

# Can Marginalized Individuals Living with Epilepsy Benefit From Online Communities?

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## Executive Summary <sup>1</sup>

This report was developed to answer the question: *Can marginalized individuals living with epilepsy benefit from online communities?* Researcher Jodi Statler was inspired to develop this report after experiencing epilepsy related uncontrolled seizures that forced her to spend an extended stay in hospital. The uncontrolled nature of epilepsy coupled with the disconnection from regular life lead Statler on a search for an online community where she could offload the burdens associated with this condition with others who share her experience. After finding that no such resource existed in her city of Calgary, Alberta, it sparked an interest on the subject of online community as an alternative form to traditional face-to-face communities for individuals suffering from isolation due to illness, specifically epilepsy. The context of this report was further shaped from the lack of education and understanding as to why epilepsy contributes to so many emotional conditions often resulting in isolation.

A review of the history of epilepsy was conducted to gain a clear understanding of epilepsy as well as the psychological conditions typically associated with the disorder. The history explores the origin of the myths and stigma-surrounding epilepsy, beginning in Ancient Greece where the belief was that epilepsy was associated with lunacy, possession or that afflicted individuals were brain damaged and contagious. Additional research has shown that many of the myths and stigma of the past are still believed today further impacting the lives of individual's living with epilepsy.

The continued myths and stigma add to the emotional conditions associated with epilepsy, contributing to a tendency to wish to isolate ones self, particularly in the case of individual's who are struggling with uncontrolled seizures. It is recognized that when individual's pull away from their community, friends, and family the impact contributes to further deterioration of their health and worsening of the condition.

The subject of 'community' was assessed identifying its fundamental requirement to individual's lives through fulfilling a basic human need. Community contributes to developing an individual's self-image, ultimately affecting their overall health and wellbeing. A lack of community has proven to increase individual's feelings of loneliness, which contributes to aging faster, higher instances of illnesses such as common colds, strokes, depression, heart attacks and various forms of cancer.

Understanding human's fundamental need for belonging to a community proved that the necessity for an alternative approach to traditional face-to-face community in the form of online community was needed. The introduction of online communities began in the late 1990's and rapidly spread in quantity and popularity. A description of how an online community can be developed and structured was explored, including mitigating any potential challenges that may exist when working with a vulnerable

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<sup>1</sup> Throughout this report, the colour purple was purposely chosen to emphasize certain points and highlight sections. Purple became the colour to symbolize epilepsy in 2008 by a nine-year girl named Cassidy Megan of Nova Scotia (Epilepsy Toronto, 2013).

community with specific health related needs. Recommendations were created, the first being the development of an online community specific to the Epilepsy Association of Calgary. The top three priorities identified include:

1. Employing a health care online community approach to the structure and development of the online community
2. Utilizing a Lifecycle approach to the structure and development of the online community
3. Including many platforms of communication within the online community such as social media, blogs, mailings list and instant messaging

The second recommendation suggests how the Epilepsy Association of Calgary will build participation to the online community. The three techniques strongly suggested are:

1. Utilizing 'story sharing' as a method of engaging the current members and encouraging new members to join
2. Defining the roles of online community staff
3. Defining the activities and goals of the online community

The overall goal of this report is to develop an online community that will create opportunities for marginalized member's living with epilepsy in Calgary and the epilepsy community as a whole offering methods to support education, specific resources about epilepsy, and to create options for communication between it's members. The main objective of the online community is to serve the marginalized and isolated individuals with epilepsy and educate the public about the facts pertaining to epilepsy. Through educating the public about epilepsy it will help diminish the myths and stigmas, ultimately allowing members to live happier lives.

## **Acronym's Used Throughout this Report**

- PWE - Persons with epilepsy
- EAC - Epilepsy Association of Calgary
- OC - Online Community
- HCOC - Health Care Online Community
- HNT - Hierarchical Needs Theory
- IM - Instant messaging
- AHS – The Accessible Housing Society
- EAE – Epilepsy Association of Edmonton

# SECTION ONE: Introduction

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Epilepsy affects a broad spectrum of the population, over 50 million people worldwide, yet the marginalization of the people living with epilepsy is largely unknown by the general population (Epilepsy Foundation, 2013). Often associated with the myths, stigmas and accompanying emotional conditions, this marginalization flows from both the physical symptoms as well as mental health issues and often means that individuals feel disconnected from their communities, further causing compounding negative effects on their lives (Feist, 2013). There is a high level of depression, anxiety, and suicidal ideation associated with people with epilepsy (PWE) caused from their seizures, and/or medication (Epilepsy Toronto, 2013). These detrimental factors put PWE at risk for further isolation (2013).

