A Framework for Designing Inclusive Online Communities

The Role of Inclusive Design for Salutogenesis in Chronic Disease Online Communities

by

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Abstract

Online health communities are often designed for clinical purposes. The user needs within a chronic care community such as cancer are as diverse and complex as their symptom and treatment for latent and long-term effects. While these communities provide the functional needs such as synchronous and asynchronous communication features, they often fail to deliver a functional design that is inclusive of all user needs. The ability to inclusively design online health communities is critical to the overall goal of user satisfaction and in turn the salutogenesis of the participants. The proactive approach to health and wellness can be supported and influenced through online communities however; to ensure the broadest reach is possible to these communities they must be designed to be inclusive. This paper will define a tool by which online health communities can be designed and evaluated for access and participation while ensuring the wide range of human diversity. The Framework for Inclusive Design of Online Communities [FIDOC] will propose the key elements that are necessary to support the notion of well-being in these chronic care communities. FIDOC addresses the process by which designers can iteratively work to achieve inclusion when designing online health communities and offers recommendations for future research.

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Always - Live as if you were to die tomorrow. Learn as if you were to live forever. Mahatma Gandhi

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Glossary of Terms

Accessibility: Extent to which products, systems, services, environments and facilities can be used by people from populations with the widest range of user needs for the widest range of goals in the widest range of contexts of use. [Insert ISO citation]

Online Community: A social network that uses computer support as the basis of interaction and communication among its members instead of face to face. (Andrews, 2002)

Disability: Refers to any short term or long term health loss. (Vos et al., 2012)

Experiential: a method engaged with the value of the experience that the user derives (Baurley, 2004).

Inclusive Design: design that is inclusive of the full range of human diversity with respect to ability, language, culture, gender, age and other forms of human difference (IDRC, n.d.).

Hospitality: Establish and extend the feelings of welcome and comfort creating awareness and affordances for the user community (Huvila, 2009).

Or Hospitality as generous and friendly treatment of visitors and guests (Webster-Merriam, n.d.).

Salutogenesis: A dynamic and flexible approach with the unfaltering focus on an individual's ability and capacity to manage (Lindström & Eriksson, 2005).

Sociability: Is defined as human-to-human interaction supported by technology (Preece, 2001).



1 Context

The World Health Organization reports that as the global aging population continues to grow, and the need to support their overall state of well-being is becoming more critical today than ever before("World Health Organization," n.d.). Aging increases the risk of developing a chronic disease and as of May 2012, one quarter of the Canadian senior population was affected by 2 or more of these conditions (Smith, 2012). At the same time, the literature suggests that on average patients accessing the web for health information are often older. The use of online health services specifically for 65 or older, are increasing faster than any other group (Ferguson, 2000). Research suggests that tools that improve self-management skills can informed decision making and self-advocacy. Online communities encourage information sharing, building a sense of self efficacy as well as architecting a social support system (Winkelman & Choo, 2003). Resulting in those patients who participate in online communities to have a profound feeling of 'being empowered' (van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008).

Data from a 2008 Canadian Survey of Experiences with Primary Care, showed that 86% of seniors (people older than 65 years of age) living with one chronic disease and 51% of those with three or more consider their health to be good, very good or excellent (Development, n.d.). These findings are consistent with what Aaron Antonovsky coined in 1979 as salutogenesis, an approach that calls for a greater emphasis on efforts to enhance health rather than on controlling disease. Since it is nearly impossible to have complete mental and physical well-being, this definition would suggest that most people cannot be healthy (Grady, Laura O. Jadad, 2008). This insight has resulted in a global conversation that yielded a re-conceptualization of health as 'the ability to self-manage and adapt' when facing physical, mental and social challenges (Huber et al., 2011).

The arrival of the Internet enabled patients and their families to have access to information, but also increased their expectation that the information would be richer and more readily accessible. At the same time, with the rise in open social network platforms, healthcare communities and nonprofit found greater opportunities to share information and creating awareness, community support, fundraisers and more. These prompted an increase in patient support groups that have grown organically as a result of access to social tools. These

users are leveraging open social network tools to influence information and knowledge exchange as well as supporting and empowering the notion of well-being in persons similar to them living with chronic illness.

The World Health Organization (The WHO) raise concerns that as the global aging population increases and surpasses the numbers for children, what will be the burden on societies, healthcare and social costs (The WHO, n.d.)? Addressing these burdens provides an opportunity to create an infrastructure that can foster a sense of wellbeing and support those living with chronic disease effectively and inclusively.

1.1 Design Challenge

In the early 1900's support groups emerged as a means by which persons could manage psychological stressors. During the 1950's, group therapy was a common practice among men and women in the armed forces affected by post war psychological stressors. By the 1970's cancer patient support groups were being reported and more recently cancer patients have begun to leverage to use of the internet as a means of support (van Uden-Kraan et al., 2008). These patient online support groups provide the opportunity for information

sharing and support, shared experience and to some degree have provided an opportunity for patient advocacy. Despite these opportunities there still remains a significant barrier to access. The diverse nature and needs of these online health communities such as wealth disparity, access to persons with disabilities, health literacy, the chronically ill, and their caregivers can benefit broadly from an inclusively designed online community (Madara, n.d.).

The barrier to access was addressed in 2004, by the Web 2.0, which shifted how online spaces were used and designed. The intent of this shift in technology was to offer users as well as communities with the necessary tools needed to stimulate collective participation with other online users. For health care applications this meant the evolution of a more participatory approach, which resulted in the practice of Medicine 2.0. The intent of Medicine 2.0 is to facilitate social networking, participation and collaboration, through the use of web based health care services and tools. These tools are intended for consumers, caregivers, patients, researchers and health care professionals.

These online social innovation tools and communities foster dissemination of information while enabling independence and

accountability. The emerging online health community tools create unique opportunities to engage and empower patients to take control of their overall health through apomediation, which is the way users identify trust in the information and services (Eysenbach, 2008). Apomediaries are individuals that help others navigate or locate information and services but are not experts or authorities. This is important as it removes the need to have health care providers at the helm and enables the users who are often patients or family members to help others online. The assistance provided can vary from navigating through an abundance of information available to providing additional credibility, as they have been users themselves at one time or another.

