



# CONSTRUCTING AN ACTIVE CITIZEN ONLINE

- A CASE STUDY OF BLOGS OF MEDICAL HISTORIES IN PUBLIC  
HEALTHCARE IN SWEDEN

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## Abstract

This paper focuses on the construction of citizenship online, through an analysis of independent blogs as well as member blogs of NGOs, all being written by young Swedish cancer patients. The findings show that citizenship is co-constructed in complex interplays. Blogging and support from NGOs open up new forms of everyday practice, extending the concept of citizenship. The importance of NGOs being online is highlighted in this context. The NGOs are supporting their members' efforts to become more active citizens as well as providing tools for non-members to become more active as patients. Individual blogs are also important, as they can be seen as self-organised networks providing an interactive link among the writer, the commentators, and the readers in the construction of citizenship.

Keywords: Citizen blogging, NGO, empowerment, participation

## 1. Introduction

Citizens' active participation is one of the most central criteria for democracy as highlighted by, among others, Dahl [1994]. In line with the increased use of information and communication technologies (ICT), opportunities and openings for participation in democratic processes have developed rapidly. Digital participation can take many different forms, such as, for example through community groups online, blogging, and accessing political and public information online. Often such participation takes off from a more personal interest, and activation is based on personal needs and demands, but still in a social context [Barak et al. 2008].

Several studies have argued that blogs have changed the way political communication works. For example, a study by Woodly [2008] show that blogs may

set the agenda for political elites. However, there is also a need to focus on how citizens in everyday life participate and express demands. Today, the thresholds for active citizens' expression and participation through on-line communication are lower than ever. Even if such forms of participation are far from representative, they may open up, and even include, alternative ways of expressing ideas towards a broader community [Meijer et al. 2012].

This paper addresses “everyday activism” – the actions of cancer patients in the Swedish health system who use blogs as a means of describing daily events. The focus is on how citizenship and participation are constructed through blogs, since blogs are personal but can still have an empowerment strategy and be(come) political. The patients who are blogging are often presenting a mix of material on their everyday lives, medical histories, and shared experiences of being active patients and expressing rights in relation to their healthcare providers.

Participation in terms of active use of public services, such as health services, and feedback regarding them has emerged as a key issue for a political legitimacy that is inseparable from democracy. This broader approach to political participation builds on welfare state integration into everyday life, in which political participation relates to use of services [Richard 2000; Rothstein 2010]. Patients are, as individuals, often seen as weak and dependent, but through organisations their interests are made visible on the political agenda. There are today several active organisations taking notice of patients and diagnoses, such as The Swedish Cancer Society and The Swedish Rheumatism Association. These non-governmental organisations (NGOs) are also active online, and provide blog space for members. Hence, patient organisations such as NGOs may have a role in supporting and constructing responsible and active democratic citizens and contributing to public services. However, in the blogosphere, other types of non-governmental structures may also play a role – for example, the way commentators and readers interact on blogs.

### 1.1. Aim of the Paper and Research Questions

By focusing on a quite particular group of bloggers, young people diagnosed with cancer, we analyse strategies of participation and empowerment embedded into personal medical blogs in order to discuss how digital participation is framing and constructing citizenship.

This paper builds on a case study of blogs written by young cancer patients in the Swedish healthcare system. The objective is addressed through three questions:

- How is patients' interaction (information, examinations, medical follow-ups, etc.) with the healthcare system presented in blogs?
- How are the NGOs supporting the construction of an active citizen?
- How are followers of and comments on blog posts contributing to the construction of citizenship and empowerment strategies?

### 1.2. Patients' Rights in the Swedish Healthcare System – An Emerging Arena for Construction of Citizenship

The focus on patient blogging, sometimes with the support of NGOs, takes place in the context of the Swedish national healthcare system. Public healthcare is a key service for citizens, and maintaining quality in the healthcare system is important for upholding democratic legitimacy in welfare states. Healthcare targets citizens in particular need and in dependent situations. The focus on patient participation is a critical issue that has been given increased attention.

Healthcare in Sweden is a public service regulated by national legislation, but funded by regional government agencies and provided by public and/or private healthcare units. The organisation and management of healthcare are based on political decisions. Over the last few decades, the system has been reorganised in line with New Public Management (NPM), making it open to increased patient involvement and public choice models [for overview, see Svanborg-Sjövall 2014]. In these settings, the patient is expected to take a more active part in the process by choosing healthcare providers and also by getting more involved in decisions regarding care [Nordgren 2011].

Initiatives such as improved rights for patients in relation to public healthcare are framed as care within the EU, the right to second opinions, and choices of healthcare providers. This shows the complex interplay of policies on citizenship roles and the practice of service provision [Legislation Prop. 2013/2014: 106]. An approach related to patient blogging is the patient-diary method, which is supposed to lead to co-creation of care and improved patient satisfaction [Elg et al. 2012]. Another development designed to make patients more informed and to take greater part in their medical situation is ICT services, which have increased rapidly [Official report, SOU 2013: 44].

