

# INQUIRING INTO POLITICS OF PATIENT DEMOCRACY THROUGH PROBING

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## ABSTRACT

In this paper, we shall focus on the gap between the idea of patient democracy and the practice of shared decision-making within cancer treatment at Danish hospitals. Through a design research project we are aiming at exploring how probes can be used to evoke moments of dissensus, which allow for a detailed inquiry into patient roles and identities and how shared decision-making works against patient empowerment. The argument we put forward here, is that the probing process have a value in understanding systems of power and the forming of identity belongings.

## INTRODUCTION

In the European welfare states social design and social innovation are being called upon today as practices that can help a shrinking public sector to maintain a continuous provision of high quality healthcare services for the “common good”. The delivery of such services can no longer be taken for granted due, for instance, to the ageing society and decreasing tax incomes resulting from a decline in labour forces (Saltman, 1994).

Over the years, various models of healthcare and management have been tried out with erratic luck and success. Health services have thus been conceptualized according to *models of efficiency* in management and workflow in the late 1970s and 1980s. Neo-liberalist politics and New Public Management have experimented with centralizing expertise into huge hospitals as well as the implementing of *models of consumerism* that give patients the right to choose their treatment at whatever hospital they prefer – much like commodities on the shelf in a supermarket. But evaluation studies from a number of countries have shown that models of consumerism are socially exclusive, they fail to work for life threatening and chronic diseases and the promise of leading to better performing hospitals has remained a Neo-liberal fantasy (see e.g. Fotaki 2009; Martin & Webb 2009).

More recently models of *patient democracy* and *patient empowerment* have entered into the vocabulary of healthcare policies expressed in slogans such as “the patient as citizen” or “the patient as partner”. Moreover, these models are manifested in attempts to implement new clinical practices such as “shared decision making” (SDM), which aims at letting patient’s interests and existential values in life have greater influence in the planning and accomplishment of their medical treatment. However, as Riiskjær (2014) and others have made clear there is often a long distance – if not a bumpy road – from the honorable idea of “the patient as partner” to its implementation in practice.

Designers are increasingly being approached to help merging idea and practice in this context. This is not least reflected in the development of shared decision-making tools, which have been made ideally to assist patients and doctors in negotiating various treatment options and, in the end, to arrive at well-considered medical decisions. (For instance see the Ottawa Decision Aids; O'Connor et. al, 2009; Elwyn et. al, 2006; Stacey et al. 2003)

Such work is praiseworthy and valuable. However, what often goes unnoticed is that shared decision making tools serve certain systems and enactments of power. This is not a striking new insight, but a commonly held assumption in political theory: that democratization in all its complex forms and processes depends on and requires exclusion (see e.g. Dean, 2009; Mouffe, 1998; J. Ranci re, 2010). As a consequence, the instrumentalist idea of designing for patient democracy and empowerment needs to be critically examined according to a set of conceptual pairings such as inclusion/exclusion, freedom/power, and consensus/dissensus.

In this paper, we shall focus on the gap between the idea of patient democracy and the practice of shared decision-making within cancer treatment at Danish hospitals. In Danish, shared decision making is often translated as "delt beslutningstagning". The adjective 'delt' has a double meaning. It denotes 'shared' or 'having something in common', but at the same time it means 'divide'. In this sense, the Danish translation actually captures the paradoxical meaning of both sharing and dividing, including and excluding, that characterizes the practice of SDM.

To convey how SDM works for some patients we start out by documenting the personal experience of three cancer patients who were all giving up on by the Danish healthcare system, but are still alive today. We use these patient stories not to criticize the healthcare system, but to generate questions and insights deemed valuable for the further development of shared decision-making and – more generally – for the welfare states' concern for public health. Hereafter, we will demonstrate how probing can be valued as a design research method for making a more detailed inquiry into the system of power that patient treatment and shared decision-making are embedded into. Probes have been described as a useful technique for inspiring designers (B. Gaver, Dunne, & Pacenti, 1999; W. Gaver, Boucher, Pennington, & Walker, 2004) or for enabling a more empathic understanding of people's private needs, emotions and values (Mattelm ki, 2006). With our account, we contribute with an expanded understanding of how probing can also be vital for addressing political structures and systems of authority – something that is only latently present in other authors.