1.2 Intended Users

The effectiveness of these tools does not lie in their functionality but rather in their intent and purpose, and whether the tools can in fact support and shape the community they were designed for. As health care professionals and researchers assess and validate the use of one tool over another to determine which tool aligns best with the intended outcomes, so should designers. It is critical that designers continuously assess and evaluate the community needs, the business

drivers and the intended purpose of the users, in order to ensure if those needs are in fact continuously met.

Currently, business drivers and clinical drivers most often determine the design of the online communities made available to user. This poses an issue, as it does not consider the user needs and or purpose for being online. Designers on the other hand are often considered a service provider to researchers and clinicians and not as a partner in the delivery of the online community. While designers deliver the needs expressed by the business and clinical drivers, this is limiting, as the community needs are equally identified and met. This results in a design produced that does not meet its intended objective. In order to address the user and community needs, it is imperative that the business and clinical drivers as well as the voice of the users inform the design in order to achieve accessible and inclusive tools.

Recognizing that user needs vary and the range of diversity is critical to evolving design practices that are inclusive, suggests that this can contribute to a larger user population. In dispelling the myth of the 'average user' as not so average, but rather diverse proposes a need for design to be as inclusive for as many users as possible to achieve inclusion. Whether it is language, cultural, physical or

psychological diversity and needs that we are considering in our designs (Haddon & Paul, 2001), for designers working in clinical settings it is that much more critical. It is through inclusive design that we enable a broader audience engagement to help influence how people, particularly those with chronic disease see and deal with their issues. This contributes to the promotion of healthy behaviours and increases the communities sense of well-being (To & Editor, 2007).

The ability to influence and empower patients with chronic disease through the continuum of care, in support of their sustained well-being is critical to health care globally. Sense of self-efficacy increases for chronic patients as they have access to tools or programs that promote self-management. These tools have many positive health outcomes, for disability, pain reduction and social functioning (Winkelman & Choo, 2003), if designed inclusively.

1.3 What is Inclusive Design?

For purpose of this paper Inclusive Design can be described as design that is inclusive (*enabling*) of the full range of human diversity with respect to ability, language, culture, gender, age and other forms of human difference (IDRC, n.d.).

It is widely accepted in the Inclusive Design community that a one-size fits all approach is unlikely to provide satisfactory results across the spectrum of the population. Individuals with varied ages, cultures, genders and abilities desire products that speak to them, ultimately enabling not excluding them (Bichard, Coleman, & Langdon, n.d.). The intent of inclusive design is to provide access to as many users as possible thereby, identifying the diverse user needs of a community plays a significant role in establishing the framework of inclusion.

The Engineering Design Centre in Cambridge England has created an inclusive design tool kit, which reflects on the what, why, and how of inclusive design. Their underlying principle consists of three key elements, user centred, population aware and business focused (Cambridge, 2013). While the design process checklist they provide is intended to determine or ensure an inclusive design, it does not recognize the unique needs of chronic online health communities, thereby failing to fully achieve inclusion. The value of these tools in health care settings necessitates that they be designed inclusively by acknowledging the diversity in these patients. In order to achieve this inclusion, designers should ensure that these tools meet three requirements: sociability, hospitality and equability.

1.4 The Design Objective

The purpose of this research is to design an inclusive framework for online health communities, which can be applied to assess the needs and evaluate a chronic disease community. The research identifies that; sociability, hospitality and equability can inform inclusive design of on line health communities and influence the feeling of well-being within chronic disease settings, which in turn helps the community to achieve salutogenesis. Figure 1.0 illustrates the research framework.

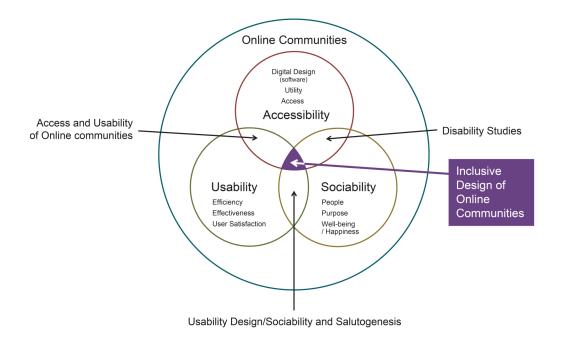


Figure 1. Research Framework

INCLUSIVE DESIGN OF ONLINE COMMUNITIES

2 Inclusive Design of Online Communities

To date, online health community designs have not been inclusive thereby limiting the ability for a wider population to participate and benefit. This further reduces the ability for self-efficacy and salutogenesis (Teo, Chan, Wei, & Zhang, 2003). When designers are considering inclusion for online health community in Information Communication Technology (ICT) the framework proposes that priority should be given to equability, sociability and hospitality. Sociability refers to the user needs and the intended purpose and expected outcomes of online communities. Hospitality refers to the member's ability to feel at ease and welcomed throughout their interaction in these communities. Equability refers to the adaptability and prediction of the online community to meet the user needs.

2.1 Benefits of Online Communities in Health Care

Online communities can be defined by a social network that uses computer support as the basis of interaction and communication among its members instead of face to face (Andrews, 2002). In recent years, online communities have enabled users to build personal profiles as active members and have provided the option for

anonymity. This has contributed to participants sharing personal health and relationship problems more freely (Pfeil, Svangstu, Ang, & Zaphiris, 2011). It is through these online health communities that people living with chronic disease are enabled to engage in social networking principles where connections between people, empowers and facilitates new levels of patient participation(Eysenbach, 2008).

In the past the key determinants of an online community's success have been defined as *sociability* and *usability*. According to de Souza and Preece (2004), sociability includes obvious measures, such as number of participants; number of messages posted, satisfaction of members, and less obvious is the reciprocity of on topic discussions and trustworthiness. Where, usability of online communities is considered to focus on errors, productivity and user satisfaction ultimately reflecting the functional elements of an online community. While these are measures of existing communities, de Souza and Preece do not address those users who want to participate but are unable to due to the inaccessible design of the online communities. While sociability is a critical element of design for adoption, the focus appears to be on the functional or rather utilitarian aspects, and not the experiential. The experiential constituents are key to welcoming and influencing the user experience. Unlike de Souza and Preece, this

framework identifies the need for *hospitality* as a fundamental variable that contributes to inclusion, as it takes into consideration member's ability to feel at ease and welcomed throughout their interaction in these communities.