Researchers have long recognized the importance of the relationship between an individual and their 'community' (Lee, 1992). Originally a Latin term, 'community' has been defined as, 'fellowship, of relations of feelings' (Plant, 2004). Writers have more recently defined community as "the coming together for mutual association, fulfilling basic needs and finding the meaning of life" (Christenson, 1980). Sunderland, Beekhuyzen, Kendall, and Walski cite McMillan and Chavis (2013) in defining 'community' as the 'feeling that members have a belonging, a feeling that members matter to one another and to the group, and a shared faith that members needs will be met through commitment to be together' (p.15). The history of the relationship between humans and community has long proven that the need is fundamental. Brown and Hannis (2008) echo this sentiment, expressing that community is essential in the development of an individual's self-image and that community plays a key role in teaching life and coping skills to individuals.

With the increasingly widespread use of the Internet since the 1990's and the relatively new introduction of social media, new unique communication possibilities for marginalized individuals offer ways to connect to communities in the virtual world. Internet based groups generally known as online communities (OCs) first emerged in 1997, and their growth has been steady and rapid (Online Community Directory, 2008). Rheingold and Hiltz were two pioneers of their development and coined the term 'online community' to describe the feelings of support that they observed individuals experiencing in online arena's (Preece, 2005). OCs consist of groups of individuals who may be dispersed geographically but can still virtually congregate online around a shared common interest (Brown, & Dugguid, 2001; Wasko & Faraj, 2005). These groups are facilitated through an online communication medium and relationships are bridged through the sharing of personal experience, ideas, and knowledge (Brown & Duguid, 2001; Chui et al., 2006; Wasko & Farajo, 2005).

Whittaker, Isaacs and O'Day (1997) have identified a number of characteristics that typify OCs (as cited in Sunderland, Beekhuyzen, Kendall, & Walski 2013, p.10). Members actively participate developing strong relationships with the other members through shared interests or activities. They also share resources and the resources are accessed through agreed policies. There is a culture of openness and sharing of information. And finally, all of these activities take place within a context of social conventions,



such as language and protocol (2013). All of the aforementioned resources of OCs help to better inform the members about their personal health, establish new relationships, and gain a new sense of empowerment through the sharing of their personal stories in a safe and impartial environment (2013). Researchers have evidence that OCs promote healthy living and can positively affect the lives of individuals suffering from the deteriorating health effects associated with isolation (Crespo, 2007), which commonly characterizes PWE.

## **1.2 Researchers Personal Connection to Epilepsy**

*Living my life with epilepsy has had many challenges including both physical and mental. The physical head and body injuries I have endured over the years have been abundant, some more extreme than others. The mental stress in the form of persistent anxiety, the headaches, the blackouts and periods of mental fog have also been abundant, again some more extreme than others. Personally, my greatest difficulty while growing up with epilepsy was always trying to keep it from people. From a young age having tonic-clonic seizures, better known as grand-mal seizures, was not an easy secret to keep under wraps as they would happen without warning. In an instant my body would suddenly drop and go into convulsions lasting for up to a few minutes, which I have been told, seemed like an eternity to onlookers.*

*In my youth I was active and athletic, and I had aspirations of participating in the Olympic games. I had talent and was so committed to my dream that I trained daily and spent every spare moment out on the track. Later as a teenager, the frequency of my seizures increased to an unmanageable level. For such a secretive person as myself it seemed a vicious joke that my condition of epilepsy was so frequently revealed to the world during high profile sporting events in stadiums filled with onlookers, or during lunchtime in the crowded cafeteria at school. With the large amount of anti-seizure medication I had to take, contributing to a persistent extreme drowsiness, it became progressively difficult to perform to my best ability. Soon my body would fail me as the seizures became too frequent and interfered with my daily living. Loosing the part of my identity of being an 'athlete' was difficult, but gaining the new identity of a person with epilepsy was harder and so began a new mental anguish with the seemingly eternal identity crisis experienced by so many people living with epilepsy. During that time, I felt that having epilepsy was a punishment. Doctors suggested wearing a helmet to protect my head from trauma during a seizure, which I defiantly refused. Walking the halls of school, I felt so very alone and isolated and didn't know who I was. With very few friends and constantly feeling like an outsider, the stigma of epilepsy was both an emotional and physical ache that conjures memories I still vividly experience today.*

