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Social innovation in the welfare system - initiated and designed by, for and with cancer-affected

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Introduction

Kraftens hus (The House of Power) is a social innovation project initiated, driven, and designed by people affected by cancer. Their 300 square meters venue opened on February 8th, 2018 and was the first cancer support center in Sweden created by people affected by cancer. It is the result of a collaboration between cancer-affected, relatives, local hospital, primary care, municipality, Social insurance agency, Employment agency, academia, local businesses, and civil society. All of these actors are often involved in people's life event of getting a cancer diagnosis, but the resources are fragmented and badly fitted for the person affected by cancer. With the ambition to act as a platform for relevant resources, Kraftens hus builds on the logic of user-driven resource integration (Vargo and Lusch, 2010). By offering emotional, social and practical support, Kraftens hus is developing a new role in the Swedish welfare system in the borderland between cancer care and other social functions.

Ambition with the manuscript

In this manuscript we focus on the empirical description of the open and distributed innovation process that has created Kraftens hus. We present the design and execution of the process, how cancer-affected and their life-event framed the design scope, and how relevant social actors collaborated to create a platform for resource integration. We want to discuss relevant and creative theoretical frameworks and models where the presented empirical case may provide interesting contributions. In the end of the manuscript we present some early suggestions on contributions we believe the manuscript may provide.

Background

One in three people in Sweden will be diagnosed with cancer during their lifetime, and almost 40 percent of these are children or people of working age. Meanwhile, better treatment and earlier detection mean that more people are living longer with the disease (Socialstyrelsen and Cancerfonden, 2013). A cancer diagnosis affects a person physically, mentally, and socially. Returning to a well-functioning life after cancer requires rehabilitation and cooperation between many different organizations involved in a person's life. However, cancer patients and relatives often experience psychosocial support as insufficient due to a lack of existing public structures. Therefore, the initiative started with the ambition to think in new ways about how public and private resources can be integrated better to provide support for cancer-affected, in a holistic way.

Method

Early in the project it was decided to include a scientific approach in the joint exploration, and an action research approach was deemed appropriate. Action research can be seen as a multitude of strategies for collaboration between researchers and practitioners to create shared learning and to achieve effective outcomes where social justice aspects play a prominent role (Reason and Bradbury, 2008). The knowledge is generated by researchers and practitioners together to contribute to both practice and science. In these contexts, praxis has also been referred to as actionable knowledge (Argyris, 2004), that is, knowledge that is local and is of benefit to the participants.

A project team was created to facilitate the cancer-affected in the innovation process. The team was composed of persons with complementing knowledge and skills. The various team members had good knowledge about cancer care, the regional healthcare system, rehabilitation, psychosocial support, innovation management, improvement science, and design methodology. One of the project members also had first-hand experience from being a cancer patient and was one of the key individuals for initiating this exploration for possible new forms of cancer support.

The social innovation process

Instead of emphasizing project management from experts, the focus has been more focused on such values and principles that can provide better conditions for conducting creative and innovative exploration. Consequently, there was no detailed and pre-planned map. Instead we set up a number of guiding principles as a compass for the exploration:

- Life event perspective
- Social innovation – exploring unknown terrains
- Design – in order to achieve societal change
- The best way to understand a system is to try to change it
- Targeting gaps between organizations
- A positive and "opportunity-oriented" approach
- Explore possibilities for sustainable organizational models

A life event perspective (the life event of getting a cancer diagnosis) was used as a starting point in order to see the situation of the patients as a whole. Through a life event perspective, the individual's needs and journey through the system were put in focus. By recognizing the complexity of the whole system, insufficient coordination between actors are revealed – and it also provides possibilities to elaborate how resources may better be integrated during a life event and identify new actors to invite to the collaboration.

The project used a design thinking process inspired by the Double Diamond (Brown, 2009) that shifts between general and specific in order to capture a richness of original ideas that then become concrete.