These new structures are open to, and might even demand, a more active and participating patient. This also leads to new forms of everyday citizenship, with the patient acting more like a customer in the public market of welfare services. This model of the role of the patient comes from the New Public Management model, in which the patient should be seen and act as a consumer, able to choose services from among a variety of alternatives. Previous studies have focused mainly on the health system as a provider of information and not on the role of patients helping each other to become active patients [see overview in Mol 2008]. In this paper we focus on the last part, namely the role of bloggers in relation to active patients. In an American study of medical blogs in 2008 and 2009, Miller and Pole [2010] found that half of medical bloggers were also employed in the health field; in addition, most of them were highly educated women in their 30s. Our study provides a new perspective on this file as well by showing how patients can take different roles online – such as those of passive patient, consumer, and citizen.

### 1.3. Outline of the Paper

This paper starts with a general discussion on digital participation and its implications for citizenship, which is discussed in the next section. In the third section we present the methods for the case study. Thereafter, in section four, the findings of the blogs are presented, following the general research questions outlined above. Based on these presentations and the contextualisation of blogging, we discuss the construction of citizenship in section five. In this section we also make some more general comments and discuss implications of the study we have conducted.

## 2. Co-constructing Citizenship Online – Theoretical Framing

In the online context, the meaning of citizenship is extended and reframed. In this paper these new settings are studied from a political science perspective, starting with what it means for citizenship and democracy to approach online contexts.

## 2.1. Citizenship as a Key to Democracy

Citizenship has always been a key to democracy. Exclusion based on sex, race and class has been ways of setting the forms of democracy and also subordinating those excluded from rights and duties [Walby 2009].

From a demo-elitist perspective, citizenship brings a responsibility to vote in elections, but otherwise the citizen can stay passive. A neorepublican democratic perspective would, on the other hand, argue that citizens are assumed to be more active, especially at micro and local levels. They construct their citizenship, and contribute to and participate in both the political arena and their own moral, social and intellectual development [Rose and Saebø 2005]. In such a setting, citizenship is constructed through relations, experiences and everyday practices, not just with the state. It can be supported by non-governmental civic organisations' activities and blogs, since emerging social media are providing new spaces for such interactions in the intersection of all other practices through which we live our lives. Through the construction of citizenship, the identity and the interpretation of the self are also developed [Massey 2005]. Hence, here citizenship is seen as constructed at the site of complex intersections of institutional arrangements, governmental practices and sociocultural conditions. We consider citizenship to be constructed through the interplay of discursive and embodied practices [Fraser 1990; Kurtz and Hankins 2005].

## 2.2. E-democracy and Citizenship

Democratic participation can take new forms when there are digital opportunities, since it departs from a public agenda and is based on broad and easy access where many can be heard. This participation can open up opportunities for debating and learning from others, and citizens can expand their democratic values. Richard's [2000] study of local citizenship shows that participation also connects to empowerment, as people feel part of a group and know that their actions can influence the decision-making process. Thus participation can have empowering implications in particular in relation to public services that in turn contribute to building democratic legitimacy.

Dahlberg [2007] elaborates on four ideal types of e-democracy: liberal-individualist, deliberative, counter-publics, and autonomist Marxist. These are interesting to set in contrast to the NPM context of the patient blogging analysed here. In the liberal-individualist digital democracy, digital media becomes an arena for democratic participation and influence. The deliberative type refers to how social media opens up a deliberative democratic public sphere of rational communication. By counter-publics, Dahlberg is referring to the role of digital media in political group formation, activism, and contestation. The autonomist Marxist perspective on e-democracy is seen by Dahlberg as digital communication networks that enable self-organised, radically democratic politics that bypass the central state and capitalist systems [Dahlberg 2007]. Bergholtz et al. [2014] have further elaborated on Dahlberg's model and identified tools/applications that support e-democracy. They stress that four positions can be found within the Dahlberg model: consensus (support forms of collective decision-making); transparency (support sharing information); pluralism (acknowledge diversity and conflicts); and autonomy (support forms for open-source culture) [Bergholtz et al. 2014: 2–3]. Dahlberg's model is constructed on ideal types and is therefore a more general model of e-democracy that does not target practical needs/problems. By focusing on tools for e-democracy, the authors bring an actor's perspective on the Dahlberg model that can be seen as a complement to the four types of e-democracy. These aspects of e-democracy may appear in the construction of active

citizenship through medical blogs. Blogging becomes an expression of citizenship and political participation.

### 2.3. Being a Citizen Online

Studies of blogging as democratic practice have often focused on direct activism, such as, for example, the role of political blogs in elections or micro blogs in the Arab spring [see, for example Griffiths 2004, Woodly 2008]. Studies have also analysed blogs as a means of political interaction between elected and citizens [see, for example, Lawson-Borders and Kirk 2005] and a means by which government can use social media to provide official information to citizen [Criadio et al. 2013; Catlaw and Sandberg 2014].