## SHARED DECISION MAKING

Ten years ago Per gets diagnosed with prostate cancer progressively spreading to his bones. The hospital informs him that his opportunities for further treatment have been exhausted and that they can only offer him life-prolonging chemotherapy. Per is not helped to select any other treatment avenues so he chooses an alternative road, and he heals himself through a special diet combined with vitamin C and heat treatments.

Another patient Ida gets diagnosed with cancer of the pancreas two years ago. For several months she participates in a chemotherapy-program until the hospital announces that the chemo does "not have the intended effect". It is predicted that she has 3 months more to live. Contrary to the doctor's recommendations she rejects further participation in the chemo-program and starts a sodium-bicarbonate treatment in combination with alkaline food. Her recovery condition improves gradually and today her cancer is considered stable.

Four years ago, Inge – a third patient – gets diagnosed with incurable lung cancer and the doctors set her life expectancy to a few months. With a prognosis so poor and no other supportive interventions, she examines treatment avenues abroad and is treated in an American clinic that gives her intestinal lavage along with oils and dietary (alkaline) guidelines. Inge reschedules her diet and today her cancer is dormant and she is alive and well.

We will use these personal patient experiences to inquire further into the nature of a "shared decision making" and to generate questions. The first question is: Did these patients have a real choice? How did they experience their encounter with the hospital in relation to shared decision-making? What knowledge did they share with the health professionals?

In a highly diversified landscape of approaches to SDM, we can outline that shared decision-making originally was seen as "a mechanism to decrease the informational and power asymmetry between doctors and patients by increasing patients' information, sense of autonomy and/or control over treatment decisions that affect their well-being" (Charles et al. 1997. See also Eddy, 1990; Ryan, 1992; Emanuel and Emanuel, 1992).

Some SDM approaches are seen as a golden midway between a paternalistic model (meaning the health professionals decides what's best for the patient) versus the consumerist model (the health professionals informs the patient, who then make a choice). Other SDM approaches (Cribb et al, 2011) try to define broader conceptions of SDM as open-ended relationships ("balancing acts of friendships") that combine patient autonomy with supportive interventions.

At the same time, critical voices have been raised against SDM as a professional practice that focus only on the importance of the individual patient choice.

Among these is Annemarie Mol (2007), who argues that good care has little to do with patient choice. Mol's point is that patients rely completely on their body; they are sick and perhaps not even able to make a decision in the moment of facing a life threatening or chronic disease. Seen from her perspective, care has a logic of its own, which needs to be protected from "choice".

Nevertheless SDM seems to be a cornerstone in promoting patient-centred care and a concept that must have a place in healthcare (Castro et al. 2016; Coulter 2011). Coulter defends the concept and writes: "Patients preferences should guide treatment decision-making, with patients being helped to select treatments that produce the best match with their values, outcome preferences and tolerances of risk. This involves making sure that patients have access to reliable, evidence-based information about the treatment options and likely outcomes and guide them through a deliberation process designed to identify the best options for them" (Coulter 2011: 186).

As a theory, SDM is at the heart of patient participation and is supposed to be a model for how the patient can be given the possibility to express thoughts and values and take part in decisions about selection of treatments (see Riiskjær: 95-96). But as Riiskjær points out, the problem is not the idea itself. The problem lies in what happens when the concept meets reality, which means the clinical practice and SDM as a materialized practice of daily routines in the hospital.

The three patients that we introduced - Per, Ida and Inge - never experienced that they were being helped to select treatments that produce the best match with their values; nor that any health professionals tried to guide them through a process designed to identify the best options for them. How come?

Before conveying how SDM works as a materialized practice and to discuss these questions further we will explain our design research methodology, which is based on probing.