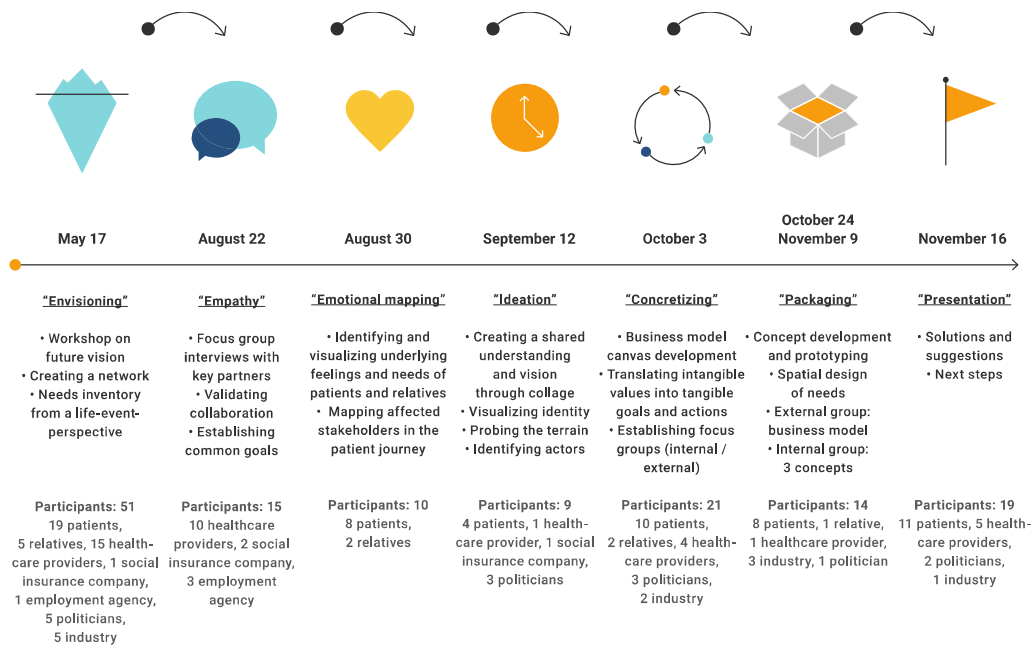


Figure 1 The seven workshops in the social innovation process

The design process was laid out in seven steps following the Double Diamond idea:

- Future scenario - establishing the network, getting acquainted with each other, creating engagement, approaching a future vision
- Discovering needs – interviewing stakeholders to understand their needs
- Emotional mapping – identifying and visualising the underlying feelings and needs, mapping affected stakeholders in the patient journey
- Joint vision – visualising a joint understanding of the future vision through the method of collage, discussing involved actors and responsibilities
- Expressing needs and ideas – creating a short film where participants expressed their point of view of what a Kraftens hus could contribute with
- Business Model Canvas – translating intangible values into tangible goals, concretising offerings and sketching a sustainable business idea
- Prototyping and concept development – creating physical mock-ups of formed ideas, spatial design of needs

The process was carried out in seven workshops between May and November 2016. The content of the workshops was not decided beforehand, but based on the results of the previous workshops in an explorative fashion.

Connect the network and identify the needs

First, it was important that all participants came together as equal parts with an open mind. As an effect of this first workshop, it could be observed that the participants started to build networks and got acquainted with each other which helped the continuation of the process.

As a next step, the main stakeholders - besides the cancer patients and relatives themselves – were interviewed by the project team in order to get a better understand of their existing challenges and needs. As a result, a visual “*map of needs*” was created. Examples of needs of patients and relatives:

- To meet likeminded in the same situation
- Receive support
- Share stories and experiences
- Get positive role models
- Share my hard-earned experiences
- Compassion/empathy/sympathy
- Cure loneliness
- Centre that enables spontaneous meetings and conversations
- Accessibility/openness/flexible opening hours
- Help to get back
- Help to change mental state
- Learn how to live with cancer
- Get away from the hospital environment

Specific focus groups were also held with three of the more critical stakeholders (local hospital, Social Insurance agency, Employment agency) to ensure their stated willingness to collaborate, get a deeper understanding of their view of the life event of getting a cancer diagnosis, and identify potential resources that could be integrated in Kraftens hus.