Despite the lack of inclusive design in online communities, they continue to thrive, often unsupported and organically nurtured. According to Stellefson et al (2013), participants feel greater selfefficacy for managing their disease(s) and benefit from communicating with health care providers and/or website moderators to receive feedback and social support. Patients with latent or long term effects of cancer treatment such as fatigue, anxiety, depression or sleep problems from radiation treatment or nausea/vomiting, swelling, diarrhea etc., (CCS, 2013), research suggests, that they often look for and become experts in the experiential aspects of living with that disease. They achieve explicit knowledge over periods of time through external sources of information and communities of practice (Winkelman & Choo, 2003). The empowerment of information exchange influences these community members to the extent where they are able to form a level of proficiency amongst their community. The opportunity to reach a broader population through the development of an inclusively designed online community can further contribute to self-efficacy and salutogenesis.

Self-help groups have proven effective and efficient in providing support (Weinert, 2000). The prospect of furthering information and knowledge transfer can have a profound impact to communities and its members. In this regard, through establishing social support and positive influence of disease management to an online community it is possible that we can extend an individual's sense of positive health or salutogenesis. If salutogenesis is a personal way of being, thinking and feeling then it suggests that despite living with chronic and often debilitating illness, most people self-rate their health as excellent to very good (Cott, Gignac, & Badley, 1999). In acknowledging that online communities foster independent and social knowledge transfer for community members, it behooves us to consider that online *inclusive* communities can be extended to a larger population and as such influence more individual's salutogenesis.

2.2 Online Communities and Accessibility

The increased use of Internet and the introduction of more social tools and open communities, offers new ways for patients and families to interact. Furthermore, there has been a significant effort to

focus on usability in ICT in the last decade; where usability is determined by ease of use and intuitiveness for individuals to learn the use and interact with others (Preece, 2001). Preece (2001) states that *sociability* is concerned with social interactions and *usability* is focused on the human interaction with the interface. Additionally, Preece (2001) suggests that over time designs need to be revised. However, in her description of 'human interaction', Preece (2001), does not acknowledge the wide range of diverse user needs and how these needs cannot simply be met through usability best practices.

ICT that is accessible and that enables individuals with chronic disease to participate in their communities is not necessarily usable or inclusive. Many of these online communities do not consider the extended and diverse needs such as language barriers, information processing limitations due to treatments or medicines, which limit the extent that members of a community can participate. Research documents that individuals with disabilities continue the use ICT to enhance their participation in communities despite these barriers ("Working for Barrier Removal in the ICT Area Creating a More Accessible and Inclusive Canada - The Information Society An International Journal," n.d.). Albeit there is increased awareness and

laws that govern accessibility and compliance for communication technology standards, they do not ensure that all design is inclusive.

Barriers for online access and use exists, and for persons with disabilities this means having access to reduced functionality of sites (Lazar, Jonathan; Jaeger, 2011). Lazar et al (2011) states, that the barriers to access in fact vary by type and the extent of the disability, where disability is defined by any short term or longer term health loss (Vos et al., 2012). This results in a significant number of people that are being left out. In Canada we have 14.4% of the population living with some form of disability, where adults between he ages of 15 to 64 account for 32.3% of the population and those 65 and over account for 91.3% of the population. While mobility and agility rank first and second in the types of common disabilities the third indicator is pain. Through creating inclusively designed online health communities, this gap can be reduced.

Consider accessibility as defined by the International Organization for Standardization [ISO] as:

Extent to which products, systems, services, environments and facilities can be used by people from populations with the widest range of user

needs for the widest range of goals in the widest range of contexts of use.

The definition is design practice based on principles that extends the accountability of design to serve all. Where design can reach the number of potential users by reducing performance limitations in a product, building or service (Klaus-Peter Wegge, 2010). However, accessibility and accessible design as currently defined warrant further exploration, when designing online health communities. These definitions are limiting for inclusive designers of ICT, because the notion of access for all and to everything does not identify the qualitative side necessary for design to meet inclusion. These definitions do take into consideration the intended and expected user If ICT designers do not recognize and take the experience. experiential elements into consider they limit the ability of design to influence experience. Furthermore, while function plays a significant role in ICT design if the experiential elements are not considered, it too fails to deliver and inclusive product. The designer who is cognizant of inclusion is likely to ensure that beyond the core function, the design engages the user and enables the notion of hospitality to prevail in the design that supports the social context of these online communities.

Adoption of usability to improve the use of ICT in healthcare is quite common and the use of participatory design is essentially adopted across most healthcare settings. Design and experience can affect the trust a user has with ICT (Nielsen, n.d.). The evolution to inclusive design across the spectrum in healthcare to improve trust and ensure access for all has not yet reached a tipping point. Chronic disease communities whose needs are substantial and varying in disabilities would benefit from inclusive design. This in turn can support and influence the notion of salutogenesis. Inclusive design of an online community beyond the need for accessible design requires both *hospitality* and *sociability*.

An online community that does not cater to its user community may fail to provide the appropriate atmosphere for its users. When designing inclusively a designer must consider *hospitality* as a key property. In *hospitality* we establish and extend the feeling of welcome and comfort creating awareness and affordances for the user community (Huvila, 2009). *Hospitality* can be considered a kindness in welcoming strangers or guests or as offering or affording welcome and entertainment to strangers, both of which are simple and behaviorally focused (One, 2007). To extend this feature to the online community, designers we must consider what the needs and desired outcomes of the users are and mirror those in the design.

2.3 The Gap of the OCF

Understanding the purpose and the user needs can further support the notion of hospitality and strengthen the social aspects of an online community. Preece (2001) describes *sociability* as a key element in her online community framework [OCF]. Where the OFC's focus is on analyzing the system designs and how they influence sociability. The critical gap is in assuming that *sociability* and *usability* will be sufficient enough to ensure access for all. The role of the designer is to influence both *sociability* and *usability* and ensure inclusion in the software design. This can only be achieved if the user needs are addressed both utilitarian and experientially. In this regard, inclusion can be achieved through acknowledging the defined needs of the business and user community and how the design reflects these elements.

