Masked Or Informed Citizens? Social Media And Online Health Consultations

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SOCIAL MEDIA AND ONLINE HEALTH CONSULTATIONS

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Abstract

The diffusion of social media is having profound impacts on the relationship between government and citizens in many areas of government service provision. In the area of healthcare the emergence of new venues of interaction between patients and between patients and doctors is challenging the government-established digital channels for healthcare service provision. In this paper we present a classification scheme with four types of online health forums and use this framework to explore data from the Danish case that illustrates trends of cost, use, and transformation of each of the types of online health forum. Although this paper is a research in progress, we put forward the hypothesis in the paper that the uptake of social media in the health sector is being used as a way for governments and corporate forces to increase control and reinforce legitimacy, rather than empowering citizens. In the conclusion, we suggest venues of future research on this emerging trend.

Keywords: Social Media, Web 2.0, E-Health, E-Government.
1 INTRODUCTION

This research-in-progress (RIP) paper addresses our preliminary findings on the impacts of substitution and complementary use of online health forums on the role and legitimacy of national health portals, given the apparent shift and uptake in online health consultations. In the UK, the National Health Service (NHS) medical director urges general practitioners (GPs) to use Skype for consultations. In an interview with the Times, the director of the NHS, Bruce Keogh said: ‘I am looking at how we can put levers into the system to encourage doctors to do online consultations… Once you have online consultations, it breaks down geographical boundaries. It opens up the spectre of 24/7 access.’ (The Times, August 30, 2011). In the Danish case explored in this paper, government made it mandatory for GPs to offer online consultations by January 1, 2009. Since then, online health consultations have been growing rapidly measured by the number of consultations and the variety of subjects covered in the consultations.

The fact that the overall number of consultations and the costs are escalating could be interpreted as an illustrative example of the productivity paradox (Brynjolfsson, 1993), but we lack longitudinal data and detailed knowledge of the content of the e-consultations to have firm conclusions on this. In our research on the uptake of health consultation we have taken onboard public administration/ e-government literature and have coined a framework for capturing the variance in form with respect to what role the citizen plays (as individual or as part of social media/network) and to whom is paying for the consultation (commercially funded or funded by tax payers).

With the point of departure in a two-by-two matrix framework, we are currently undertaking a comprehensive study of the frequency of consultation in each of the four types of consultations identified (e-consultations, patient forums, health professional forums, and patient focused forums) and developing a methodology for how to explore whether there is substitution or complementary use of the four types and to find out whether there is a potential migration between the four type.

We are hoping to move the research on the uptake of online consultations forward to a more theoretically founded approach on whether the public sector is receding due to the general uptake of social technologies in the health care area and whether citizens are the ones at the steering wheel. The underlying mechanism of change could be viewed as an apparent actor-driven phenomenon, with citizens wearing character masks, as described by Karl Marx in The Eighteenth Brumaire of Louis Bonaparte: “Men make their own history, but they do not make it as they please; they do not make it under self-selected circumstances, but under circumstances existing already, given and transmitted from the past. The tradition of all dead generations weighs like a nightmare on the brains of the living. And just as they seem to be occupied with revolutionizing themselves and things, creating something that did not exist before, precisely in such epochs of revolutionary crisis they anxiously conjure up the spirits of the past to their service, borrowing from them names, battle slogans, and costumes in order to present this new scene in world history in time-honored disguise and borrowed language.“ (Marx, 1852).

The remainder of the paper is structured by first outlining the setting of the e-health study and we then present the framework we have developed in order to study the uptake of social media and e-consultations. We then proceed to outline the preliminary analysis for each of the four e-health forums we are studying and then conclude the paper by pointing to the research that remains to be done within our project.

2 SOCIAL MEDIA LITERATURE AND THE GOVERNMENT SETTING WE ARE EXPLORING

General practitioners (GPs) in the Danish context operate like private companies that are licensed and reimbursed for health consultations with the citizens. What and at what rate the reimbursement is being paid is being negotiated between the GPs and government. Since 2009 online health consultations have been made mandatory to offer to the patients. Thus, each of the GPs has to offer
this service. Since this field is highly regulated and the costs for the consultation is paid by
government, we view this as part of the e-government field. Parallel to the mandatory supply of e-
consultations from the GPs to the patients, the government has established online patient forums
where patient assisted by health care professionals can engage in debates and conversations. This
development could be interpreted as illustrative of what Ho (2002) describes as “a transformation
from the traditional bureaucratic model to the e-government paradigm, which emphasizes the
customer-driven mentality and interorganizational collaboration and coordination” (p. 440). Research,
however, highlights the challenges lying ahead the use of e.g. social media in healthcare: professionals often lack knowledge of the technologies or are hesitant to use social media, due to fear
of ethical and legal consequences (Cain, 2011; Mansfield et al., 2011; Penn, 2012; Sneddon, 2012).
On the other hand, there is growing evidence for the potential of social media to empower citizens as
patients or potential patients (AlGhamdi and Moussa, forthcoming), for instance by creating new
types of interactions with family, providers, and peers (Yamout et al., 2011), and improving patient
welfare and safety, together with serving as an educational tool (Saleh et al., 2012).