#### METHODOLOGY: PROBING AS A DESIGN RESEARCH PRACTICE.

Probes are traditionally understood as design-oriented tools for users' self-report. However, Mattelmäki (2008) has shown how probes can also be explored in co-design activities with users meaning that designers and users are simultaneously present and work together in making and interpreting probe results. In this sense, probing becomes closely aligned with what Sanders and Stappers (2008) call 'generative tools' or what Brandt (2006) refers to as 'design games'. However, even though these techniques have much in common, we still prefer the term 'probing' as being the most appropriate label in describing our co-design research practice. While generative tools and design games have been introduced to help users and stakeholders express their ideas, experiences, creativity and dreams to design teams, ever since its inception probing has connoted a certain art-activist or political awareness that is not always reflected in the other approaches to co-design.

Originally, Gaver, Dunne and Pacenti (1999) introduced 'Cultural Probes' as an artistic method to enrich and inspire the design process (see also Boehner et al. 2007; Boehner et al. 2014). In their original approach to probes, Gaver et al., were influenced by techniques used by the avant-garde art movement and especially the Situationists, who believed in art's capacity to turn passive consumers or spectators into political actors revolting against capitalist power and ideologies. Moreover, art practices should result not in works of art, but in situations using subversive techniques such as *dérivé* and *détournement* to wrist people out of their routines, ingrained habits and entrenched patterns of daily life.

There is a clear conceptual lineage from this to Gaver et al.'s heralding of probe tasks that evoke 'ambiguities', 'uncertainties' and the 'unexpected. Similarly, Gaver et al. remain sceptical towards a rational and scientific understanding of probes according to which it is a method used for gaining knowledge about the user (Gaver 2004). He sees probing as part of the design process that may open up for conversations with people, leaving room for ambiguity, uncertainty, failures and the unexpected.

In line with this tradition we use probes to question how different forms of power, ideologies and organizational structures limit people's daily life. However, we do not buy fully into Gaver et al.'s scepticism concerning probing being a method valuable for learning about people's lives (Boehner et al. 2010). We have used probing in this research project both as a method to gain specific knowledge about a patient's everyday life, challenges, feelings and decisions in relation to a given treatment, but at the same time as a method to question the notion of patient democracy and the practice of SDM. Here a set of evocative design tasks has been designed that gave the patients the possibility to express themselves in collaborative sessions together with the design researchers. In this regard, our approach to probing is more closely aligned with Mattelmäki (2008), who sees it as a co-design activity between users (in our case the patients) and the design researchers.

Mattelmäki (2006; 2008) provides a more comprehensive understanding of various approaches to probes and explores how probing can be applied to different contexts. She suggests that the probing process - apart from having the value for inspiration and information - might also add value to user participation and collaborative dialogues between users/participants and designers. Further, she argues that probing as a method can take various forms and have various purposes. Notably, she identifies four different starting points for the use of probing: 1) inspiration for enriching the design process; 2) collecting information; 3) user participation in ideation; and 4) dialogue to build up understanding and interaction between users and designers (Mattelmäki 2006).

In the research literature it has been discussed what notion of probing is viable. Should it primarily be considered as an experimental artistic method, which allows the design researcher to become inspired by the user or as an ethnographic method, where the design researcher gains insight into the users' lives? This epistemological division is irreconcilable for Boehner et al. (2014), who present the artistic conception almost like an article of faith. However, what is somewhat lost in this discussion of probes belonging to either art or science is probes' potential to unmask invisible power structures and undesirable orders of domination. Admittedly, the strong insistence on probing being an artistic practice connotes the tradition of the Situationists, where artistic techniques are looked upon as autonomous practices with capacity to subvert systems of authority and power. However, this inherently political aspect of probing has remained largely unexplored. In the next section, we attempt to establish a third perspective, where probing is conceived of as an aesthetic-political practice.