According to the OCF an online community should be defined as the people, purpose, policies and software which together form the basis of the online community framework (Preece, 2001). The premise of the OCF research is in recognizing the social components before designing the software and that the success of a community is based on the sociability and usability as well as function of the software. While usability is recognized as an element it is assumed as addressing

form and function of the resulting software. The fundamental gap in the OCF is the idea that usability can police the development of community software enough to be inclusive of the diverse needs of the community. Furthermore, that the sociability components will enable the designers to create a community that is fulfills the expectations of the people and their purpose. de Souza & Preece (2004) recognize that the extent of an individual's experience of usability comes from the interaction with the computer infrastructure as well as the particular design of the online community's software. However, that is only one part of the usability experience in that in fact the design of software extends beyond the technical elements as depicted in Figure 2 The GAP. Design software must encompass inclusive design principles if it is to be usable and accessible, thereby reducing limitations and contributing to user satisfaction and ultimately empowerment of the user.

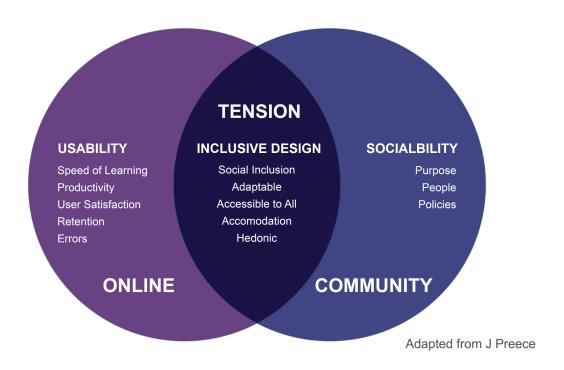


Figure 2 The GAP

If the barriers of the users experience are not addressed, then we continue to exclude the diversity of users. If designers understand the users values and barriers that are experienced, then the designer limits the ability to create sociability in the community. Moreover, to ensure that online communities are designed inclusively, usability and accessibility must be present to meet *equability*. Consequently, to create inclusive design that meets the users needs and purpose, create an atmosphere of ease and welcome as well as be adaptable and predictable, three key elements are necessary. The FIDOC

recognizes the three key elements of sociability, hospitality and equability are key contributors to inclusion as depicted in Figure 2.



Figure 3. Three Key Elements of the FIDOC Framework

FRAMEWORK FOR INCLUSIVE DESIGN OF ONLINE COMMUNITIES

3 Framework for Inclusive Design of Online Communities [FIDOC]

Research suggests that older people with varying capabilities benefit from the use of technology that in turn can lead to a better quality of life. It is equally important that users are empowered by technology to the greatest extent, which will ultimately promote and enable independence. Recognizing how design can meet the functional demands while at the same time addressing lifestyle can in turn lead to a greater sense of individual well-being. This is essential when designing online health communities for chronic disease patients (Sze & Lim, 2010).

The needs of online community members differ from one chronic disease community to the next and there is no one size fits all model, for all online health communities. However, by introducing the three factors of *sociability*, *hospitality* and equability it enables designers to evaluate the needs, determine the function and assess the desired outcome. In addition, recognizing that subtle changes to each community will need to be monitored and the design process should allow for iterative changes as needed. **Sociability**, **hospitality** and

equability provide the basis to ensure designers of online health communities can deliver inclusion as shown in figure 3.

The goal of the FIDOC is to provide tools that designers can work with to recognize and define the wide range of diversity and needs, in order to strive for successful inclusion and as an extension, salutogenesis. Each factor is defined by two properties. *Sociability* is about people and purpose, *Hospitality* is about hedonic and accommodate, and *Equability* is about accessibility and usability (see figure 3). These properties when understood and applied to design help achieve the factors. This contributes to inclusive design, thereby enhancing salutogenesis, further reducing social isolation for online chronic disease community members. In other words the benefits of designing an inclusive online community are extended beyond the technical scope.

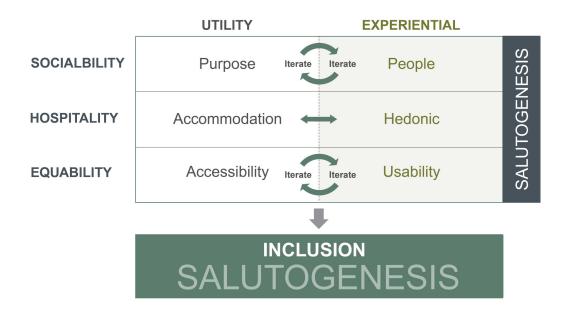


Figure 4. Framework for Inclusive Design of Online Communities

3.1 Sociability

Sociability as defined by (Preece, 2001) is concerned with software development, policies and practices that influence social interaction. While this definition provides considerable insight into quantifiable properties of sociability it does not allow for the qualitative nature required of sociability. Rather, it is suggested that sociability is a result of social policies that support a community's purpose. Whereas, (Kreijns & Kirschner, 2002) define sociability, as applied to computer-supported collaborative learning [CSCL], which aligns with the social characteristics of inclusion. A system's sociability for a

collaborative environment is the extent to which the environment is able to give rise to such a social space. This provides a basis for both the social design of systems as well as the social presence. Social presence within the context of communication media is the degree to which a communication partner appears to be physically real to the one communicating. This reinforces the qualitative outcome of sociability, in that a system supports and influences the user participation and ultimately user satisfaction.

As designers work to achieve harmony between systems, how the user interacts with the design as well as, use the sociable tools - sociability should be characterized by the degree in which the design of the environment is able to support and influence a social space. Moreover, where the people, and their purpose define the social outcomes of an online community.

- People: the user needs, user expectations, anticipated interactions and expected interactions and flexibility to adapt to needs
- Purpose: the intended and expected outcomes, needs and information, support and

Designers understanding of the purpose and the people influence the initial and potential ongoing sociability of an online community. As a community matures and expectations evolve it is critical that the design is flexible enough to meet the needs of the community and be able to evolve. Also, that the flexibility of social interaction is placed in the hands of the community members.