Table 1. Needs and perspectives express by key stakeholders

| Hospital | Social insurance agency | Employment agency |
|---|---|--|
| - sees a benefit that cancer patients can meet others in similar situations | - aware that staff often feels inadequate in handling cancer patients | - wants to offer a contact person for patients and families |
| - doesn't want patients to get "stuck in their disease" | - expresses a need to develop skills how to handle the system for cancer patients | - open for dialogue around job training and similar activities |
| - sees the value of a support function outside the hospital | | - can provide information evenings |
| - confidentiality policies make it difficult for staff to connect patients | | |
| - healthcare focuses on the disease | | |
| - realizes that there is an "information problem" | | |
| - expresses that there is a lack of time to connect with patients | | |

Emotional mapping – a deeper understanding

After that, the underlying needs of cancer patients were uncovered through visually mapping feelings and emotions a cancer patient is living through during a “patient journey” (the experience from cancer diagnosis to “successful” treatment or medication). This exercise appreciated the dramatic emotional journey a cancer patient typically goes through.

To share a vision

Next, the participants created a collage of images representing the joint vision of Kraftens hus. Through using images rather than words, the participants had a greater possibility to associate individual perspectives to this vision but also came to a deeper meaning of their joint vision since the soft values are accessed easier by taking away the layer of (written) language.



Figure 2 Collage created by the participants illustrating the joint vision of Kraftens hus

After having collected a lot of insights around needs, emotions and future visions, the project team helped the participants to capture some of these needs and ideas in a short film named “What if?”. It included views and thoughts from many different stakeholders: patients, partners, children, healthcare staff, employer, staff at Social insurance agency, and visualised that they are all affected by cancer in different ways. This film gave the participants the possibility to express and communicate their perspective to a broader audience and at the same time create awareness for the topic.

Creating a business model

The design process was complemented with the creation of a business model (Osterwalder & Pigneur, 2010) that generated a number of value propositions, each of which integrated resources for a specific purpose. The Business Model Canvas made the ideas, aims and dependencies of this venture more tangible and lead to a concrete time plan for a way forward.

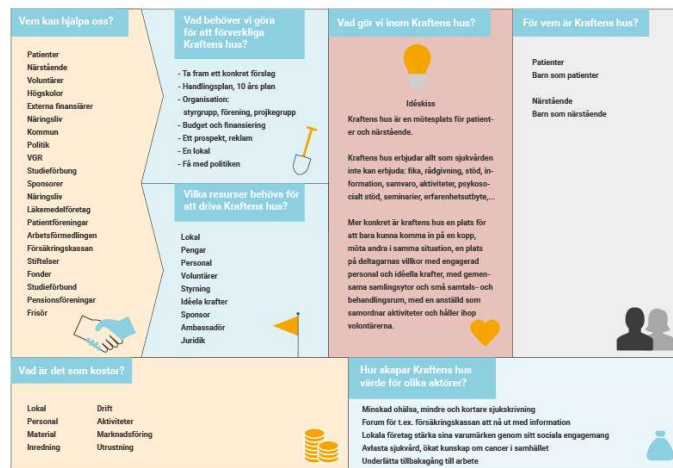


Figure 3 Visual output of the business modelling and the first draft of the Business Model Canvas

Prototyping - translating needs to physical or spatial expression

The last step included prototyping and concept development. Prototypes are a good way to visualise ideas and helpful as conversation starters. In this case the prototypes were used to create a physical or spatial expression for the identified needs. The participants were discussing needed functions of physical spaces, they were moving images of furniture and interior on a prepared workspace depicting the envisioned layout of Kraftens hus.

