to help a patient and/or caregiver on the development of a solution to cope with a patient's need. The collaboration in the development process cannot be based of financial benefits or self-interests in the result obtained, irrespective of their profession.

Stage 4: assign appropriate ***tags*** to the post. For that matter, an accurate list of keywords will ensure correct indexing and help showcase the solution to interested groups. This in turn will increase the chances of the solution being found on the PI's platform search tool and Google. The ***tags*** are organized in 6 categories:

- **Condition** – check what other conditions could benefit from the solution described – (e.g. the solution of suspending balloons with different heights to stimulate kids with Angelman syndrome can be also applied as a stimulus to kids with autism).
- **Symptom** – identify the symptom perceived by the patient. Symptoms are common to many diseases, and there are solutions to overcome specific symptoms, which can be used by patients with different conditions – (e.g. stress, back pain).
- **Activity** – there are several solutions developed to improve an activity performance – (e.g. several diseases have a direct consequence on walking and each patient develops his/her own solution to overcome this consequence. However, all those solutions have one activity in common: walking).
- **Location** – several solutions, despite their usage purpose, can be associated to a specific part/organ of the body – (e.g. arm).
- **Device** – several devices can be grouped in sets that share some commonalities and that describe the type of solution provided - (e.g. crutches, 3D printed, DIY, Software).
    - LC is responsible to decide, in each stage of the screening process, to contact the solution author to either ask for more information or to rewrite the description of the solution.
    - LC has to translate to English all the local language written solutions before sending them to the PI medical team.

4. A few simple rules to ensure a long-term relationship

Besides being a wonderful and worthwhile project, PI touches many sensitive topics. We can only ensure our long-term vision of truly empowered patient innovators if we work together. As we grow and learn, we need to make sure that we are doing the right thing and in the right way. We need to communicate. Please, consider the following responsibilities only from this perspective.

Responsibilities of the Local Chapter (LC)

- LC shall post and share any type of PI-related content only if there is an explicit approval from PI GCC;
- LC shall let PI GCC of all changes in the LC's team;
- LC shall plan to report to PI all the information on their upcoming events;
- LC shall manage and control the quality of all the platform-user-generated content which originates from their region of interest and for all the local languages from the region.

Responsibilities of the (PI GCC)

- PI GCC shall keep LC up to date with all PI planned activities and events;
- PI GCC shall provide LC the information and existing material required for promoting PI;
- PI GCC shall provide means to keep timely flow of information regarding medical screening of solutions written in local languages and originating from the LC.
- PI GCC will advertise the Local Chapters in all the events and marketing material, if the available space allows such an advertisement.