An alternative perspective is that the uptake of new technologies is an institutional reaction to a crisis
in the health care sector. This crisis is initiated by the emergence of commercial online consultations
and Web 2.0 forums, where patients seek advice outside government, hence threatening the very
legitimacy of the state. This can be considered as illustrative of the many forms of response to
changes in an environment in order to manage legitimacy (Suchman, 1995). Following this argument,
Web 2.0 technologies in the health care area, on the one hand, provoke stability in government. On
the other hand, the response by government to incorporate these new technologies indicates how
powerful the mechanisms of seeking stability in a Weberian sense are (Weber, 1972). It is appealing
to view Web 2.0 as a technical platform that helps to solve budget crises in the public sector by
making citizens solve problems via collective engagement (Brabham, 2008).

Eurostat's data on the use of the Internet to search for health related information in the population
between 16 and 74 years old indicates an overall growth in Europe's network use for this purpose
during the period 2004-2010. This data indicates that almost every other Dane uses the Internet to
search for health-related information, while the EU-15 countries are only good every third average.
The second interesting observation is the increase throughout the period. While in 2004 the
percentage of individuals who sought information on the web was 27, in 2009 it grew up to 46
percent.

<table>
<thead>
<tr>
<th></th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
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</thead>
<tbody>
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<td>19</td>
<td>24</td>
<td>28</td>
<td>33</td>
<td>34</td>
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<td>38</td>
<td>36</td>
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<td>n.a.</td>
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<td>18</td>
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<td>25</td>
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<td>35</td>
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<td>10</td>
<td>8</td>
<td>12</td>
<td>19</td>
<td>24</td>
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<tr>
<td>Greece</td>
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<td>2</td>
<td>6</td>
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<td>10</td>
<td>15</td>
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<td>14</td>
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<td>21</td>
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<tr>
<td>Luxembourg (Grand-Duché)</td>
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<td>41</td>
<td>27</td>
<td>48</td>
<td>44</td>
<td>54</td>
<td>58</td>
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<tr>
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<td>28</td>
<td>25</td>
<td>32</td>
<td>36</td>
<td>40</td>
</tr>
<tr>
<td>UK</td>
<td>26</td>
<td>25</td>
<td>18</td>
<td>20</td>
<td>26</td>
<td>34</td>
<td>32</td>
</tr>
<tr>
<td>Island</td>
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<td>39</td>
<td>40</td>
<td>44</td>
<td>39</td>
<td>37</td>
<td>42</td>
</tr>
<tr>
<td>Norway</td>
<td>29</td>
<td>26</td>
<td>34</td>
<td>37</td>
<td>41</td>
<td>40</td>
<td>47</td>
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</tbody>
</table>
3 OUR FRAMEWORK TO HELP BOXING-IN THE CURRENT IN THE WATER

We acknowledge that there is a lot of merit into the position that Web 2.0 is mainly used as a piece of jargon, as Tim Berners-Lee expressed in a podcast on the IBM site (http://www.ibm.com/developerworks/podcast/dwi/cm-int082206.txt), and that Web 2.0 might have created what Keen called a cult of amateurs (Keen, 2007). However, we propose a more diversified approach to study the uptake of Web 2.0 in areas where government is involved as organizer, operator, and/or financing the services. We have in our earlier work developed a framework with four types of digital health forums and consultations (Andersen & Medaglia, 2009, 2010):

- **E-consultations**, where neither the content nor the nature of the consultation are changed, but the booking, change, re-booking of appointments, or answering of very specific questions occur online;
- **Patient forums**, where it is patients who set the agenda, but with the possibility of involving health professionals;
- **Health professional forums**, where it is health professionals that provide content and the agenda, and it is public authorities that pay for the operation of the online community;
- **Patient-focused forums**, where health professionals take part in the establishment and running of the community on an equal basis with the patients.