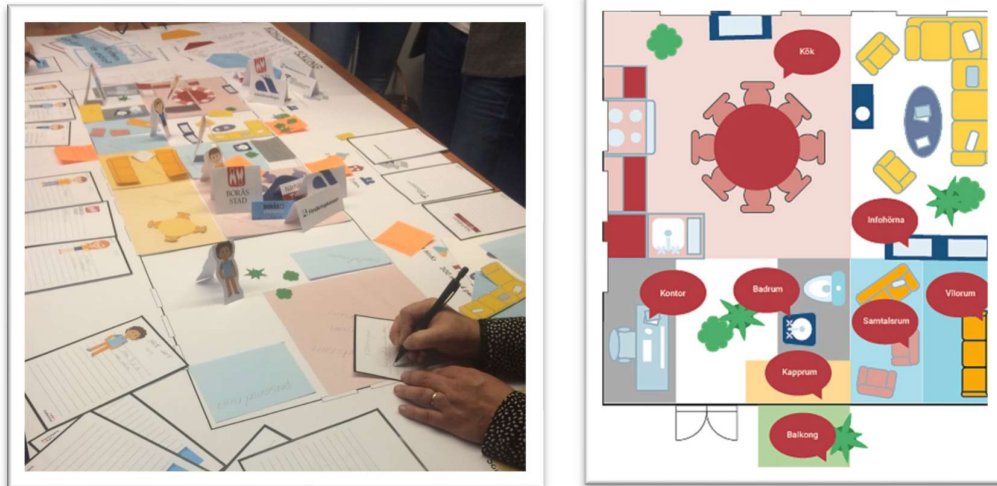


Figure 4 Prototyping workshop and an early draft of the interior design of the venue

The opening of Sweden's first support center for people affected by cancer

Kraftens hus opened on February 8th, 2018 – the first Swedish support center for people affected by cancer. The design is based on the user-driven design workshops that created commitment and co-ownership of all actors. We have worked at individual and system level; developed business model with public-private collaboration. Through the focus on the life event for cancer patients, the design project has also acted for a stronger interaction between involved actors and has explored mutual benefits such as supplementing the healthcare system's cancer rehabilitation, the Social insurance agency's ability to offer customized information, employers' need for support when they have an employee that has been diagnosed with cancer. In the translation of needs to spatial design, the patients and relatives highlighted the kitchen as the natural meeting place for spontaneous meetings and conversations. Like in many modern Swedish homes, an open kitchen with a kitchen island and dinner table was seen as the heart of the venue. There are also rooms for consultation, meetings, workshops and physical activities.



Figure 5 The staff at Kraftens hus - one experienced therapist and two with own experience of cancer (Photo: Nicke Johansson/Cancerfonden)

Potential contributions

- **Conceptualization of co-production in general, and co-innovation in particular.** Osborne et al (2016) state that co-production is one of cornerstones of public policy reform across the globe. It's however very poorly formulated. They present four ideal types of value that are co-created; co-production, co-design, co-construction, and co-innovation. The latter resonates well with our empirical case where cancer-affected not just improve the existing services but rather co-innovate new forms of welfare services for others and for the future. The authors highlight that further work is required to refine the framework, e.g. the explicit focus on service-user and lack of wider perspective. Consideration is also needed of the different contexts, modes of production, and conceptualizations of 'value'.
- **Life-event perspective as a frame for innovating in the welfare sector.** How life-event perspective inspire and drive social innovation that is better integrated and fitted for the purpose.
- **'Lead-users' driving social innovation in the welfare sector.** How people with 'lived-experience' and lead-users (Bogers et al, 2010; von Hippel, 1986) can play a role in the development of novel social services. Especially, relevant to address issues regarding lead-users with a severe (and often deadly) disease like cancer.
- **Design approaches in the welfare sector.** Empirical description of the design process, user involvement, collaboration between private and public actors, and creation of a social business model (Voorberg et al, 2015).

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