Positive health outcomes have been associated with giving users flexible tools that allow them better control and choice resulting in greater satisfaction and sustained engagement. As Stellefson et al., (2013) points out, (Stellefson et al., 2013) there is a need for a greater understanding of the barriers that prevent continuous access for chronic disease self-management tools. He states that health care policy makers would benefit from identifying the way older adults are using technologies and recognizing patients as experts in their own disease process management. This suggests that online tools can influence and endorse an individual's well-being.

(White & Dorman, 2001) White & Dorman (2001) propose that people with care giving responsibilities also benefit from online communities. They are able to participate including those with geographic and transportation barriers. Furthermore, they suggest that people with mobility, speech and hearing disabilities are also

supported through an online community environment. While this may be true to some degree, there is a significant gap due to the limitations of the design, where sociability is one of the factors that need to be considered. Sociability can contribute to identifying part of the barriers to participation, individual and functional needs along with their purpose and support salutogenesis. While users are able to access information and communicate with others, these designs are utilitarian in that they meet the goals expected, without the experiential presence.

3.2 Hospitality

The hospitality factor addresses how software design should be able to prepare and cope, both efficiently and respectfully for the end user. When considering the role of designers, hospitality encourages us to consider the needs and differences in users as well as prepare the design of these online communities to take into consideration the individual needs of the users. Where sociability speaks to the individual needs and requirements of the online environment, hospitality urges the designer to consider the individuals, the whole and the unknown (Huvila, 2009). In doing so, designers need to prepare for those individuals who have not been considered and who will need to use the system - the un-definable group. Hospitality

serves as the pulse, ensuring designers create affordances and manage constraints accordingly, to support and influence a better user experience. The key properties of hospitality are in the accommodation and hedonic approach to the design. Where accommodation and hedonic define the hospitality of an online community.

- Accommodation: affordances in technology, language and interface, recognized diversity of needs for participation and engagement
- Hedonic: where users find the site welcoming, managed and alive, to the extent that needs are anticipated and satisfaction is predictable

(Huang, 2003) Huang (2003) states, users view websites as a bundle of attributes, looking to technology to satisfy technology and user oriented attributes. The technology delivers on structural elements such as the interactive modalities and user oriented attributes, which are the qualitative experiences to these structural properties; for example, navigability and ease of use. Even though this design element is structural in nature, it addresses the qualitative measure of an individual users experience with that tool. The notion is that an individual's satisfaction can be measured through the utility or usefulness of the technologies, and that this measure is an extension

of their well-being (Nordbakke & Schwanen, 2014). This property within the *hospitality* element is referred to as hedonic, in that users evaluation of a website beyond the structural or utilitarian aspect is to be assessed by the amount of pleasure they anticipate or experience from the site. Huang (2003) suggests there are three characteristics that can be used to describe the hedonic experience: complexity, novelty and interactivity. For the purpose of this research our focus centres on novelty and interactivity, as the concept of complexity is not related to the experience of the design. Novelty is the experience of the unexpected, the renewal of the content or the new ways technology is used to inform or provide context. Where, interactivity is the extent to which the site enables user interaction with the site. While the hedonic aspect is essential it does not address the utility component of the hospitality factor.

In the hospitality industry, accommodation is utilitarian in that it supports the individuals experience as a service. For the purposes of the FIDOC accommodation is defined as a set of features that provides comfort to users of on online communities. It is by layering accommodation onto the structural component of design that the utilitarian attributes can serve to eliminate barriers and further extend the hedonic experience to a larger group. This in turn results in

community members achieving a greater sense of belonging, which further influences the notion of salutogenesis amongst its members.

3.3 Equability

Usability is defined as "the effectiveness, efficiency and satisfaction with which 'specified' users achieve specified goals in particular environments" (9241, n.d.). The ISO defines accessibility, in terms of the range of scope as products, systems, services, environments and facilities, used by people with the widest range of user needs and goals. Usability is more about the utilitarian needs of inclusion and does not consider 'satisfaction' or rather qualitative measures by which ICTs can be made more accessible. The benefits of extending usability, is to encompass the experiential aspect of design that facilitates the influence that these communities have on the salutogenesis of their users.

Accessibility and usability are often used interchangeably despite their very clear and distinct definitions. *Equability* presents accessibility and usability as both uniform in operation and effect. The World Wide Web Consortium [W3C] recognizes that accessibility is often usability only where the issues being managed are cognitive or visual representations either in colour or design. In fact, usability alone

does not always meet accessibility, in that usability for one group may mean inaccessibility for another. The W3C recommend that usability should be integrated into the accessibility process (9241, n.d.).

- Accessibility: user needs are predicted and the site design and technology are responsive and adaptable to the user needs
- Usability: where the flow of information, type of information and tools enable the user in an easy and consistent

Online communities are multifaceted and extend the reach of the community by supporting a wide range of perspectives and experiences, as information sharing and enabling of communication. People with chronic diseases such as cancer, heart disease and diabetes can be active, contributing members of their society (Liu, 2004). Accessibility and usability within these communities as it pertains to the functional design is critical if designers specifically work to achieve inclusively designed sites. The benefits of information and communication technologies [ICT] would have far greater reach. In fact, if ICT were designed to be accessible so that people with disabilities could participate and experience the benefits of

socialization, information gathering, sharing and ultimately social inclusion would be achieved.

In ensuring designers have the necessary tools to make the online communities inclusive; the framework must embrace accessibility and usability as distinct properties but not exclusive of one another toward the intended goal. The ISO states the usability is predominately form and function, however, the FIDOC proposes that while form and function are both critical to the overall user experience it is further enhanced by the notion of satisfaction. The user is recognized beyond the utilitarian function through accepting the experiential feature, going so far as call out 'comfort' as a key descriptor of satisfaction. The idea of pleasure and comfort is what distinguishes usability and is further complimented by the use of hedonic in hospitality.

3.4 Inclusion and Salutogenesis

The purpose of FIDOC is to provide tools for designers to imagine and deliver inclusive online health communities that enhance the individual's well-being. Patients in chronic disease settings deal with varied health and wellness challenges. Supporting patients through these communities re-enforces self-management that is

recognized as being integral to improved patient outcomes (Coleman & Newton, 2005). Self-management through the use of online communities is recognized as a critical motivator in achieving positive health outcomes (Kamal, Fels, & Ho, 2010). The positive influence of online health communities in establishing self-efficacy re-enforces the need to ensure the design of these communities as inclusive.