## PROBING AS AN AESTHETIC-POLITICAL PRACTICE

In order to understand probing as an aesthetic-political practice we will draw upon Rancière's notion of *aesthetic dissensus* (J. Rancière 2010). Aesthetic dissensus is the effect of a critical aesthetic practice (e.g. within art or politics) that interferes and disrupts ways in which a system of power and control dominate and limit certain groups in society (Markussen 2013). Dissensual activity makes invisible forms of domination visible and has the potential to disrupt or disturb hierarchical orders, where certain groups and individuals rule over others (Rancière 2010).

In the tension between feeling oppressed and disempowered as opposed to feeling free and empowered, identity, self-awareness and social consciousness play an important role. As an example, Rancière uses the working class in the 19th century and states that it was not the workers' ignorance about their situation that made them unfree and oppressed. On the contrary, they were very conscious of the forms of power that ruled over them. What they lacked was an alternative conception of themselves - an image of themselves as someone who could someone else (Rancière 2013). For the same reason Rancière resists using notions such as the 'working class' or the 'poor proletariat'. These are sociological and philosophical categories or representations that keep the workers in a place to the benefit of the authorities (Chambers 2013: 5).

Politics, for Rancière, occurs as moments of dissensus, which have the potential to effect a redistribution of the social order in terms of, for instance, reconfiguring who has the right to speak, to be heard, to take part and to decide. More specifically, Rancière understands politics as happening when two logics come into conflict: the

logic of inequality and the logic of equality. The logic of inequality is unmistakably sustained by those in power and authorities, which are referred to in Rancière's work as "the police". The police rely on mechanisms of dividing up and distributing the various parts that make up a social whole. This dividing is, for instance, carried out through ways of counting actual groups defined by difference in birth or ethnicity, by different functions, locations or interests. It is, as Chambers (2013: 42) argues, "a manner of counting that excludes the possibility of any supplement to that order". Yet, this order can be brought into question by a moment of politics, which renders visible the logic of equality. Thus, politics refers to such a rupture of a hierarchical order and it may be invoked through art (Rancière 2004; 2009) or heterogeneous material design objects (Rancière 2003) that allow for a renegotiation of fixed roles of identity and ways of doing, seeing, acting and speaking. Because it concerns these fundamental conditions for human experience, politics is, for Rancière, inseparable from aesthetics.

We can now use these analytical distinctions to better understand the power structures underlying the idea and implementation of SDM and how probing can be a valuable aesthetic-political practice for making them open for closer scrutiny and design. In particular, it is evident that our three patients belong to what Rancière would see as an "excluded supplement", which cannot be counted for by the existing health system. In fact, they do not take on the patient role, which this system has allotted for them. Through our case study we are aiming at exploring how probes can be used to evoke moments of dissensus, which allow for a detailed inquiry into patient roles and identities and how shared decision-making works against and prohibits patient empowerment. The argument we put forward here is that the probing process - in addition to inspiration/information/participation/ collaborative dialogues - have a value in understanding systems of power and the forming of identity belongings. More specifically, probing can be used as a method that opens up for a renegotiation of the user's identity and social consciousness (in our case patient's own self-image and alternative conception of one-self), which adds a new dimension to the ethnographic and artistic approach to probing offered by Mattelmäki and Gaver.

## CASE STUDY

The case study presented in this paper is part of a larger 3-year research project "Prometeus", which is a collaborative project between the University of Southern Denmark, the Health Service Research Unit at Vejle Hospital, Aarhus University and Kiel University Hospital. The project aims at developing concepts that can strengthen cancer patients through their course of treatment.

The study consists of an explorative phase (probing, sketching user experiences) and a development phase (developing profiles, constructing concepts and tools). In this paper we focus only on the patient's experiences -

and not on the doctors and nurses' experiences of the treatment. The making process of probe described beneath has been informed by previous studies, which have included a series of field observations and design experiments in the hospital as well as in the homes of patients (see Knutz & Markussen 2014; Knutz et. al 2014).

#### METHOD & MATERIAL

The design research material we examine in this paper is the probe results related to three particular cancer patients – Per, Ida and Inge – who were introduced earlier. They have been chosen because their individual experiences with the healthcare system are useful for understanding the limitations of SDM. They have participated in the project for about a year, together with other cancer patients. In this period of time they have fulfilled several probe tasks.