*Entering the Community Development program at the University of Victoria, the possibilities for final projects were abundant. During my second year of studies, I had a relapse with my seizures and they began to increase in frequency resulting in my hospitalization for a four-week stay. While in the Seizure Monitoring Unit I was monitored 24-hours a day via electrodes glued to my scalp and where my mobility was limited to a 10 by 10 foot room. This month of isolation forced me to reflect back on my life living with epilepsy, which brought forth all the negative emotions and memories I had associated with it. In need to connect to others I began to search for an online group dedicated to people with epilepsy (PWE) and found*

*that no such group existed in Calgary. This inability to connect and share meaningfully with others that have shared my experience became a catalyst for a new personal interest in OCs and how important they may be in fostering a sense of community among marginalized individual's who are isolated on account of specific health or other disabilities.*

*Now at age 36 with a child, I have a new outlook on the important role an OC could play in the lives of PWE. PWE may feel isolated not only because of their condition, but also because of the ramifications and restrictions it puts on their lives such as the inability to drive or to participate in many daily social activities. There may be days when a local PWE feels a deep need to express an emotion - maybe good, but more likely bad; perhaps they have just had a seizure or just endured a week of seizures one after another; perhaps they just need to talk to someone who will understand. Regardless of why a PWE may feel isolated without a physical community to connect to an online community may fulfill just such a need. As I have personally experienced in myriad forms throughout my life living with epilepsy, without a sense of 'community', we really are all alone.*

### **1.3 Epilepsy Association of Calgary's Question and Objectives**

This report will answer the question: *Can marginalized individuals living with epilepsy benefit from online communities?* This project will examine the spectrum of mental and emotional conditions that co-exist with the disorder of epilepsy contributing to isolation and marginalization and the potential for OCs to address these issues and the benefit it may bring to individuals living with epilepsy.

The context of this report was shaped from the lack of education and understanding as to why epilepsy contributes to so many emotional conditions often resulting in isolation (Chen, & Rodgers, 2006). Specifically, the issue of isolation experienced by PWE will be studied, and the viability of an OC will be assessed for creating a sense of belonging for its members similar to that found in a traditional community.

### **1.4 Client Organization: Epilepsy Association of Calgary**

The Epilepsy Association of Calgary (EAC) is a Calgary based, charitable, social service agency governed by a voluntary board of directors (Epilepsy Association of Calgary, 2012). The EAC has a mandate to support independence, quality of life, and community participation for those living with and affected by epilepsy (2012).

Its mascot is a penguin which encourages people to ask the question of "why the penguin?" which then provides an opportunity for discussion around epilepsy (2012). The penguin has proven to be a great tool for spreading valuable information and educating the public about the facts about epilepsy, first aid and seizure response. The information spread in these short moments with people can sometimes help to improve the lives for PWE and at times save the life of someone living with epilepsy (2012).

The EAC has developed an informative website encouraging members to take part in events and fundraisers providing epilepsy awareness to the public. The website also provides information on epilepsy first aid, support meet-ups, and general information on epilepsy (2012). EAC is considering expanding their website to include an interactive forum for their members in effort to create a stronger sense of community. The EAC's Director Kathy Fyfe, however, has expressed apprehension to the prospect of developing an OC for their members indicating concerns that the associated risks may be too high (personal communication with Kathy Fyfe, 2012). Her concern stems from the reality that the ultimate responsibility of the participating members in an EAC hosted OC would be that of the EAC. These potential risks include but are not limited to: members sharing intimate information that could lead to further stigmatization; the sharing of medications could influence members to make unwarranted changes to their own health plan; the emotional conditions present in PWE could attract negative feedback from other members resulting in possible serious emotional repercussions or even suicidal ideation; and with a lack of monitoring of the site possible necessary medical interventions for members may be missed (2012).

## 1.5 Research Methodology Used in This Report

The research methodology used in this report was gathered from publicly accessible resources including online databases, journals publications, bibliography information from published studies, articles, and published books. The online searches included utilizing Google Scholar, and the University of Victoria Library database accessible searches. This report will include:

- How do the stigma, myths and emotional factors that co-exist with epilepsy contribute to isolation and marginalization in those individuals living with epilepsy?
- Why do humans have a basic desire and fundamental need of belonging to a 'community'?
- What are online communities?
- What types of online communities exist?
- What challenges exist for participants of an online community who are marginalized by illness?
- What methods exist to mitigate the challenges that exist for participants of an online community who are marginalized by illness?