The concept of inclusion primarily extends the core benefits to a larger community of potential users. By eliminating barriers that prevent users to participate we widen the reach of wellness. Technologies continue to change at alarming rates in some industries. While users have come to expect newer better tools for their business and personal use, consistently looking for a 'silver bullet' fix-all. FIDOC proposes a framework that will compliment this rapid change. Inclusive Design is about making sure the products and services work irrespective of an individual's age, ability, cultural, and educational background. Salutogenesis is the experiential expression of inclusive design for online health communities. We live in an era where people are deeply engaged in their health as they search for answers. The successful growth of online communities shows a culture shift where people trust other people with similar issues and having conversations in groups about and with one another. By including and empowering

all users we set the stage for individuals with chronic disease to reach a salutogenic, a homeostasis of well-being. The application of FIDOC to an online health community would satisfy inclusion criteria and through this achieve salutogenesis.

ELEMENTS OF THE FRAMEWORK

4 Elements of the Framework

The purpose of FIDOC is to help designers understand the factors needed to design an inclusive and thereby salutogenic online health community. Recognizing that the factors and the relationship between them harmoniously achieve inclusion and salutogenesis if applied as designed. The inclusive design segment as shown in figure 4, demonstrates how the three elements; hospitality, sociability, equability and user, operate with one another to achieve inclusion. Each factor works with the defined user needs to achieve inclusion through the distinct features and understanding of the interchangeable elements. Sociability, hospitality and equability provide the requirements motivation for designing inclusive online and communities.

has Inclusive Design has has Inclusive Design has Hospitality Creates Understanding Share Welcoming Welcoming Access / Ease of Use

The Relationship of Inclusive Design Segment

Figure 5. The Relationship of the Inclusive Design Segment

User Needs

4.1 Designers Checklist

FIDOC proposes a checklist for designers to use as a primary tool for inclusive design of an online health community. The checklist is broken down by each element as part of the design process to achieve inclusion. It enables designers to evaluate the specific factors required to design an inclusive online community. The checklist reflects sociability, hospitality and equability intended input through a series of questions. These questions are meant to provide the necessary requirements to achieve inclusion.

4.1.1 Sociability Checklist

The two properties *purpose* and *people* define *sociability*, where each of these establishes the necessary requirements for designers to identify needs of the online community (see Appendix A, Table 1). The questions are to be used to establish the users and business requirements for the community. These questions will provide the designer with the defined expectation of its user community and the end goal of the health professional leading the design. It will address the functionality and the communication goals.

4.1.2 Hospitality Checklist

The two properties accommodation and hedonic define hospitality which complement and support the concept of welcoming (see Appendix A, Table 1). The questions for the hospitality checklist determine the enriched scope of function that the user community could benefit from. The questions under the hospitality checklist address the belief that through the accommodation of needs and identification and delivery of comfort, that inclusion is further extended in the community of users.

4.1.3 Equability Checklist

The two properties *accommodation* and *usability* define *Equability*, where the design must be both accessible and usable (see Appendix A, Table 1). These properties, which are complementary but not exclusive, must be present to deliver equability. The questions are adapted from W3C's recommendations for accessibility and usability (W3C, n.d.-a)(W3C, n.d.-b).

4.2 User Survey

The purpose of the user survey is to compliment the designer checklist throughout the iterative design process to validate the effectiveness of FIDOC, in meeting the needs of the community (see Appendix D). The intent is to enable the users to iteratively assess if the site is designed inclusively to meet their needs and most importantly to ensure that through the iteration the user community is engaged and their everchanging needs are met.

The survey is broken down into the following sections, Understanding Expectations, Recognizing Needs, Enabling Functions. The questions in the survey are derived from the FIDOC Designer Checklist to validate the inclusive design frameworks success. These questions can and should be modified according to the answers to the

checklist that have been documented by the designer each time it is applied, to articulate the specific user goals, needs and function of the desired community.

THE PROCESS OF DESIGN USING FIDOC

5 The Process of Design Using FIDOC

In healthcare the rational for the development of online health communities is related to clinical research opportunities or cost effective ways to distribute the burden of healthcare in the system and support patient self-efficacy. Given the intention is to empower patients - the design process should not be considered as an afterthought for these online health communities. Business drivers do not readily consider the user needs but rather define the tools that the users may need to achieve what the community is set to support. This is a critical flaw in that the designs of these communities are then designed for the system and not the user. There should be a joint driver defined by the business needs and expected health outcomes as well as the user needs along with the guidance of a digital designer.

A collaborative approach to design will not take away from the business drivers if participatory design principles are used at the forefront of the process. These principles bring all the critical stakeholders together to ensure that everyone has a voice. In healthcare participatory research is carried out with and by the community rather than on them. This must be extended to the development of digital tools for any user community. Whether the

stakeholders, are the business owners, researchers or hospital administrators - designers, developers and community members must be equally engaged in defining the scope of work and function. This is necessary if we are to achieve inclusion and thereby reach the widest audience or user community.

FIDOC helps to define the categories and further highlights the need for utilitarian and experiential elements to be equally acknowledged for inclusion and or salutogenesis. The design process should be to meet with each stakeholder separately and collectively forming a committee by which all stages of the design processes are reviewed and vetted to ensure the application of FIDOC meets its goal of inclusion.

What a healthcare administrator believes is required to deliver online synchronous and asynchronous chats for example, may differ from that of the user community. For instance a business owner may not feel the need to allow users to personalize their profiles with pictures and may see this as excessive. However, the community of users may have a different lens and deem that the use of profiles allows them to feel more engaged within the community and to some degree more 'real'. Assuming users feel more comfort by having the freedom of posting a profile picture and in so doing, it may encourage

more participation in the forums and discussions - the business logic or assumed low priority of this feature is quickly propelled into a high priority. Particularly if this feature encourages other users to participate and or further the dialogue in these communities. In essence, working to be inclusive of not just the design outcomes but inclusive of the needs of each stakeholder group.