Due to the length of this paper we have limited our study to include only one probe task called *Mapping Islands*.

The purpose of *Mapping Islands* was to probe how patients connect things/people/daily activities/routines in relation to what makes them feel good or bad. What has helped them overcome a period of cancer and treatment? What has worked against them?

The probe tasks were completed in the patient's own home-environment and on a day and time that suited the patients the best. The design team were present during these sessions and the patients completed their tasks in collaborative dialogue with design researchers. The probe-session lasted 3-4 hours and all dialogues were recorded.

The probing session was conducted by first explaining the probe task to the participant. The probe task *Mapping Islands* consist of six paper carton "islands" (figure 1) each of which has a name and includes a question that connects it to an emotion or feeling.

- The Island of "Earthlings": What makes you feel calm or present?
- The Island of "Drones": What give you an overview or control.
- The Island of "Drains": What makes room for sadness?
- The Island of "Gigglers": What provides an opportunity for joy?
- The Island of "Enemies": What bring out frustration, anger or hatred?
- The Island of "Energizers": What gives you excess energy?

The probe also contained an empty island with no name, which can be used by the participants to define a "missing" island (see figure 1).

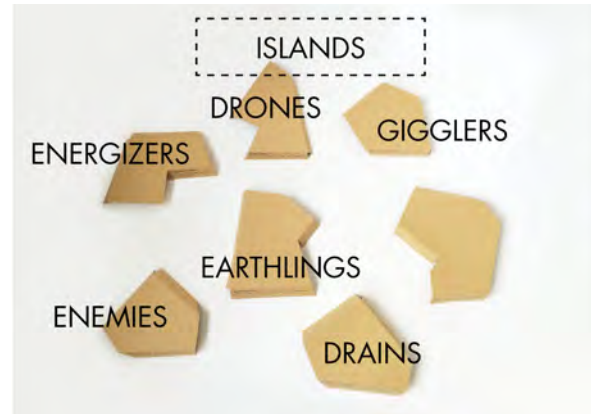


Figure 1

The participants were then asked to write down keywords on colour labels, which represent different categories (see figure 2) and place these on one of the islands where they felt they belonged (see figure 3)



Figure 2



Figure 3

During the probe-session the participant constructed a mapping of how things, people and interactions were connected to a specific island (emotion/feeling/belief). The coloured labels could be moved around and re-organize in a formation that made sense to the participant. During the probe-session the design researchers asked clarifying questions to understand the participant's descriptions of meanings.



ANALYSIS OF PROBE-RESULTS

Below is the probe result of two particular islands: the island of “Enemies” (representing things that brings out frustration, anger or hatred) and the island of “Drones” (representing things that give you overview or control).

Officially Per's health profile would contain the keywords "incurable prostate cancer" and "has deselected chemo therapy". Yet, the probing material gives us a completely different picture; a picture of a man who has managed to cure himself through a diet and whose only real choice is "to dare to take responsibility for one's own health".