## 1.6 Summary

This report has been intentionally organized to provide background information prior to tying topics together. The Introduction discusses and defines *community*, introduces the Internet, and the development of online community (OC). The context of community will help the reader understand the impacts that it has on humans overall health, and explains how individuals can suffer from depression, anxiety and loneliness, when they are unable to participate in a community, which is relevant to this

report.

Section Two gives an in-depth literature review on epilepsy and the myths and stigmas that individuals living with epilepsy experience. This section reviews the emotional conditions associated with epilepsy and illustrates why PWE are marginalized due to their condition. Section Three covers community and the impact it has on individuals lives. A discussion on the history of community and how individuals utilize it today is assessed. Furthermore a list of community opportunities available to individuals with epilepsy living in Calgary Alberta, Canada is explored.

Section Four discusses OCs, how they are organized and structured and the most common forms of OCs that exist. Health care online communities (HCOC) are specifically explored to see how they can offer participants with unique vulnerabilities a sense of community in a safe environment.

Section Five discusses the strengths and challenges that exist with popular forms of OCs for participants marginalized by medical illness. Section Six provides recommendations to the Epilepsy Association of Calgary (EAC). These recommendations lead into Section Seven, which concludes this report.

# SECTION TWO: Literature Review on the Myths, Stigmas and Emotional Conditions Associated with Epilepsy

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The background of epilepsy as well as the myths, stigmas and prejudices that have shrouded this disorder will be explained in this section. These are essential to better understand the factors that contribute to a person living with epilepsy (PWE) becoming isolated and marginalized without a sense of community. Exploring the emotional and psychological factors that are common to PWE including depression, anxiety, and identity crisis which further stigmatize and isolate PWE from typical community involvement is necessary to this report.

## 2.1 Epilepsy

Over 50 million people live with epilepsy worldwide including approximately 300,000 Canadians. Epilepsy is a condition that afflicts the central nervous system where a person has a tendency to have seizures, which can range from mild sensations or interruptions in normal thought, uncontrolled movement, odd sensations, loss of consciousness, or severe and prolonged convulsions. It is an unpredictable disorder that looks different from patient to patient, which complicates diagnosis. Some PWE will only have a few seizures in their lifetime whereas other PWE have hundreds of seizures a day (Epilepsy Foundation, 2013). While there are individuals who experience seizures following head trauma, the diagnosis of epilepsy is defined by the occurrence of two or more unprovoked seizures. Further complicating diagnosis and treatment, over 40 different types of seizures exist of which PWE may suffer from any combination of them. This condition can happen in an individual at any age, although most cases are diagnosed early in life (2013).

There are a number of things that can cause epilepsy including head injuries, pre-birth trauma, chemical imbalances, strokes, brain tumors, and certain infections of the brain such as encephalitis and meningitis (Epilepsy Association of Calgary, 2012). A cure for epilepsy has not yet been found which means that it is typically treated with medications to control the seizures, however, 30% of those on medication continue to have them. It is common for PWE to have to take more than one different medication to reach a dosage that will best control their seizures. These medications have many different side effects that affect mood, cognitive ability, concentration, and energy levels for the individual (2012). Surgeries are being conducted on individuals to control the frequency of seizures, however, due to the unpredictable nature of epilepsy they are not always conclusive. This often means additional surgeries and in some instances a lifetime of dependency on medications (2012).

For most people, seizures are brief and infrequent, and do not prevent them from leading healthy,

active lives (Epilepsy Foundation, 2013). This is not the case for every PWE. As when the seizures are not controlled, PWE live a life of uncertainty, anxiety, and fear, which can drastically affect behaviour and feelings of wellbeing as well as the ability to interact socially. Compounding the physical difficulties of living with epilepsy are the societal perceptions of the disorder predominantly comprised of myths and stigma.