Democratic participation can thus mean new things and take other forms when there are digital opportunities to reach the public and extensive public services to discuss and relate to. Such participation can facilitate broad and easy access by which all can be heard. And the participation can also open opportunities for debate and learning from others, and citizens can even expand their democratic values. Citizen participation is also connected to empowerment; people feel part of a group and know that their actions can influence the decision-making process in which they participate [Richard 2000]. Thus digital participation can have empowering implications in relation to public services in particular. In addition, openness towards broad groups of citizens and online communities can also improve access to public services and might also develop public services based on information shared online as a form of co-production [Meijer et al. 2012].

To sum up, this analysis will apply a constructive perspective on citizenship. Here we add the online construction of citizenship to the political science perspective. Since further studies related to new types of media are needed, this paper will analyse the role of blogs and new communication channels in the construction of citizenship. Other studies have also argued that digital participation is political; however, the interrelation between the private (everyday life) and the political needs to be understood better. This paper also complements previous studies related to different types of citizenship by addressing patient-consumer-citizen roles and how these are constructed by new communication channels.

## 3. Methods and Material

### 3.1. Selection of Blogs

This case study builds on a text analysis of ten Swedish cancer-patient blogs (see appendix A for a summary of the key characteristics of the bloggers). The blogs include both patients who have chronic, life-threatening cancer diagnoses and non-life-threatening diagnoses. Half of the blogs have been selected from the portal of an NGO and the other half from independent bloggers using either general blog platforms or their own.

As previous studies have shown, participation can be connected both to a group as well as to an individual's actions. In order to capture these two dimensions, we have selected blogs based in NGO patient organisations and independent patient blogs. The blogs based in patient organisations are mainly related to the organisation Young Cancer (Swe: Ung Cancer). This is a non-governmental organisation that was created online by two young cancer patients. The organisation aims to improve conditions for juvenile cancer patients. This NGO has a good Internet structure and the blogs related

to this platform are updated regularly. These blogs are embedded in the structure and aims of the organisation.

The NGO blogs are contrasted with four independent blogs. They were selected using Google search and the Swedish keywords “cancer blog” (in Swedish). We were interested in blogs that had a high amount of traffic and were highly visible online, since these are the blogs that people searching for patient blogs encounter first and that have the most readers. High traffic on blogs might also indicate that the blogger and the reader are co-constructing new perspectives on personal and political issues through an intensive interaction. The participation and construction of active citizenship might be most visible here. We therefore chose the blogs that appeared first on the search engine. We chose to use Google for the search, since this is the most common search engine in Sweden (used by over 95 per cent of searchers), and we assume that others searching for blogs might also use Google (<http://www.befound.se/tips/statistik-over-sokmotorer.aspx>). A strategic based non-probability sampling method has been used in other studies as well, and is often proposed for increasing the validity of results in studies of this type [Miller and Pole 2010]. It is important to note that we do not aim at statistic generalisation with our results; instead, our aim is to understand the construction of citizenship online, and this also motivates our use of a non-probability sampling method [Bryman 2008].

All blogs we have analysed have been running for some time, but their lifespans vary from six months to several years. There is also variation in posting frequency. This varies both among the blogs, but also over time within each of the blogs. In some cases this can probably be explained by the medical conditions of the bloggers.

### 3.2. Analysing the Blogs

All quotes from the blogs have been translated from Swedish to English by the authors. The blogs are available and searchable online, but we have chosen not to display their names and addresses. Individual bloggers’ names are not relevant to the results of the study, and for ethical reasons related to patients’ privacy they remain anonymous. The selection of extracts and quotes from the blogs is based on the overall research questions and qualitative text analysis.

Qualitative text analysis focuses on understanding the subtle or implied meanings of a text [Burn and Parker 2003]. It provides a reading that helps the audience to see a text in new and valuable ways. For this study we are interested in the narrative structure of the blogs/texts, capturing the transition of the blogger into an active patient, getting a diagnosis and then living with the diagnosis and the changes that occur during this period. We are also interested in analysing the interactions among elements and the relationship between different characters in the texts. In order to capture the interaction, we included an analysis of the commentary that is found below the blog post.

Texts have then been categorised into different themes, grounded in our theoretical perspective and in their own narrative. This means that the analysis is influenced by a qualitative perspective grounded in the theoretical tradition rather than in a statistical approach of summarising the themes into comparative tables; the latter would be normal if we were using a quantitative approach [Burn and Parker 2003]. The main aim is to deconstruct strategies of participation and empowerment in order to discuss how democratic digital participation is framed in the construction of citizenship.

## 4. Telling My Story – Findings

In this section we present and discuss the analysed blogs. The material is divided into five sections; motives for blogging; the relevance of medical histories; acting as a responsible and active patient; the role of patient organisations and lastly the construction of citizenship through blogging.

### 4.1. Different Motives for Starting to Blog about Cancer

Patients blog for different reasons. Overall, the blogs examined here can be categorised into two different categories. The first category is “lifestyle blogs” that patients maintained before they got cancer. These blogs concern everyday life and the activities that interest the blogger – their children, sports, fashion, etc. The authors of these blogs were blogging before they were diagnosed with cancer, but after being diagnosed their blogs shifted focus to concentrate on their cancer history.