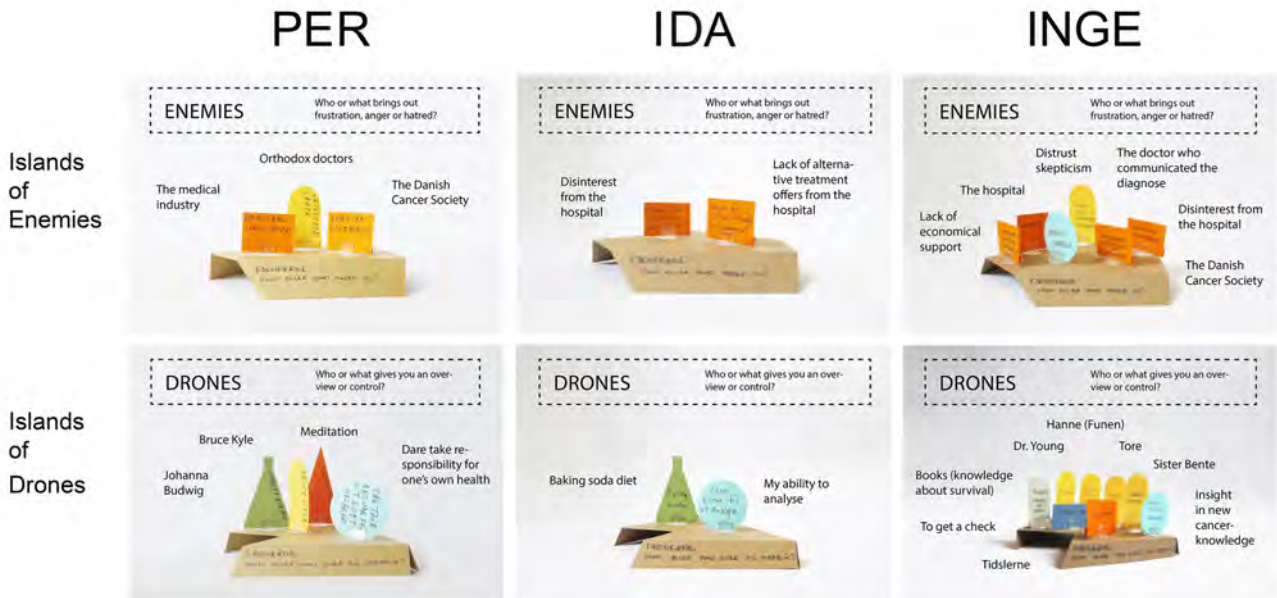


Figure 4: Probe results

If we look at Per’s mapping of the island of enemies we find three keywords; “the medical industry”, “orthodox doctors” and the Danish cancer society “Kræftens Bekæmpelse” (figure 5). Per explains that he believes that the medical industry is unreliable as its main objective is to make huge profits on cancer through chemo-based medicine. He is critical towards the Danish Cancer Society (Kræftens Bekæmpelse), which are sponsored directly by the pharmaceutical industry. The same applies to “the orthodox doctors” who will not understand nor listen. Per has heard nothing from the hospital in the years that has passed and he even had difficulty in getting an "after-check" and scanning after his recovery.

If we look at what gives him overview or control (the island of Drones) we find “Johanna Budwig” “Bruce Kyle”, “Meditation” and “Dare taking responsibility of own health”. Per explains to us that he gets overview of his situation through his doctor Bruce Kyle, who heads a private clinic in Aarhus (which provide vitamin C treatments) and who has given him guidance throughout the treatment. He also gets overview and control through meditation and through Johanna Budwig’s theory on cancer. Budwig (1908-2003) developed a thesis around the connection between diet and cancer cells that implies a special diet, which Per followed to recover. The last thing Per describes as a "drone" is "to dare to take responsibility for one's own health".