Financial limitations frequently present barriers to delivering fully fleshed out online communities. The financial restrictions often result in phased work releases of features/tools. FIDOC will allow both the business and the user to assess and prioritize based on an evaluation of what must be delivered to ensure the success of the community. This has been a decision often made by the business, whether this is the health administrators or health researchers or a combination of both. Ensuring the voice of the community is present for these decisions will only serve to deliver a successful and inclusive online community.

The application of FIDOC through a participatory design process will allow the end product to serve a wider audience for a greater good. Allowing the designer to help document and voice the needs and expectations of the various stakeholders in an iterative process, which

will allow for the delivery in the form of tools to provide an online inclusive community.

FIDOC serves as a tool to analyze the distinct needs of a diverse stakeholder group. It is intended to be a thorough tool for assessing the business and user community needs. It accounts not only for system function, but values the experiential aspects of community that the technology can facilitate in delivering. The value is in the tools it provides the designers to assess and document the needs in an iterative process that can be further validated by the user community. It takes into account the diversity of needs of the users and the intended outcomes of the business to ensure a barrier free environment where a larger community can engage and benefit from.

CONCLUSION

6 Conclusion

In Canada 14.4% of the population live with disability and with an aging population, this statistic is projected to double in the next two decades (Hadi, Salah, Hyun-Duck, 2014). The types of disabilities vary from physical, emotional and cognitive and they can be visible and invisible. In the scope of design and development work, accessibility is often perceived as a 'nice to have' and not a 'need to have'. If we are to reach the broadest audience then designing inclusively which encompasses accessibility is the right thing to do.

Accessibility and usability are key design principles for ICT. Where, usability is linked to increased productivity, reduced errors, reduced need for system support and training, and overall acceptance (Maguire, 2001). While accessibility is seen as the access window of opportunity in ICT for people with disabilities, in that it strives to reduce or eliminate many of the disabling ICT barriers that prevent the disability community from engaging with, learning, working and entertainment etc. (D'Aubin, 2007). Although these principles are becoming more commonly accepted as principles of design, and while they are not new concepts - they are often observed as rules to design 'by' not 'with'. Designers to date have not been adopted these

principles to ensure accessibility is part of their initial discussion or part of their design process.

FIDOC serves to provide designers with defined tools that can facilitate how they envision and ultimately deliver on these inclusive online health communities. The benefit of providing patients with chronic disease access to information that supports their selfmanagement and motivates self-efficacy is imperative to positive health outcomes. In 2010 there were an estimated 524 million people aged 65 or older by 2050 this number is expected to triple to about 1.5 billion (The WHO, n.d.). With the rise in those aged 65 or older we will see an increased burden on our healthcare systems globally. It is a pivotal time as the increased use of the Internet and the everchanging technology landscape is making access to sources and information more available. Canadian statistics show that in 2009 over 69% of individuals online were searching for medical or health related information. At the same time 1 in 3 Canadian's over the age of 65 are accessing the internet from home (Canada, 2010). Suggesting that perhaps smart technologies, including smart phone adoption and use, drives the urgency and sets the expectations of users.

Research indicates that online social tools support and transform care either through practical or experiential information sharing

between patients. These online environments provide a convenient method for access and support. Such that, online communities are recognized as supporting the social points of patient interaction to the degree that it reduces feelings of isolation and ambiguity, thus, enabling patients to become better informed about their condition (Bender, O'Grady, & Jadad, 2008).

Globally we are approaching an apex for healthcare where technology and online tools can facilitate and advance change in support of salutogenesis for those living with chronic diseases. As the global aging population continues to increase, so does the use of the Internet within that age group. While the removal of technology and information barriers, work in favour of inclusion and access for all. However, the increased aging population brings with it an increased burden of chronic disease and as such recognition and removal of barriers in ICT is critical to ensuring the widest access and benefit of the online communities.

In addition to using the framework as it has been described there is opportunity for FIDOC to be further evaluated. A recommendation can be to design an online health community using the FIDOC checklist (such as outlined in the example in Appendix A) using a participatory and iterative approach and evaluate for gaps that

can be addressed in future iterations of the framework. Other research areas of interest may be to engage researchers to include FIDOC as the basis of their design for a variety of health communities to determine success and performance of FIDOC. While this framework is able to evolve and contribute to further research, it has incorporated three elements; sociability, hospitality, equability that can inform inclusive design of online health communities today.

This research proposes the adoption of FIDOC by designers will create an environment for users to feel welcomed, supported and accommodated. Allowing those users who know more to lead those who know less and as it does the role of social scaffolding will enable these members to keep rising to higher levels of knowledge and skill. Designing inclusively enhances the users experience and limits the frustration as well as the isolation. Patients with chronic conditions find the common challenges that other users express in these online communities as endorsement of their personal experience/challenges. The relative anonymity of the users helps them share sensitive information about their health, financial and personal problems. Older populations are participating more and more in these online health communities, with benefits being; reduced social isolation, increased

self-confidence and as a result improved quality of life. The extent to which FIDOC can further strengthen and extend the reach of these outcomes is the point where inclusion becomes a supplement for salutogenesis.

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APPENDIXIES

8 APPENDIX

8.1 Appendix A FIDOC Designer Checklist

Sociability checklist establishes the necessary requirements for designers to identify needs of the online community, establishing the users requirements for the community. **Hospitality** complements and supports the concept of welcoming, addressing the understanding that accommodation of needs as well as the identification and delivery of comfort further deliver inclusion. **Equability** identifies how the design can be created to deliver accessibility and usability to meet the criteria for inclusion.

Table 1 FIDOC Designer Checklist

Framewo Checklist		usive Design of Online Communities	It is recommended that Notes must be taken for each question and for each iterative design phase
Initial (I) Iterative		SOCIABLITY - PURPOSE	NOTES
I	I II 1. What is the intended use of the space?		