In Table 2 we have displayed the framework with citizen involvement in the health forum as being either individual or as part of an internet-mediated social network (horizontal dimension in the table), and finance and governance models as being either taxpayer-financed or commercially financed (in the vertical dimension). Each of the four categories of online health forums features different characteristics concerning financial impacts, management challenges, types of measurements required, and impacts on citizens.

<table>
<thead>
<tr>
<th>Finance and governance model</th>
<th>Citizen involvement</th>
<th>Social network</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tax payer-financed e-forums</td>
<td>Online one-on-one consultations between patient and general practitioner (type I)</td>
<td>Health forums with involvement of citizens/ patients and assigned health professionals to perform quality assurance of the content (type III)</td>
</tr>
<tr>
<td>Commercially financed e-forums</td>
<td>Patient-led health forums with no or ad hoc involvement of health professional (type II)</td>
<td>Health forums with permanent involvement of health professionals to consult and perform quality assurance of the content (type IV)</td>
</tr>
</tbody>
</table>

Table 2. Online health forums: financial model and citizen involvement

4 ANALYSIS

4.1 Online One-on-one Consultations between Patient and General Practitioner (type I)

Starting from 1 April 2003, Danish GPs have been reimbursed by government for each consultation conducted via email. At the national level, approximately 4,000 private GPs gain most of their income by cost reimbursement from central government. In the past, the strategy has been to have as much as possible of the patient contact to take place with GPs at the local health centers in order to avoid costly treatments at the hospital. In line with this, more diagnoses and follow-up treatments after hospitalization are carried out by GPs. As a result, there has been a shortage of supply of GPs and a
constant problem of finding qualified GPs. E-consultations are thus now seen as a cost saver, but also as a way of re-allocating some of the work from morning telephone consultations to e-mail consultations. Moreover, e-consultations are seen as a more time-independent service in comparison to physical and telephone consultations, given their asynchronous nature.

To stimulate its uptake, the cost reimbursement from the government to GPs for e-consultations (DKK 49.68) is about double that of telephone consultations (DKK 24.84), whereas the cost reimbursement for physical consultations (DKK 126.86) is about four times that of telephone consultations.

The GPs send electronic invoices to the central government in Denmark for the three types of consultations analyzed in this paper. Thus, the GPs are operating as private companies, having the costs for the consultations reimbursed directly by government. Citizens do not need to have a private health insurance coverage plan to use the three types of consultations, nor do they need to pay the GPs directly. In order to access e-consultations, citizens need to be patients that are pre-assigned to the GP. Thus, patients cannot randomly start an e-consultation with any GP, but only with the GP they are assigned to.

In 2007, the cost of consultations amounted to an equivalent of almost 350 million Euro, whereas online consultations amounted to approximately 5 million Euro. Table 3 provides an overview of the number and cost of consultations in 2010. It should be emphasized that the actual total number of consultations is considerably greater than indicated in the table since, for example, home visits and ancillary services outside the public consultation were not included in the table.

<table>
<thead>
<tr>
<th>Proximity</th>
<th>Consultations (N)</th>
<th>Cost of consultations (million DKK)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daytime</td>
<td>19,013,000</td>
<td>2,451,365</td>
</tr>
<tr>
<td>Nighttime</td>
<td>882,000</td>
<td>175,328</td>
</tr>
<tr>
<td>Telephone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daytime</td>
<td>13,747,000</td>
<td>347,033</td>
</tr>
<tr>
<td>Nighttime</td>
<td>1,596,000</td>
<td>157,806</td>
</tr>
<tr>
<td>E-consultations</td>
<td>2,252,000</td>
<td>113,719</td>
</tr>
</tbody>
</table>

Source: Danish Public Health Insurance Statistics, Statistics Denmark

Table 3. Consultations by general practitioners. Proximity, number of consultations and costs of consultations, 2010.

4.2 Patient-led Health Forums with No or Ad Hoc Involvement of Health Professionals (type II)

Social networking media (type II) such as Facebook host a number of health forums in both Danish and other languages. The use of these is often free for patients, but there are also forums where one can buy online consultations, or networks where the social medium is associated with both other patients and medical professionals. The number of users on the commercially-driven media is significantly higher than those of the Health Protection Agency. We are currently monitoring the traffic on these platforms by using key topics comparable to the ones used in the patient forums of the Danish national health portal, sundhed.dk.

4.3 Health Forums with Involvement of Citizens/ Patients and Assigned Health Professionals to Perform Quality Assurance of the Content (type III)

The Danish health portal, Sundhed.dk, is a technical platform aligning communication within the healthcare system, such as appointments with doctors, practice declaration, public health insurance, etc. The portal aims at ensuring consistent patient treatment and at improving the patients’ ability to
take care of their health. We are currently monitoring the traffic on the subject network (number of postings and number of registered users). Table 4 displays the accumulated figures by end of July and end of November 2011. Although we have not completed the data collection for the 12-month span we are covering for this patient forum, data clearly indicates that there is a very modest growth in number of users and number of postings.