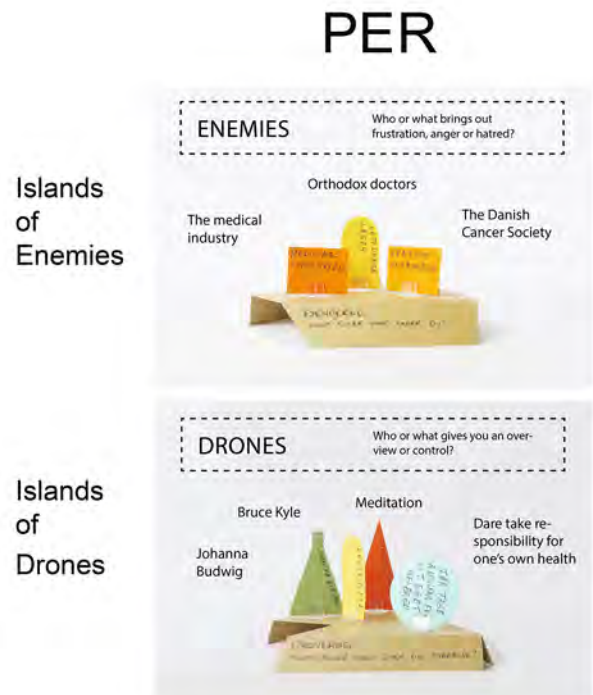


Figure 5

Ida places two keywords on her island of enemies; “disinterest from the hospital” and “lack of alternative treatment-offers from the hospital” (figure 6). Ida explains to us that she doesn’t understand the lack of interest from the hospital in her well-being; especially not during the chemo-free period when her body gets noticeably better every day. She also doesn’t understand their lack of interest in the alkaline diet. The diet the hospital offers is completely inadequate according to her because it’s a diet that supports chemo (which she has opted out) and which is designed to put on as much weight as possible and not aimed at reducing acidity in the body. When Ida tells a chief physician at the cancer ward that she is convinced that it is alkaline diet and the bicarbonate of soda that helps her body fight the cancer, he answers: "It does not interest me", "there is no money in such a cure". A nurse says directly to her: "The hospital is a chemo-store and that it is from these shelves you can choose". Ida feels the hospital acts unresponsively compared to the battle she fights.

On Ida’s island of Drones we find “baking soda diet” (treatment with bicarbonate of soda) and “my ability to analyse”. Today – after more than 12 chemo-free months - her blood-measurements (so-called haemoglobin) looks fine. “Statistically I now belong to the 10% who survive the disease. If I live five years more, I am among the 0.5% who survives,” she tells us. Ida believes that the only reason that she has survived is her ability to say no to chemo and to choose a different path. Even though she officially is admitted “an interim break” she knows she will never take chemo again. "I'm lucky I have the mind I have and I dare to take a path myself," she says.

Ida’s official profile would contain the keywords "incurable cancer" and " "has been accepted an interim chemo-break". Her profile is different from Per's in the sense that she first accepts chemo, but later opts out of it because she feels that she can no longer survive. She must therefore fight for permission to be allowed a "chemo-break", because the doctors do not share her decision.

On Inge’s Island of “Enemies” that bring out frustration, anger or hatred, we find labels with keywords that is similar to both Per and Ida; keywords such as “Disinterest from the hospital” and “the Danish Cancer Society” (“Kræftens Bekæmpelse”). But we also find new issues such as “The doctor who communicated the diagnose”, “Lack of economical Support” and as “Distrust and Scepticism” (figure 7). Inge explains that the chief physician from the oncology department, told her that she would not survive - and her only chance to live "a little longer" was taking life-prolonging chemotherapy. Inge encounters only scepticism among the health professionals towards alternative therapies. Yet, this is for her the only way forward. For that reason, Inge decides to be treated at an American clinic for alternative medicine. Staying at hotels and flights are expensive and are all together a major economic challenge for Inge and her family.

## IDA

### Islands of Enemies



### Islands of Drones



Figure 6

## INGE

### Islands of Enemies



### Islands of Drones



Figure 7

If we examine what gives Inge overview or control (the island of Drones) we find “Insights” and “books” about knowledge on how to survive cancer; friends and family members who have supported her in her difficult choices; the American doctor (Dr. Young) offering alternative therapies as well as the Danish patient association “Tidslerne” which contributes with

information and discussion about complementary and alternative therapies. Among the “drones” we also find the keyword “to get a check”. Inge tells us that she is being screened (from time to time) through private agencies for abnormal development in her blood cells.

Inge’s official health profile would resemble that of Per and contain the keywords "incurable cancer" and "has deselected chemo therapy". But the probing material gives us a far deeper profile. Inge’s profile is different from Per’s and Ida’s in the sense that Inge undergoes treatment abroad, whereas Per’s and Ida’s healing-strategy contains self-medication in the form of the Budwig diet (Per) and the diet of bicarbonate of soda (Ida). Our probe result demonstrates that Inge’s self-awareness and her alternative conception of herself depends on the back up she gets from her close network of friends and family members, who supports her health strategy on a practical and ideological level.