Appendix 3: List of interviews

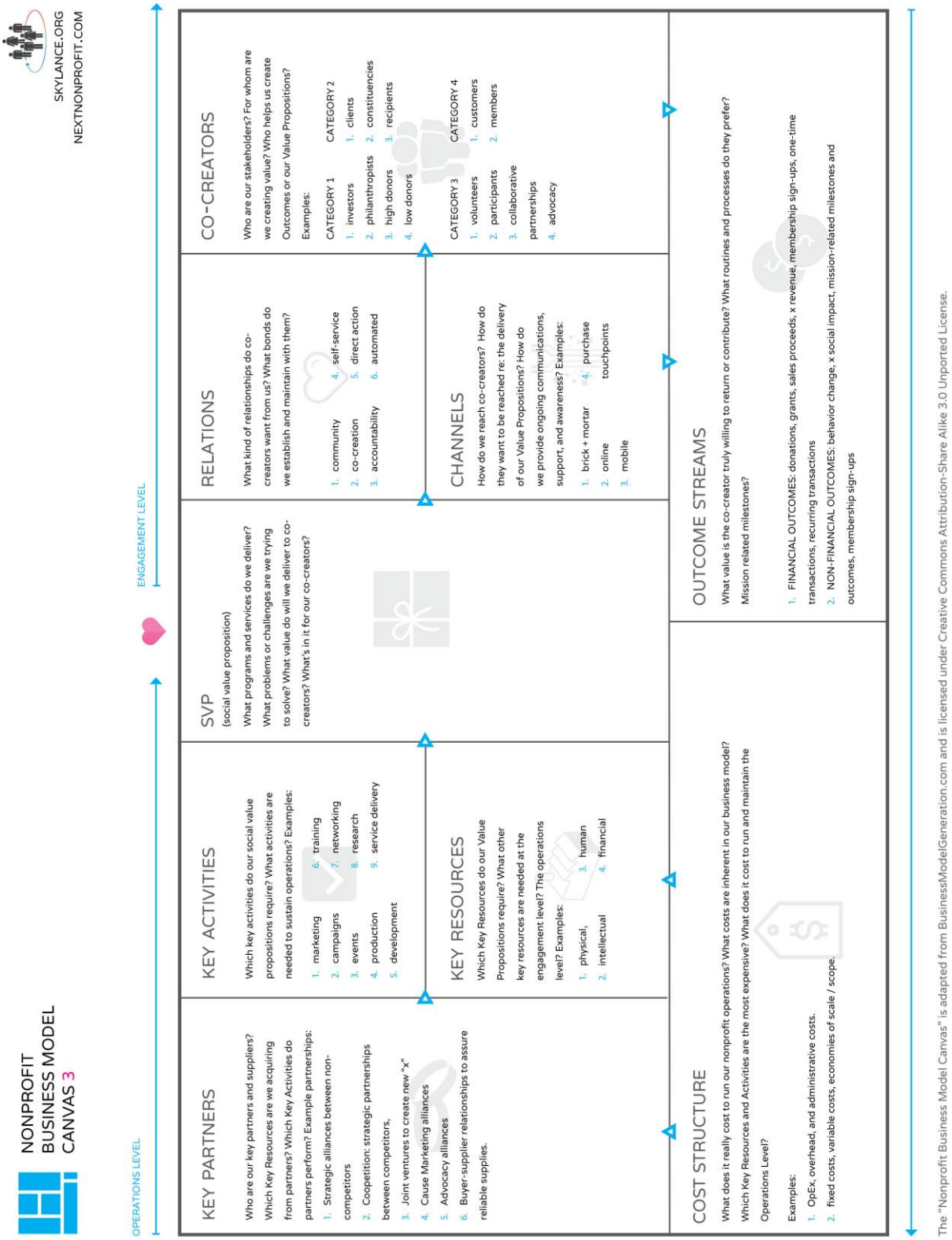
Interviewee	Date of interview	Data collection technique	Objectives	Interview summary
Tatiana Iakovleva Professor UiS Stavanger (Via Skype)	Feb 2, 2017	Open-ended interview	First understanding of the case	The initiative of PI's Local Chapter in Norway, the plan so far
Salomé Azevedo Platform manager **Helena Canhão** Project leader and chief medical officer PI GCC Portugal **Tatiana Iakovleva** Professor UiS Stavanger (Via Skype)	Feb 10, 2017	Open-ended interview	First understanding of the case	Questions about PI, the status now, IPR challenges, the Local Chapters in Berlin and Slovenia, some success story about the patients
Arild Kristensen CEO NSCC Stavanger (Via Skype)	Feb 28, 2017	Open-ended interview	First understanding of the case	The background story of why the Local Chapter should be in Stavanger and why NSCC has the initiative to launch the Local Chapter in Stavanger
Pre-springboard panel presentation with **Dagfinn**, **Terje**, **Sture** Tromsø	Mar 22, 2017	Unstructured interview	Feedback for the presentation of the case	Suggestions to approach corporate donators, partnership with organizations, funding estimate, commercializing the solutions, and not to approach government for funding
Pedro Oliveira Project leader and principal investigator **Helena Canhão** Project leader and chief medical officer PI GCC Portugal **Tatiana Iakovleva** Professor UiS Stavanger (Via Skype)	Apr 7, 2017	Open-ended interview	The activities of the Local Chapter	Discussion about student involvement in PI, and the activities of the Local Chapter in Germany, and the staff / volunteer turnover issue
Geir Ringvold Action Leader	April 18, 2017	Open-ended interview	Feedback from patient point	The activities of Kreftforeningen, the main donators are individuals