<table>
<thead>
<tr>
<th>Patient Network</th>
<th>End of July 2011 (accumulated)</th>
<th>End of November 2011 (accumulated)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of postings</td>
<td>Number of registered users</td>
</tr>
<tr>
<td>Recurrent miscarriages¹</td>
<td>935</td>
<td>388</td>
</tr>
<tr>
<td>Cervical cancer¹</td>
<td>266</td>
<td>362</td>
</tr>
<tr>
<td>Incontinence (children and young patients)</td>
<td>32</td>
<td>83</td>
</tr>
<tr>
<td>Rape and other sexual harassment</td>
<td>29</td>
<td>65</td>
</tr>
<tr>
<td>Lymphoedema</td>
<td>6</td>
<td>22</td>
</tr>
<tr>
<td>Modic changes</td>
<td>32</td>
<td>44</td>
</tr>
<tr>
<td>Overweight</td>
<td>4</td>
<td>12</td>
</tr>
</tbody>
</table>

Table 4. Patient Network at the portal sundhed.dk: number of messages and registered users (July and November 2011)

Note. 1) has existed since 2008, the others since Summer 2011. Source:sundhed.dk

One reason for the modest growth could be that a platform such as Sundhed.dk increasingly faces competition of the privately funded and operated forums, and of patient-driven forums that often use Web 2.0 applications, such as Facebook. These health forums do not aim at minimizing online traffic and interaction, but at maximizing it. The underlying business logic of Web 2.0 applications and that of the majority of private health forums is to reach a high volume of traffic and a high turnover ratio. This stands in direct contrast to the Danish health sector on the web, which similarly deals with the improvement of health, but in a cost-minimization approach. One can well imagine that the massive use of Web 2.0 and of public health forums could ultimately help reduce the information needs of the public sector; however, existing data suggest the opposite.

4.4 Health Forums with Permanent Involvement of Health Professionals to Consult and Perform Quality Assurance of the Content (type IV)

Forums such as NetDoktor (type IV) have a lot more unstructured form of communication and a more user-driven approach when compared to sundhed.dk. We are currently monitoring the traffic in order to generate an overview of the platform use. Our preliminary results are displayed in Figure 4, that shows the number of new topics and the number of responses.
5 PRELIMINARY FINDINGS AND FURTHER RESEARCH

Our research reported in this paper clearly indicates a rapid uptake of new media in the healthcare area, as all four variations of health forums are growing by numbers and in ways not seen before. Our clear proposition is that public administration and information systems communities need to help understand whether citizens are at the steering wheel, driving the involvement and content of the state’s involvement in the health care area, or otherwise.

Scanning the activity on the various health forums, citizens appears to be wearing character masks and playing the online health information game willing while, in parallel to this, governments are trying to find ways to reinforce their power and legitimization (Danziger et al., 1982). The apparent endless consumption of online health data can be interpreted as serving the interest of the dynamics of capitalism, rather than of making people more healthy per se. If such an interpretation is to be further explored, it will require additional research on the nature of the innovation in this type of e-health not being in the technology adoption or use, but in the forces that are at play in masking citizens.

Moreover, the diffusion of different types of online health forums can be also interpreted as evidence that institutions respond to changes, in particular to changes in demand by citizens, in the relationships between citizens and government, and between citizens themselves. These changes suggest future possibilities to explore the driving force behind them. For instance, concerning the changes in demand by citizens, we still need to explore whether the increase of demand of healthcare services is due to an actual worsening of the citizens’ health conditions, or is attributable to changes in the perceptions of citizens’ own health, also as a result of the diffusion of social media use to seek and share information on health conditions.

In our future collection of data we aim at exploring these research directions in more detail. Besides interviews with key players in the four types of health forums, and meta-analysis of medical studies on the use of online consultations, we are monitoring traffic on the four forums, using the patient network forums on Sundhed.dk to structure the data collection.

Data on comparable topics on the four forums can help us furthering the knowledge of the content of the consultations. Besides this, future research could focus on:

- Identification of methodology and types of data/analysis of data that can be applied to capture the frequency of consultations in each of the four ideal types;
- Assessment of substitution and complementary use of the four types of consultations;

Potential impacts for the role and legitimacy of national health portals, given the apparent shift and uptake in online health consultations.
References