### 2.1.1 *Myths and stigmas of epilepsy*

The stigmas, prejudices and misconceptions of epilepsy have varied from insanity, to possession, to criminality, to the belief that PWE were “god-like” (Temkin, 1971). In his book, *Stigma: Notes on the Management of Spoiled Identity*, Ervin Goffman defines ‘stigma’ as an “attribute that is deeply discrediting” (1963, p.3) and reduces the individual “from a whole and unusual person to a tainted, discounted one” (Goffman, 1963). Goffman believed stigmas resulted from the transformation of the body, blemish of the individual character, or membership in a despised group. Link and Phelan continued research to Goffman’s work adding that “stigma exists when a person is identified by a label that sets the person apart and links the person to undesirable stereotypes that result in unfair treatment and discrimination” (Link & Phelan, 2001).

Retracing the origins of the myths and stigmas of epilepsy goes back to ancient Greece, where the term *epilambanein*, (Temkin, 1971) was a word attributed to individuals who had seizures, resulting in branding and tattooing, deeming them criminals, and ultimately outcast from society (Thomas, 2011). Later, the term ‘Sacred Disease’ was a phrase used by many authors to define PWE and held by many authors. This was perhaps ironic on account of the disorders anything but sacred nature (Pierce, 2002). At times, however, it was used literally by medical practitioners and religious leaders who believed that PWE were possessed by deities afflicted with other supernatural agents that resulted in this disorder (2002).

At the extreme, past stigmas and misconceptions of epilepsy include a 13th century German preacher who warned the public that the breath of PWE could infect others. This belief continued well into the 18th century where it was assumed the condition to be infectious and advised spitting on PWE to prevent contracting the disease (Temkin, 1971). During the Middle Ages in Western society, epilepsy was associated with possession and said to be connected with the ‘moon’, which affected many disorders of the mind including lunacy (1971). The Ancient Greeks understood that a person ‘got’ epilepsy by offending the moon goddess Selene, perpetuating the belief that epilepsy was caused from an individual’s evil doings, or as a consequence of the cycles of the moon or mystic magical phenomenon (1971). Continuing with the belief in contagion, in the late 1600’s it was believed that PWE should be locked up in mental hospitals where they were kept separate from others including other institutionalized patients who could fall ill with the symptoms of epilepsy (Pierce, 2002).

Remarkable scientific advances have been made in epilepsy research making it possible for some patients to have complete seizure remission with surgery, and with the aid of medication breakthroughs many PWE can have their seizures well controlled (Epilepsy Foundation, 2013). After years of fighting the

myths of epilepsy, more recent biomedical explanations for epilepsy have replaced those earlier magical stigmas. The myths that PWE are brain damaged, or the condition is contagious, or that PWE may be dangerous or violent can cause other individuals to shy away or be unkind (Epilepsy Foundation, 2013). The judgments can be very harsh, contributing to anxiety, depression, stress and isolation, all of which prove to worsen the condition of epilepsy and increase seizure frequency (2013).

When an individual experiences a shunning due to stigma, it can result in what sociologist Goffman defined as the “tainting” of social identity where it can discredit an individual, making that PWE feel worthless contributing to isolation (1963). This is not true for all individuals who possess the possibility of a stigma, as stigma traits are not always obvious to the public eye and can be concealed or kept secret. For PWE this can mean hiding the traits of their disorder until a seizure occurs in public (Thomas, 2011). Many PWE prefer to conceal their disorder rather than be labeled upon diagnosis, which can severely interfere with timely access to healthcare, early diagnosis, treatment, and lifestyle recommendations (2011). Illness-related stigma has proven to affect an individual’s economic status, psychological wellbeing, social interactions and overall health, all of which are even greater than the initial illness itself (Baker, 1990).

Stigma and social discrimination regarding epilepsy is partly due to people’s inherent habit of labeling and distinguishing people and themselves into categories (Bhattacharya, 2011). Epilepsy stigma has been attributed to the ‘horror of the symptoms’, and the popular belief that epilepsy is incurable further contributes to its fearful reputation (2011). As recent as 2012 reports included that it was believed that during a seizure a person might swallow his or her tongue, that women with epilepsy should not get pregnant, that epilepsy is a benign disease, and that epilepsy simply cannot be controlled. Other widely believed myths are that people with epilepsy look different, or that epilepsy is contagious, and that people with epilepsy can not handle high-pressure demanding jobs because they are not as smart as other people, and finally, that epilepsy is rare (Cleveland Clinic, 2012). Many patients today consistently report feelings of being ostracized from society as they did ten, twenty, even thirty years ago (Bhattacharya, 2011), proving that public education and stigma prevention is still very necessary.