## DISCUSSION

The probe sessions gives us a window into a moment of life in relation to Per, Ida and Inge’s course of treatment. Per enacts dissensus towards the orthodox doctors who will not listen to what he have found out in relation to his own body, despite the fact that he has become an expert in controlling his cancer through alkaline food and oils. Per shows - through his way of organizing his islands - that not only is he in opposition to the doctors. He also acts on it by placing his self-chosen treatment - a treatment that doctors do not believe in - on the island, which gives the overview and control. Per possesses a patient expertise, but he speaks a different language than the medical language. He speaks from the experience of his body.

Through Ida’s interaction with the probe material we learn that Ida disrupts her identity belonging and constructs “a pseudo-identity” in relation to the hospitals protocol and policing order. She does not trust the cancer-program of the hospital and she knows they do not trust hers. So she agrees to make a "shared consent" and commits to a "chemo-break" that serves no other purpose than to "allow" Ida to participate in the public health community for further check-ups. Through the probing-session we learn how she has avoided actual participation in chemo-program without being excluded from the hospital.

Inge expresses frustration towards the medical authority who gave her a death sentence – with no other options than chemo. Through her use of the probe material we understand how she has used her friends and family to surpass the medical authority, exterminate the official health plan and then construct and implement an alternative survival strategy.

The probe-sessions enable the three patients to make decisions about undesirable forms of domination - as well as to negotiate how things (people / routines / treatments / feelings / convictions) are interlinked.

The island landscape is created in the interaction between participant and probe-material, and it is this interaction that is political because it is about determining what must be visible and what should be invisible; what needs to be heard and what not. Through the participant's materialized formations (their individual landscapes) - politics gets an aesthetic form.

Upon returning to the discussion of SDM, the case material inform us that in both Per, Ida and Inge’s case the official patient profiles seem to be embedded in the SDM program in the sense that they are institutionalized fixed identities that refer to whether a patient accepts or rejects the health plan offered by the hospital. The purpose of these is to establish participation in the cancer-program and not to clarify preferences in relation to, for instance, alternative avenues of treatment. In Ida’s case we see the ambiguous understanding of the conception of “shared decision” being brought into practice. Through her interaction with the probe material we learn that "shared decision making" is a concept that, apart from "sharing" also “divides” and “parts”.

The doctors do not share her decision and since they are in power, they can decide whether Ida is “out” or “in” the healthcare system. SDM in her case supports the distribution of a policing order that determine who has the right to receive treatment. And since Ida wants to be “within” the public healthcare system (to be allowed check-ups) she must lie, cheat and pretend.

In relation to some of the definitions of SDM outlined earlier we can see that Coultner's approach to SDM - as a concept that ought to benefit patients and help them to choose according to their preferences - will be difficult to implement with patients such as Per, Ida and Inge, who has no other choice than to opt out of the hospital treatment offer.

Annemarie Mol’s argument – that SDM seems to undermine the care-perspective and therefore needs protection from “choice” is more useful since our material makes it clear, that we are facing a huge gap between patients and health professionals in relation to the civil practices, i.e. what the patients are doing to survive or live with their disease (self-medication, self-care, coping strategies) and what the medical staff has to offer their patients (patient-doctor consultations, shared decision making, cancer treatment programs).

## CONCLUSION

With our account, we contribute with an expanded understanding of how probing can be vital for addressing political structures and systems of authority. More specifically we are able to get insight into how fixed identities can be unmasked and reveal a rich patient profile that gives us a fine-grained picture of patients who rejects chemotherapy and chooses alternative treatments. Due to this study Vejle hospital has been able to synthesize the system's need for more



insight into the patient's self-medication and special diets. At this moment we are planning a follow-up study related to this issue.

The probing sessions allow participants to involve themselves in moments of dissensus and to materialize what – according to them - needs to be visible/invisible/heard/unheard. From this we can conclude that probing has the potential as a valuable aesthetic-political practice for design research and - in addition to inspiration/ information/participation/ collaborative dialogues – give us a better understanding of systems of power and the forming of identity belongings.

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