I	II	2. Why would users need to revisit?	
I	II	3. What is the goal of the community owner?	
I	II	4. What control do users have over their profiles?	
I	II	5. Can user profiles be private, public or combination of?	
I	II	6. Is there a community manager?	
I	II	7. What role does a community manager play?	
I	II	8. Is the site intended to be web based and mobile friendly?	
I	II	9. What must exist for this site to meet the needs of the community?	
Initial (I Iterative		SOCIABLITY - PEOPLE	NOTES
I	II	10. Describe your audience?	
I	II	11. What are their needs/goals in relation to this online community? Describe	

I	II	12. How will the needs be addressed? Describe	
I	II	13. Why do they or would they visit the site more than once? For what purpose?	
I	II	14. What languages do your community member's need supported?	
I	II	15. How will community members be encouraged to participate in discussions?	
I	II	16. Will community members be allowed to create their own discussions?	
I	II	17. Will users be allowed to personalize their profiles e.g. pictures, timelines	
I	II	18. Will users be crowdsource information into library(s) resources for their peers? I.e. list of books, articles, music etc.	
I	II	19. What types of social tools i.e. blogs, one to one or one to many chats, discussion threads, libraries (audio, video, docs), webcasts; be made available to the user community.	
Initial (I Iterative		HOSPITALITY - ACCOMODATION	NOTES
I	II	20. Does the site offer more than one language?	

I	II	21. Does the site provide alternative formats? Describe format needs.	
I	II	22. Will the site provide easy access to help/support materials	
I	II	23. Are users expected to manage their own identity and online presence?	
I	II	24. Is the site intended to prepare and inform the users of what support is available?	
I	II	25. Is the site intended to offer users various predetermined options for navigation or access to information?	
I	II	26. Will the site accept user feedback and act on the feedback to ensure it meets the needs of the user community?	
Initial (I Iterative		HOSPITALITY - HEDONIC	NOTES
I	II	27. What is the sites governance model? Restrictions and limitations, reviews and policies? Describe	
I	II	28. Describe how the site will be managed? I.e. Community manager(s) made up of expert users, clinical support models?	
I	II	29. How timely and responsive are community managers expected to interact with members and address needs and questions? Describe	

I	II	30. What control do users have over their profiles?	
I	II	31. Can user profiles be private, public or combination of?	
I	II	32. Is there a community manager?	
I	II	33. What role does a community manager play?	
I	II	34. Is the site intended to be web based and mobile friendly?	
I	II	35. What must exist for this site to meet the needs of the community?	
Initial (I) Iterative		EQUABILITY - ACCESSIBILITY	NOTES
Ι	II	ac will the site offers to the site of a second	
		36. Will the site offer text and sensory alternatives?	
I	II		
I		alternatives?	

I	II	40. Will captions be provided for prerecorded material?
I	II	41. Will audio descriptions be provided for other media?
I	II	42. Is the site intended to support the use of assistive technologies?
I	II	43. Should the use of assistive devices to access the site not alter the experience and access presented to those who do not use assistive technologies?
I	II	44. Should the site be designed to present contrasting colours for visual distinction?
I		45. Should the font and or text have a resize support function?
I		46. Should the user be able to control the audio available e.g. captcha, background audio, captioning
I		47. Should users without keyboards be supported by other input methods? E.g. motion, audio, handwriting?
I		48. Should users be able to navigate the site with or without a mouse? Either through the use of a key boards or motion detection etc.
I		49. Should limits be made adjustable or able to be controlled by users?

I	II	50. Will users be able to navigate the site and locate content sequentially?	
I	II	51. Should users be able distinguish links?	
I	II	52. Should the design and layout of the pages be navigable and in a predictable order?	
I		53. Should error detection provide visual and audible input fields?	
I	II	54. If errors are detected should the solution be able to understand/interpret and the make the change.	
I	II	55. ACCESSIBLITY Standards must be applied	
Initial (I) Iterative		EQUABILITY - USABILITY	Notes
I	II	56. Are user requirements and or user scenarios provided and leveraged as part of the design process?	
I	II	57. Will the user experience be consistent? Explain	
I	II	58. Should the user recognize where they are on the site? Describe how	
I		59. Describe the navigation and flow of content or function and how the user is	

I	II	60. Should the user be able to search for data/information independent of the navigation?	
I	II	61. Will the information be presented in a logical manner for the user community needs? Describe considerations	
I	II	62. Has the information gone through appropriate plain language principles?	
I	II	63. Should the design support common tasks e.g. search, feedback, updates, and synchronous and asynchronous chats? List and describe	
I	II	64. Will the site support creating and managing user profiles? E.g. secure profile, limiting access. Describe features and function	
I		65. Will the design have good error messages?	
I		66. Will the site provide clear messaging for errors?	
I	II	67. Will the site allow users to find others easily? Describe	
I		68. Will the site support one to one connections?	
		69. Will there be restrictions on joining group(s) discussions or to create group(s)?	

APPENDIX B

8.1 Appendix B FIDOC User Survey is

The FIDOC User Survey is complimentary to the FIDOC Checklist (see Appendix A, Table 1). It enables the evaluation of the design and the framework, iteratively for the user throughout the design processes.

Table 2 FIDOC USER SURVEY

FIDOC USER SURVEY Section 1				
Understanding Expectations	YES	NO	DESCRIBE	
Were your expectations of the features online met?				
2. Did you achieve your intended goals?				
3. Was there a community manager?				
4. Were you able to find what you wanted?				

5. Was the design flexible to your needs?			
6. Do you feel the site was welcoming?			
7. Did you find the site friendly and easy to use?			
8. Were you able to easily navigate the site?			
Was information easy to locate and easy to understand?			
10. Would you return to the site?			
Recognizing Needs	YES	NO	DESCRIBE
Recognizing Needs 11. Does this community meet your expectations?	YES	NO	DESCRIBE
11. Does this community meet your	YES	NO	DESCRIBE
11. Does this community meet your expectations?12. Would you invite or let others know	YES	NO	DESCRIBE

15. Did you find the support you were looking for in this community?16. Were you left feeling better having accessed the site for information or			
through your participation with other community members?			
Enabling Function	YES	NO	DESCRIBE
17. Did you find the site accessible? Audio, Visual, Navigable			
18. Were you provided with information gathering or sharing opportunities? Describe			
19. Was the site navigation flexible but structured enough for you to move through the content in a predictable order?			
20. Did the site offer you're a variety of formats for information sharing and gathering? E.g. pictures, videos, documents			
21. Did you feel that your experience form section-to-section or function-to-function was whole or seamless?			
22. Were you able to connect with others online?			
23. Was it easy to locate people like yourself?			

24. Were groups easily identified?		
25. Did you experience error messages?		
Were these messages clear and next		
steps easy to follow?		