Sustainability of e-health Infrastructures: Inviting Different Domains

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Abstract: Many promising e-health initiatives do not pass the ‘pilot phase’, despite considerable financial investments and tangible end-products. This leads to questions about the long-term sustainability of e-health. Using two case studies, we show how Dutch e-health initiatives develop within a plural environment with different stakeholders and domains (i.e. ‘government and politics’, ‘market’, ‘healthcare professionals’ and ‘civil society’), with multiple, different values and logics. We argue that stimulating sustainability requires being sensitive and giving sufficient attention to all the domains and to include actors from these domains from the beginning of an initiative, even when they have conflicting interests.

Introduction

Many promising e-health innovation initiatives, often intended to stimulate patient empowerment or improve quality, fail to pass the ‘development’, ‘pilot’, or ‘scaling-up’ phases, despite financial investments and tangible end-products. In this paper we use two case studies from the Netherlands to examine the consequences of these failures for long-term sustainability of e-health initiatives and to explore how this emerges in its plural context (i.e. stakeholders, institutions, etc.). We view e-health innovations not as independent entities, but as being mutually shaped in interaction with other objects and/or subjects (Cresswell et al. 2010). The case studies, MijnZorgnet.nl (MZN) and Zorgportaal Rijnmond (ZPR), are portals, each created for the purpose of giving patients more control in
their own care processes through better access to personal health information. In this paper we outline how these portals were initiated and describe developments they have passed. We examine how their potential sustainability was influenced by the interaction between actors, which could be useful for developing sustainable e-health innovations in the future. In order to contextualise these developments, we first give a short explanation of the Dutch context, a framework for analysing these developments and the methods used in researching the portals.

The Dutch Context: Different Domains

In 2006, the Dutch government implemented a new insurance structure as part of a move to a regulated market model for healthcare (Enthoven & van de Ven 2007). Because patient organizations have a longer-standing third-party role next to healthcare insurers and providers in the Netherlands, four domains are relevant when analysing developments in healthcare: ‘government and politics’, ‘market’, ‘healthcare professionals’ and ‘society’ (Putters 2009). Each domain has different values, logics and interests, but they share mutual dependency on one another with regard to money, expertise, support and information. This dependency can lead to uncertainty for entrepreneurs seeking space to develop innovations. This framework is therefore relevant for developments in e-health and we use these four domains to examine the problematic issue of sustainability.

Methods

To analyse the case studies (MZN and ZPR) we used a qualitative approach. We juxtapose these empirical cases because each has the potential to contribute to patient-centred care, yet both struggle to survive. Highlighting examples from both cases provides more insight into influences on the sustainability of an e-health initiative. The examples are taken from data collected via semi-structured interviews (n=18), observations and document analysis. Interview respondents were asked to describe the development of the project and the anticipated future of the portal. The interviews were tape-recorded with permission and transcribed verbatim. Observations were performed over a period of 18-36 months. We observed meetings, colloquia, and the everyday work situation. Documents such as meeting minutes, strategy documents and (PowerPoint) presentations given by employees or other stakeholders were also collected. The research data was analysed using in vivo coding (creating codes using words from the empirical data, without paraphrasing). When a saturation point was reached, codes were clustered into themes that were used to structure the results section below.
Results

MZN and ZPR were both financed by governmental (ministry) and non-governmental parties (such as hospitals). With three-year funding, the project ZPR started in 2009 and was led by a consortium of hospitals, commercial and non-commercial enterprises and a university. ZPR was intended to become a portal for healthcare and wellbeing in the Rotterdam Rijnmond area and to become the information and communication portal of the region. MZN started in 2008 with four-year funding. It was initiated and led by two healthcare professionals wanting to change the current healthcare system into a more patient-centred system.

Given the temporary nature of the funding (three to four years, during which the new initiative must also be developed, launched, etc.), the importance of finding structural financial solutions was self-evident in both initiatives. The prospect of seeking financial independence within a certain time frame by developing a product that fits user needs and a viable business model, however, leads to great uncertainty. Especially in an unstable financial climate and healthcare context, where stakeholders are highly dependent on each other, much depends on how (professional or patient) ideas are translated into ICT applications by technical experts. This uncertainty often leads to a delicate balancing act between activities focused on the ‘here and now’ and efforts to make the initiative sustainable for the future, which makes concrete decision-making more difficult.

Both projects attempted to eliminate the uncertainty. In both cases a new manager was appointed halfway through the project to facilitate the transformation from ‘project’ to ‘business’, with the realization of an appropriate business model. Given the difficulty of demonstrating the effectiveness of the portals in terms of health gains and/or cost reduction (especially given the relatively short length of the pilot), a proxy was used to indicate success. Both projects focused on the number of users. MZN explicitly targeted high user numbers, because “mass is money” (observation 4-Feb-2011), or, as the manager put it: ‘with a large volume, you can apply any business case’ (observation 2-Sep-2011). For ZPR, the prospect of creating an “empty shopping street” was repeatedly uttered in meetings as a scenario of failure. Members of both projects felt that user volumes would play a positive role in negotiations with possible investors or prospective long-term partners, such as healthcare insurers.

Because the business model was seen as an important aspect of a sustainable e-health initiative (without financing, the portals are not viable), the members of the projects paid considerable attention to the market domain of healthcare, with its investors, regulations, product focus and collaboration opportunities (with competitors or investors). Negotiations on the development of both projects were mostly performed with stakeholders from this domain and to a much lesser extent
with political actors and institutions, healthcare professionals and, especially, healthcare users. While patients, for example, were often a subject of discussion, they were rarely invited to participate in developments or negotiations. Although focusing on the market domain was necessary and legitimate, this nonetheless led to elements from the other domains – ‘government and politics’, ‘healthcare professionals’ and ‘society’ (Putters 2009) – being overshadowed in the portals.

Discussion & Conclusion

These case studies show that when trying to establish patient-centred care by means of sustainable ICT infrastructures, the development of the initiative is not only about investors, competitors or the organization and innovation itself (with its structure, technical possibilities, etc.); stimulating sustainability of the e-health initiative also requires being sensitive to and giving sufficient/balanced attention to the four domains in interaction with one another. Including actors from all four domains from the beginning and enabling their participation in various phases of project development, even though they may have conflicting interests, is crucial for dealing with uncertainty and meeting larger goals. Including these actors potentially reduces the uncertainty of meeting users’ needs by incorporating more care-related knowledge in product development early on. Including potential users can also contribute to increasing user numbers earlier, which is assumed to play a significant and positive role in negotiations with possible investors – a thus reducing financial insecurity. Finally, including various actors at different phases is needed to facilitate translation of the product or project such that they co-produce the e-health initiative in question may be more effective in stimulating the sustainability and scaling-up of initiatives over the long term.

References