Kreftforeningen Tromsø			of view, possible partnership	and private corporations, suggest to contact staff in Oslo for possible partnership verification
Morten Pedersen Marketing Radisson Blu Hotel Tromsø	April 18, 2017	Open-ended interview	Possible partnership or donator	Possible of special price for nonprofit organizations' events, donate universally, but not on regular basis
Anonymous (N) Volunteer Vardesenteret Tromsø	April 24, 2017	Observation, Unstructured interview	Feedback from potential users	Observation of cancer patients and their families, talk about the activities of the volunteer, feedback about the platform, need more solutions for the cancer patients
Tove Hanche-Olsen General secretary Norsk Pasientforening Oslo	May 2, 2017	Open-ended interview	Healthcare system in Norway, patient point of view, possible partnership	The problem of the healthcare system in Norway, patient always complain about the discontinued communication between healthcare actors, suggestion to reach out to other health organizations, possible partnership
Karoline Vårdal Communication manager FFO Oslo	May 2, 2017	Open-ended interview	Feedback from patient point of view, possible partnership, statistic data of the disabled people	Communication with patients through social media, possibility to share PI's platform through social media, suggestion to contact BUFdir, link to statistic data of disabled people in Norway
Rune Soma Advisor Fellesorganisajonen Oslo	May 2, 2017	Unstructured interview	Feedback, Possible partnership	Suggested to reach to Norges handikapforbund (nhf.no), Norsk sykepleierforbund (nsf.no) and FFO
Haakon Aspelund Senior Advisor Deltasenteret BUFdir Oslo	May 3, 2017	Open-ended interview	Feedback, suggestion, possible partnership	Explanation about the roles and activities of Bufdir, gave contact to possible grant provider (UnIKT), suggestion to reach individual and corporate donators that have the experience of being patients of have the patients as family
Arild Kristensen CEO NSCC Stavanger	May 4, 2017	Open-ended interview	Information about NSCC, discussion about PI's possible donators, and business model	Explanation about the organizations and activities of NSCC, discussion about PI's existing business model, suggestion that PI needs support for the first 3 years, and NSCC will possibly support with 50K NOK per year, suggestion to search for the drivers of CSR
Tatiana Iakovleva Professor UiS Stavanger	May 4, 2017	Open-ended interview	Discussion about possible donators, business model, PI's platform	Possible donators UiS, Lyse, and Esso; suggestion to search for sustainable business model for nonprofits, discussion about PI's platform related to anticipation (RRI)
Tone Larsen Advisor Deltasenteret	May 10, 2017	Unstructured interview	Possible funding application	UnIKT funding application possibility, but not this time, since the program is different, but there's

BUFdir Oslo (Via email)				a conference worth to attend on 20th June
Springboard panel presentation with **Dagfinn, Uni, Kim, Eric** Tromsø	May 10, 2017	Unstructured interview	Feedback, market strategy	Suggestions for marketing strategies, Suggestions for approaching corporate donators
Lars Hovind Business development IBM Oslo (Via phone)	May 11, 2017	Unstructured interview	Feedback, possible support	Discuss about the CSR program of IBM and the possible support, resulting in possible partner introduction (Medicloud), client of IBM