*I started this blog when I was expecting my youngest daughter, so friends and family could follow my pregnancy and her development. June 23, 2011 changed our lives unexpectedly when I was told that I had inflammatory breast cancer, so now the blog is more about me and my battle with cancer. [Blogger 1]*

The other category is blogs that started when the author was diagnosed with cancer. Among these blogs, we have identified two different motives for writing. One is to write the blog as a diary for themselves or for their families and friends.

*This blog is mainly for myself – but you are of course welcome to read and comment if you wish. Here I reflect on the past and present, writing about dark thoughts and superficial reflections, mix personal with the impersonal. [Blogger 2]*

The other motive is to inform others about cancer and the process of overcoming it. “The idea of my blog is to describe cancer treatment today and share my thoughts about then and now” [Blogger 3].

The blogs connected to an NGO platform are found in both categories; hence, “lifestyle blogs” are sometimes linked to an NGO platform such as Ungcancer.se. This may be because the patient has become involved in the NGO and identifies with the organisation, and also wants to get other persons with cancer to read the blog. Some bloggers also indicate that there is increased traffic when they add their blogs to an NGO. The NGOs here have an empowering function. Relating to the tools developed by Bergholtz et al. [2014], we place the motive for starting the blogs mainly in the category “consensus”; several of the bloggers used the blogs to share information and reflect on and discuss cancer with themselves or with others.

### 4.2. Medical Histories – The Construction of Active Patients

By analysing the blogs, we can follow patients’ perspectives, the actors they meet during their treatment, and their roles as patients. Since several of the blogs we are analysing have been active for many years, they also provide a historical possibility to analyse patients’ medical histories. During this journey we can see that the bloggers are becoming much more active in the health system and are playing a responsible role in their medical situations.

It is clear that several of the bloggers went through a difficult process before being diagnosed, and they are critical of local healthcare. One blogger writes about struggling with pain in her breast for over six months before she got her diagnosis. She writes how she demanded to see different doctors and tried to look up information online. In the end she was relieved that she got her cancer diagnosis, since this proved

that she was right in the first place, despite the scepticism from doctors [Blogger 1]. Also other blogger expresses a feeling of not being trusted.

*When I sought treatment for my problems at the local health centre, I only got the lovely comment that I should go home and take a pregnancy test. Two weeks later I was diagnosed with acute to chronic leukaemia. [Blogger 6]*

Once they have gotten their diagnoses, the bloggers rather quickly become their own managers, playing the role of active patient. The bloggers write in a very rational way, often describing their days in terms of task and meetings.

*I got out of the ear clinic, I had my hearing checked at 14:00, and before then I had an x-ray taken of my arm. [Blogger 7]*

The blogger quoted above also writes that she logged on to the online medical page [minavardkontakter.se](http://minavardkontakter.se) and checked the status of her medication and what needed to be refilled, etc. [Blogger 7]. It is clear that the patients meet many different professionals, from staff working in reception and the pharmacy to cancer specialists. However, the blogs show that it is the patient who is muddling through this web of actors and who should be seen as a mediator among the different actors. It is important to stress that it is not only the meeting with the doctor that is important for the bloggers; it is the whole chain of persons they meet and the infrastructure surrounding the patient role. One blogger writes about her struggle with her insurance company:

*For a year now I have had daily problems with the insurance fund. Once you're diagnosed with cancer, you don't get much help, despite asking on my knees for it. To fight every day without getting anything back for it makes me very frustrated and disappointed. [Blogger 5]*

In a similar way, they write about medical practices as if they were in charge of what happened. They have often tried different types of medication. A typical example occurs when one of them is writing about the prioritisation and choices of medicine and gives the impression of being highly involved:

*I have managed to find the best medication for me; but I have tried my way, like in a candy store, a crown for that, five crowns for that.... [Blogger 9]*

Some bloggers have also participated in medical trials and reflect on these experiences. These actions are all examples of a patient being responsible, but also showing how much responsibility is put on the patient. It is clear that the doctors possess the medical skills, but it is the patient who is the manager of the overall situation. Being the manager of one's own treatment shows an ambition to be an active and responsible patient in charge of the medical process. Such actions and perspectives on the patient role can be related to the neorepublican perspective on citizenship.

#### 4.3. Acting as a Responsible and Active Patient

Being an active patient can also mean being a critical patient. Some bloggers openly criticise the healthcare system or a particular medical staffer, a health unit or a government agency. These types of posts are often very personal, reflecting the fact that the author feels mistreated. There are also examples of more general posts on how the health system is organised, and how patients in general are mistreated or not listened to [Blogger 6]. One example of an open letter is from Blogger 2 who describes the importance of being able to get a second medical opinion and how patients need to take an active part in getting this second opinion. We have also identified bloggers who write posts on other web pages as well, for example at The Swedish Cancer Society page [Blogger 9]. Some bloggers also describe other written actions they have taken to



influence the system or politicians: “I spent time trying to get a little feedback to the Stockholm County Council regarding cancer care” [Blogger 3]. Posting online is one way to stay active as a patient and to try to influence society in general.