Being saddled with the unpredictable burden of not knowing when a seizure will occur can have a crippling effect on one’s life, though mainly psychological, which ultimately effects one’s social relationships (Hixson, & Kirsch, 2009). Andelman, Fried, and Neufeld (2001) noted that individuals with generalized epilepsy who experience unpredictable seizures undoubtedly have a tendency to experience higher levels of depression and anxiety disorders on account of constantly being faced with potential embarrassment in the event of a seizure in public.

### *2.1.2 Depression and anxiety*

Depression is the leading cause of disability worldwide, and is defined as a diminished interest in almost all activities as well as having other physical or psychological symptoms present (American Psychiatric Association, 1994). The increased risk in PWE who experience psychiatric conditions such as depression is high (Feist, 2012). Studies show that 50% of PWE whose seizures are not controlled by

medication suffer from depression and that the treatment of the depression in PWE is often mistreated due to the focus being on controlling the seizures (2012). Factors contributing to depression in PWE include:

- Loss of a job due to their condition of epilepsy
- Loss or lack of a relationship due to the epilepsy
- Psychological effects of living with epilepsy created by the uncertainty of their condition
- The side effects of the medications used for treatment of epilepsy
- Oxygen deprivation and head injuries caused from seizures (Epilepsy Foundation, 2013).

In a recent study on depression in epilepsy, conducted by Feist (2013), it was hypothesized that the link between epilepsy and depression is bidirectional, meaning that the depression is caused from the seizures and seizure frequency is increased from the higher rate of depression. For PWE, the vulnerability of induced helplessness of not knowing when the next seizure may occur creates a feeling of less control over their lives as compared to their peers, which can manifest in a depression anxiety disorder (2013). Table 1 shows the prevalence of psychiatric disorders in PWE and the general population from 2007 data (Hernandez-Frau, 2011) and demonstrates an elevated rate of psychiatric disorders in PWE than the general public.

**Table 1- Psychiatric controls vs. PWE**

Psychiatric disorder	Controls	Patient with epilepsy
Major depressive disorder	10.7%	17.4%
Anxiety disorder	11.2%	22.8%
Mood/anxiety disorder	19.6%	34.2%
Suicidal Ideation	13.3%	25.0%

Anxiety is a condition experienced by many PWE. Anxiety is characterized as a constant sense of worry, feeling nervous and on edge, with intermittent panic attacks (Comprehensive Medical Centre, 2011). Anxiety disorders common in PWE include obsessive-compulsive disorder, panic disorder, generalized anxiety disorder, and post traumatic stress disorder (2011). These anxiety disorders exist with many forms of generalized anxiety disorders; however, they are more common in PWE. The common treatment for anxiety disorder in PWE is more medication, adding further to their overall cocktail of medications consumed by PWE, which may alleviate the nervousness but also contributes to feelings of lethargy (2011).

When there is a presence of anxiety and psychiatric disorder in PWE there is an increased rate of suicide (Hernandez-Frau, 2011). Researchers agree that the relationship between epilepsy and suicide is difficult to determine due to the compounding psychological factors that play a role. Over 30 years of data demonstrates that social disadvantages, psychiatric disturbances, and the use of antiepileptic drugs



have played significant role in the higher rate of suicide for PWE (Bell, 2009). Researchers have suggested reducing stigmas related to epilepsy could play an important role in reducing the rate of instances as well as treating the psychiatric symptoms in PWE. Bell went on to add that treating the seizures with the least amount of antiepileptic drugs as possible could be one of the best preventative measures to the high rate of suicide (2009).

'Felt stigma' refers to the experience of feeling shame due to having epilepsy (Jacoby & Austin, 2007). PWE who experience felt stigma live a life of fear and anxiety preventing them from social interaction (2007). The biggest force in a PWEs life is their family, and the way that family members react to a PWE plays a significant psychological role on how well PWE will respond to their own condition (2007). In one example, if a child living with epilepsy learns from a parent that epilepsy is a negative condition, this begins the stigma of rejection and leads to social withdrawal, potentially causing the child to want to avoid public exposure of seizures and greater attempts to conceal the condition all together. Children who experience 'felt stigma' have lower self esteem, depression, and anxiety (2007).