Appendix 4: Nonprofit Business Model Canvas

Source: http://nextnonprofit.com/content/nonprofit-business-model.html



Appendix 5: Cash Flow Statement

Cash Flow Statement
PI's Local Chapter in Norway

Year =>	2018				2019			
Month =>	Jan-18	Apr-18	Jul-18	Oct-18	Jan-19	Apr-19	Jul-19	Oct-19
Funding	350,000	0	650,000	0	300,000	20,000	500,000	20,000
Wages	31,500	31,500	31,500	31,500	32,200	32,200	32,200	32,200
Payroll tax of wages			13,500				13,800	
Employers' national insurance contributions			3,555				3,634	
Marketing	61,250	30,625	15,313	30,625	23,958	23,958	23,958	23,958
Rent	7,500	7,500	7,500	7,500	7,625	7,625	7,625	7,625
Other payments regarding management	3,750	3,750	3,750	3,750	3,756	3,756	3,756	3,756
Accounting	0	0	0	0	0	0	0	0
Travelling (not car expenses)	2,500	2,500	2,500	2,500	2,500	2,500	2,500	2,500
Sum payments	106,500	75,875	77,618	75,875	70,040	70,040	87,474	70,040
Sum - liquidity by start-up period	0	88,265	-111,345	321,115	0	75,013	-57,774	219,806
Cash inflow this period	350,000	0	650,000	0	300,000	20,000	500,000	20,000
VAT payment (cash outflow)	0	0	0	0	0	0	0	0
Expense (cash outflow) in this period	106,500	75,875	77,618	75,875	70,040	70,040	87,474	70,040
Total cash outflow in this period	106,500	75,875	77,618	75,875	70,040	70,040	87,474	70,040
Changes in this period	243,500	-75,875	572,383	-75,875	229,960	-50,040	412,526	-50,040
Sum - liquidity by the end of this period	243,500	12,390	461,038	245,240	229,960	24,974	354,753	169,766

Cash Flow Statement
PI's Local Chapter in Norway

Year =>	2020				2021			
Month =>	Jan-20	Apr-20	Jul-20	Oct-20	Jan-21	Apr-21	Jul-21	Oct-21
Funding	300,000	50,000	500,000	100,000	300,000	100,000	300,000	300,000
Wages	53,200	53,200	53,200	53,200	76,300	76,300	76,300	76,300
Payroll tax of wages			22,800				32,700	
Employers' national insurance contributions			6,004				8,611	
Marketing	46,875		93,750	46,875	68,750		68,750	0
Rent	8,750	8,750	8,750	8,750	9,000	9,000	9,000	9,000
Other payments regarding management	4,188	4,188	4,188	4,188	5,075	5,075	5,075	5,075
Accounting	0	0	0	0	0	0	0	0
Travelling (not car expenses)	2,500	2,500	2,500	2,500	2,750	2,750	2,750	2,750
Sum payments	115,513	68,638	191,192	115,513	161,875	93,125	203,186	93,125
Sum - liquidity by start-up period	0	92,730	-14,466	152,585	0	503	-53,944	5,248
Cash inflow this period	300,000	50,000	500,000	100,000	300,000	100,000	300,000	300,000
VAT payment (cash outflow)	0	0	0	0	0	0	0	0
Expense (cash outflow) in this period	115,513	68,638	191,192	115,513	161,875	93,125	203,186	93,125
Total cash outflow in this period	115,513	68,638	191,192	115,513	161,875	93,125	203,186	93,125
Changes in this period	184,488	-18,638	308,809	-15,513	138,125	6,875	96,814	206,875
Sum - liquidity by the end of this period	184,488	74,092	294,343	137,072	138,125	7,378	42,870	212,123

Cash Flow Statement
PI's Local Chapter in Norway

Year =>	2022			
Month =>	Jan-22	Apr-22	Jul-22	Oct-22
Funding	300,000	100,000	300,000	300,000
Wages	77,770	77,770	77,770	77,770
Payroll tax of wages			33,330	
Employers' national insurance contributions			8,777	
Marketing	75,000		75,000	0
Rent	9,125	9,125	9,125	9,125
Other payments regarding management	5,081	5,081	5,081	5,081
Accounting	0	0	0	0
Travelling (not car expenses)	2,750	2,750	2,750	2,750
Sum payments	169,726	94,726	211,833	94,726
Sum - liquidity by start-up period	0	56,607	-9,015	30,485
Cash inflow this period	300,000	100,000	300,000	300,000
VAT payment (cash outflow)	0	0	0	0
Expense (cash outflow) in this period	169,726	94,726	211,833	94,726
Total cash outflow in this period	169,726	94,726	211,833	94,726
Changes in this period	130,274	5,274	88,167	205,274
Sum - liquidity by the end of this period	130,274	61,881	79,152	235,759