Several of the blogs also offer learning possibilities for readers, as bloggers explain what different things means. “This is a sampling needle, it is called the Butterfly” Blogger 7 explains. Beside the text she has posted a picture of the needle. Bloggers also indicate where readers can get more information. Several bloggers link to information pages and other blogs about cancer, being responsible citizens by informing others.

Our analyses of the blogs show that the bloggers as responsible and active patients. They are forced to steer among different health units and also provide arguments and try to help others by posting information online. However, another picture also emerges from these blogs – that of patients who feel they are not doing enough to influence their situation. For example, Blogger 1 writes that she “knew” that she had cancer, but still trusted the doctor when he said that it was influenza. Several bloggers write about guilt, and blame themselves for the extent of their problems and the fact that they did not seek medical attention earlier than they did. However, it is important to point out that the guilt they are writing about relates to events that happened in the past. By reading the blogs from a historical perspective, we can see that the bloggers did not have a great deal of knowledge about the healthcare system when they were diagnosed. They have gained increased knowledge over time. The guilt of not being active patients should be seen in proportion to this learning curve; however, this is not a reflection evident to the bloggers.

The feeling of guilt also affects bloggers’ trust in the healthcare system in general. Several bloggers seem to struggle with relying on doctors and also being forced to participate and take responsibility for their own medical decisions. It is clear that the bloggers do not see themselves as “passive patients”; instead, they see themselves as participants and not only receivers of treatment and healthcare. They are taking a citizen role similar to that assumed in the neorepublican democratic model of citizenship [Rose and Saebø 2005]. It is not always clear whether this is a role the bloggers want to have; however, the structure of the medical system in Sweden today is one in which the patients are passed among doctors and health care units, forcing the bloggers to become active and responsible patients.

#### 4.4. The Role of Patient Organisations in the Construction of Active Patients and Everyday Citizens

This section highlights the question of how and whether NGOs can make a difference in patients’ and citizens’ active online participation. We have identified some differences between the blogs that are connected to an NGO platform and independent blogs. The main difference is that NGO-based bloggers are part of a community that helps them be what we call an “everyday citizen” as well as being more active cancer patients. This involves processes such as constructing an identity and the interpretation of itself. When blogger are part of an NGO, the organisation provides numerous activities in which the blogger can participate. The bloggers who are connected to the NGO Young Cancer platform write about different activities that the organisation arranges and that they have attended. The NGO arranges different local meetings; for example, one blogger writes about an activity that involves horseback riding, and in this post she also points out how happy she is that she has gotten to meet new people:

*We do not talk about cancer in particular, but about everything fun that happens to us. We laugh and joke about everything! And if on the other hand someone*

*wants to share about their disease, all are there and listen and support.*  
[Blogger 6]

These activities contribute to a feeling of the blogger being an “everyday citizen” – being able to do activities that non-cancer patients do. The activities are not directly related to cancer, but often shaped in the context of the illness. The bloggers also use their blogs to inform others about activities that are happening within the NGOs [see, for example, Blogger 9].

The NGOs also help member-bloggers to become more active patients by meeting with different government agencies, providing information material, and arranging member meetings. On the Young Cancer webpage, we found the following services, helping patients manage problems with governmental agencies:

*Having problems with Insurance Agency, CSN [governmental agency managing study grants] or some other agency? We know there is a lot to consider, guidelines to follow, papers to be filled out and submitted. If you have questions, thoughts and ideas about this, then you are more than welcome to contact us and we will help you. It may involve helping you find your way through a jungle of forms or assisting you in your case – we are here for you! [Ungcancer.se]*

The above is an example of how an NGO can offer its members help in becoming active patients. Another activity that the NGO Young Cancer has initiated is a mentoring program for cancer patients. This program aims to help participants build self-esteem. The activities are promoted on the NGO’s blog as well as on blogs of those who are participating in the program [ungcancer.se; Blogger 6].

We also see that the NGOs are promoting members’ blogs on their own websites and are posting interviews with the bloggers. Hence, there is an interaction between the bloggers and the NGOs. Some bloggers are also working actively in arranging activities within the NGO. For example, one blogger, who is active in sports, compete in races in the name of a cancer organisation [Blogger 4]. It is important to stress this exchange – the bloggers are important for the work of the NGOs, in providing information and promoting their activities. The bloggers becomes spokespersons and the “faces” of the NGOs when sharing their life stories online. These actions are similar to what Dahlberg [2007] refers to as counter-public, using digital media in political group formation and activism.

Several NGOs work with information that helps both non-members as well as members to become active patients. The NGOs thus play an important part in making active patients of non-members as well. The NGOs have websites that provide information that can be used by anyone. An example of information is found on the Young Cancer platform. This NGO has posted a checklist online that patients can take with them when meeting doctors after a cancer diagnosis. The checklist consists of a number of questions that are good to ask when meeting the doctor. The list relates questions regarding health situations and medications, etc. but also questions related to the health organisation itself, such as, “Is it possible to get a second medical opinion?” and “What should I do if I would like to get healthcare through another county council?” (ungcancer.se). The NGOs also provide other information concerning the Swedish healthcare system and where to turn to get more information.

It is clear that these NGOs play an important role for non-members by providing information on how they can become more active patients in the healthcare system. However, there is an important difference between members and non-members of NGOs, and this is the role the NGO plays in encouraging members to live life as everyday citizens. The group activities that we refer to above, such as horseback riding, seem to be very important to the bloggers we studied. It is in this role that the NGOs

are contributing the most by introducing cancer patients into a community life and encouraging them to become everyday citizens. These activities are not things in which non-members can take part. The NGOs thus help member-bloggers in both their “patient role” as well as in their citizen role. In this section we also see that online tools such as blogs and NGO websites are central to interactions among patients. The blogs are expanding in their role as tools of e-democracy, from consensus shaping to autonomy.

#### 4.5. Blogging as a Way of Constructing Citizenship

Our third theme emphasises how the construction of the active patient and citizen relates to bloggers and readers online. There are several instances found in the blogs we studied in which the bloggers are relating to other blogs. For example, blogger 6 writes:

*Sandra on Young Cancer gives me strength every time I read about her struggle.  
[Blogger 6]*

This blogger is referring to a blog that is posted on the NGO young cancer, and the quotation shows how one blogger can give strength to another. It is also clear that people use these blogs when seeking information on cancer-related issues. For example, a blogger diagnosed with breast cancer described how she first suspected something was wrong with her breast:

*Around this time I started to follow a blog about a woman who had inflammatory breast cancer, Linda; her symptoms were similar to mine...  
[Blogger 1]*

Blogs comments also give the impression that many readers find these blogs when they get ill and are trying to identify what is wrong with them (see, for example, comments under Blogger 6).

There is an interaction between bloggers and readers. This interaction has many features. The bloggers post questions to readers, for example. The questions are sometimes related to medical conditions, such as “Did you also feel this when taking medication XXX?”. Sometimes a blogger asks for readers’ advice regarding what they would have done if they were in a specific situation. Other questions concern the everyday life of a cancer patient. For example, one blogger asked a question related to when she should cut her hair:

*So the question is if I should cut off my hair now, or wait a bit. I understand that I have some readers who also are leukaemia patients. Please contact me if that is the case. :) [Blogger 7]*

The blogger who asked about her hair had gotten her cancer diagnosis three weeks before the post, and she reached out to her readers for advice.

The comment thread, with its interaction between blogger and readers, plays an important role in the construction of the new citizenship. It is used as a forum for questions, often directed toward the blogger, and concerning a wide range of topics, including cancer diagnoses and treatments and more administrative questions such as those related to insurance (see, for example, Blogger 9). There are also questions that are not directly to the blogger and that are asked more generally to the other readers of the blog; they often start with, “Does anyone know...?”.

Many bloggers are very active in responding to comments. Sometimes they relate comments or questions to their own situations, but often they refer readers to organisations or websites where more information can be provided. Several bloggers write that they are thankful for the feedback they get from readers and that they see that their blogs are making a difference.

*I have gotten a lot of positive feedback. New emails came each day last week. I have answered different surveys, done interviews, been part of a book, helped various schoolchildren with their projects at school, etc. There have also been several people who wrote to me, being in similar situations and looking for someone to talk to. I think it's super fun when people give me so much energy and feedback! [Blogger 5]*

The quotation above symbolises how the blogger takes on a broader role than just writing about her medical condition. She or he becomes a mentor, a spokesperson, and a person to whom other people can turn. Hence the blogger goes beyond being a patient and becomes an active citizen, influencing others.

It is important to note that the readers who comment on the blogs also play an important part in encouraging patients to become active consumers by providing constructive information regarding the healthcare system. The readers of the blogs are also commenting on other comments, and by this helping with information and giving support. Hence there is an interdependent relationship among the readers of the blogs, as well as between the blogger and the readers.

The comment thread is also for readers to write about how they are feeling. An example of such a comment is found in Blog 10:

*I took a new test yesterday in relation to the chemotherapy. It turned out that my white blood cell count had gone down in value so I have to take new samples on Monday. Probably it's because of my pollen allergies. At least I hope so. [Comment on Blog 10]*

The quotation above is not related to the blog post but rather to the commenter's own condition. Hence the comment section provides an opportunity for readers to write about their conditions as well.

As we have shown, by commenting and helping readers, bloggers take responsibility for creating more active patients, and in a sense, make patients into critical consumers in the healthcare system. However, we have noted that this role can also be a burden for bloggers. The quotation below illustrates the struggle of both trying to help others and deal with one's own fear of cancer:

*I become paralysed with fear when I get emails from people whose husband, wife, boyfriend suffers from cancer. A woman whose husband died three weeks ago. A young married girl whose husband's cancer had spread to his bones, though he seemed to be virtually cancer-free and had a very good prognosis only one month ago. I ask them to email their blog addresses, and I think they are right to contact me. I just do not know whether I should read or not... I am ploughing through one terrible history after the other. Some blogs are closed or are not updated because of death; other blogs are like mine, a fight between chemotherapy, waiting, children, family life. Before I became ill, I spent not a second on those fates out there. [Blogger 10]*

Hence the new citizenship is co-constructed in a self-organised network [Dahlberg 2007] of bloggers, readers, and commentators, in which the blogger is the main actor of this co-construction. Within this network, the blogger takes on many roles besides being a patient; he or she is an information provider, therapist, coach, and source of inspiration. There are components of this that are also found in different professions within the healthcare system, but in an online context these are constructed in the interaction of bloggers and readers. The network around the patient and the context of the NGO supports these empowerment strategies. The blogs can, as shown here, also be tools for e-democracy [Bergholtz et al. 2014]. These blogs have a role to play in the formation of consensus in discussions as well as in personal autonomy. The

transparency in terms of sharing information fosters others' trust in both the blogger and her story, and it is a key to pushing the healthcare system towards improved quality.

## 5. Conclusion and Discussion

Even though this study is based on individual bloggers and their personal experiences, some more general implications can be made. We will show here that what can be seen as tools for participation also have impact on the construction of citizenship and thereby on democratic participation. In this study we have focused on some key issues, and from this the following conclusions can be drawn:

*Firstly*, our study shows the importance of NGOs as an arena for personal bloggers, but also for support and empowerment of other patients, since the NGO supports and give advice on how to manage everyday life as a patient. This is done through the blog as an open letter criticising the medical situation and the healthcare system. The blogs are also used to promote the NGOs' activities and are open for dialogue with other patients. This can be related to the deliberative aspect of e-democracy, since it is a strategy of constructing a community and empowering peers in similar situations.

*Secondly*, the NGOs encourage members to be active as well as be "everyday" citizens, and their websites also encourage non-members to become active patients. The blogging patients and the NGO are thus co-producing a community that supports care and also increases awareness of the situation for cancer patients in general.

However, there is also an emphasis in the blogs on the patient as a manager of his/her patient role. The blogs tend to promote the idea of being in charge of the medical process as an active patient. This can on one hand be seen as a liberal-individualist approach to e-democracy, in Dahlberg's [2007] terms. But in line with the NPM-structure of the Swedish healthcare system, one could also argue that this is an autonomist Marxist approach, in which the patient develops the capacity to bypass the state and its authoritarian medical professionals. Here is an alternative approach discussing different treatments and expressing demands through blogs, not in the manner of a customer in the market but as a citizen with rights and duties. Hence, our *third* conclusion is that citizenship is co-constructed in complex interplays, and the blogs, as well as the support of NGOs, may even open up new forms of everyday practice, extending the citizenship concept even farther.

The main purpose of the blogs we have analysed is not, from the bloggers' perspectives, political; the blogger may not even see his or her blog as a tool for democratic participation. The blogs may rather be seen as a way of making the private and personal into a political issue. This is a different perspective on online democratic culture, taking into account participation by "non-activist" citizens. This new perspective presents opportunities for a broader theoretical inclusion of the citizenship concept. By analysing medical blogs from a democratic perspective, we also show that citizenship and political legitimacy are built through active use of public services. This research makes a contribution to the study of e-democracy, since we point to the politics of the *use* of public services such as the healthcare. The findings also contribute to existing studies on the role of patients online, and provide a new perspective on the medical field by showing how patients can play different roles online – passive patient, consumer, and citizen.

The main impact of this study is that what seems to be a personal empowerment strategy also can have a broader impact on the construction of citizenship in a larger context. An obvious consequence of sharing personal stories online is that it can contribute to the conceptualisation of citizenship, public services, and democracy. This perspective has to be taken into account in more research, since it challenges political

theory and models of participation and citizenship, and shows the demand for new theories on participation and democratic development in a digital society.

This paper has also discussed different types of citizenship, in terms of patient-costumer-citizen roles, and shown how these are constructed by new communication channels. These findings are relevant to the study of e-democracy and citizenship, as well as to studies related to the healthcare sector. An analytical framework that focuses on different roles within citizenship, identified through new communication channels, can also be applied to and further studied in other public services as well.

## References

- Barak A, Boniel-Nissim M, and Suler, J. 2008 Fostering Empowerment in Online Support Groups. *Computers in Human Behavior* 24(5), pp. 1867–1883.
- Bergholtz M, Ekenberg L, Hansson K, Johansson P, and Snygg J. 2014 Framework for Evaluating Tools Used in E-democracy: Transparency, Autonomy, Consensus and Pluralism. In Writers Hut, Department of Computer and Systems Sciences, Stockholm University.
- Burn A and Parker D. 2003. *Analysing media texts*. Continuum, London.
- Bryman A. 2008. *Social research methods*. 3rd ed. Oxford University Press, Oxford UK.
- Catlaw T J and Sandberg B. 2014. “Dangerous Government”. Info-Liberalism, Active Citizenship, and the Open Government Directive. *Administration & Society* Nov. 29, pp. 223–254.
- Criado I, Sandoval-Almazan R, and Ramon G-G. 2013. Government Innovation through Social Media. *Government Information Quarterly* 30(4), pp. 319–326.
- Dahl R. 1994. A Democratic Dilemma: System Effectiveness versus Citizen Participation. *Political Science Quarterly* 109(1), pp. 23–34.
- Dahlberg L. 2007. Rethinking the Fragmentation of the Cyberpublic: From Consensus to Contestation. *New Media & Society* 9(5), 827–847.
- Elg M, Engstrom J, Witell L, and Poksinska, B. 2012. Co-creation and Learning in Health-Care Service Development. *Journal of Service Management* 23 (3), pp. 328–343.
- Fraser N. 1990. Rethinking the Public Sphere: A Contribution to the Critique of Actually Existing Democracy. *Social Text* 25/26, pp. 56–80.
- Griffiths M. 2004. e-Citizens: Blogging as Democratic Practice. *Electronic Journal of e-Government* 2(3), pp. 155–166.
- Kurtz H and Hankins K. 2005. Guest Editorial: Geographies of Citizenship. *Space and Polity* 9(1), 1–8.
- Legislation, Prop. 2013/2014: 106. Patientlag. [Proposal on Legislation regarding patients].
- Massey D. 2005. *For Space*. Sage, London.
- Meijer A J, Curtin D, and Hillerbrandt M. 2012. Open Government: Connecting Vision and Voice. *International Review of Administrative Sciences* 78(1), pp.10–29.
- Miller E A and Pole A. 2010. Diagnosis Blog: Checking up on Health Blogs in the Blogosphere. *American Journal of Public Health* 100(8), pp. 1514–1519.
- Mol A. 2008. *The Logic of Care: Health and the Problem of Patient Choice*. Routledge, Abingdon, Oxon.
- Nordgren L. 2011. Healthcare Matching: Conditions for Developing a New Service System. *International Journal of Quality & Service Sciences* 3(3), 304–318.
- Official report, SOU 2013: 44. Patientmaktsutredningen. Ansvarsfull hälso- och sjukvård: slutbetänkande. [An investigation on patient influence. Accountable public healthcare]. Stockholm

- Rose J. and Saebø Ø. 2005. Democracy Squared: Designing Online Political Communities to Accommodate Conflicting Interests. *Scandinavian Journal of Information Systems* 17(2), article 5.
- Rothstein B. 2010. Happiness and the Welfare State. *Social Research* 77(2), pp. 441–468.
- Richard M-P. 2000. *Lokalt medborgarskap i Sverige*. Arbetsrapport 26. Cefos. Göteborgs universitet, Göteborg.
- Svanborg-Sjövall K. 2014. Privatising The Swedish Welfare State. *Economic Affairs* 34(2), pp. 181–192.
- Walby S. 2009. *Globalization and inequalities: Complexity and contested modernities*. Sage, London UK.
- Woodly D. 2008. New Competencies in Democratic Communication? Blogs, Agenda Setting and Political Participation. *Public Choice* 134(1–2), pp. 109–123.

## Appendix A: Blogs Quoted in the Article

<b>Blog number</b>	<b>On the platform of “Young Cancer”</b>	<b>Description</b>	<b>Age (present, 2014)</b>	<b>Started blogging (existing blog)</b>	<b>Post-frequency</b>
Blogger 1	No	Female blogger diagnosed with inflammatory breast cancer	40–45	Jan. 2009	<1/week
Blogger 2	No	Female blogger diagnosed with breast cancer	35–40	Jan. 2013	< 5/week till May 2014. Now less frequent, < 1/month
Blogger 3	No	Female blogger diagnosed with breast cancer	Over 50	March 2011	Varies. < 5/week to <1/month
Blogger 4	Yes	Male blogger diagnosed with lumbar cancer	25–30	March 2009	Has no dates on post, but approx. < 1/week
Blogger 5	Yes	Female blogger diagnosed with brain cancer	20–25	Feb. 2013	Varies. < 5/week, but also periods with large gaps
Blogger 6	Yes	Female blogger diagnosed with leukaemia	20–25	Oct. 2011	< 5/week to < 1/month
Blogger 7	Yes	Female blogger diagnosed with leukaemia	25–30	Aug 2009	< 5/week
Blogger 8	Yes	Female blogger diagnosed with myeloma	45–50	Jan 2014	< 1/week
Blogger 9	Yes	Male blogger diagnosed with malignant mesothelioma	40–45	June 2009	<5/week Over the last year fewer posts, approx. 2/week
Blogger 10	No	Female blogger diagnosed with colon cancer	40–45	Feb 2007	< 5/week