### *2.1.3 Identity crisis*

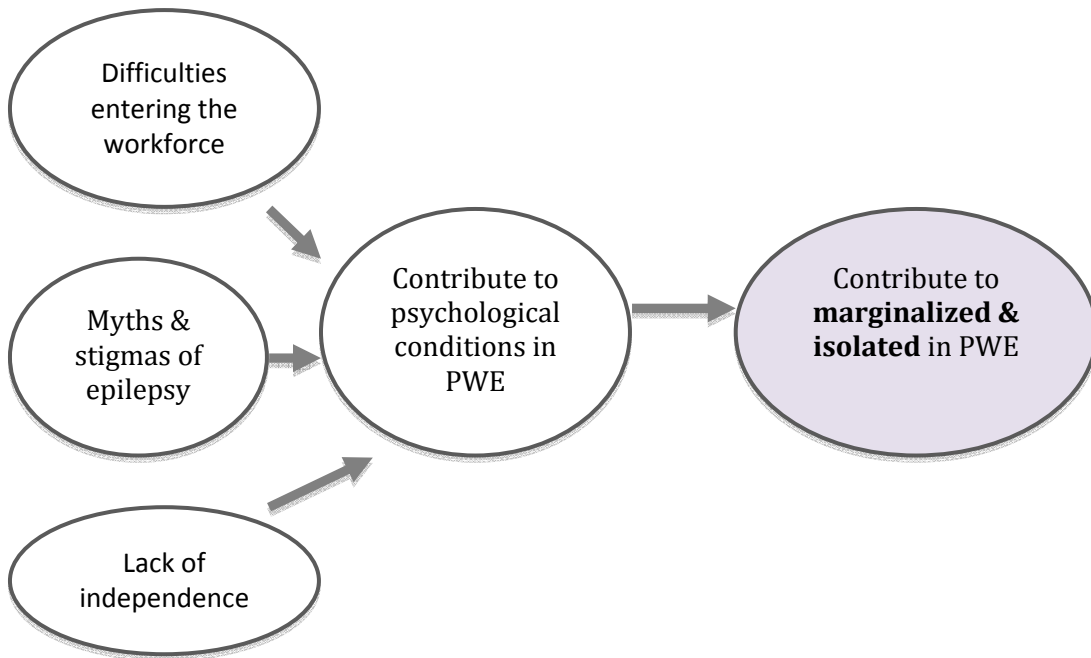
Epilepsy has been referred to as the "storm of the brain" (Bhattacharya, 2011), which on account of its unpredictability leads individuals to want to separate themselves from the condition completely. Researchers claim that historically, feelings of being ostracized from society have not changed and that having an "identity crisis" can be very normal (2011). Patients feel that because their brain is working against them and differently from others in their community, that denying their condition all together and separating themselves from the condition can feel empowering. Because PWE typically have alienated themselves from social activities, friends, and family, further separating themselves from the disorder of epilepsy in the form of an 'identity crisis' can be very lonely and depressing (2011).

Bhattacharya (2011) discusses the issues of identity crisis and social discrimination for people living with epilepsy. Known as the "invisible" disease, due to the experience of seizures with no apparent cause, creates a fear in the patient and the family members, and a much different reaction of fear for observers of the seizure (2011). A PWE may experience discrimination, anxiety, apprehension, a constant state of depression, fear, shame, and social withdrawal; whereas the family may experience fear for their loved one and anxiety of the unknown (2011).

As Michael D. Hills from the Department of Psychology at the University of Waikato reports individuals with epilepsy deal with identity crisis that force them to question who they are (Bhattacharya ,2011). Many patients describe concealing their disorder and feeling that they are already alienated from their community simply because their brain functions differently. This desire to hide the disorder from others may mean isolation and "a world of loneliness as they struggle to come to terms with a disorder that attacks without warning and accept themselves as different" (2011).

On account of a PWE experiencing the burden of myths and stigma, depression and anxiety and identity crisis due to the fears, unpredictability, losses and concealment that come with living with epilepsy it can often result in isolation and marginalization. Figure 1 shows the progression of how a PWE may arrive at feeling isolated due to the contributing factors of their condition.

**Figure 1 – Factors contributing to PWEs becoming marginalization and isolated**



## 2.2 Isolation and Marginalization

According to a New Yorker article (May 26, 2009), the worst thing that can happen to an individual is isolation that is being removed from human companionship for extended periods of time. The author, Gawande, states, “Human beings are social creatures. We are social not just in the trivial sense that we like company, and not just in the obvious sense that we depend on others. We are social in a more elemental way: simply to exist as a normal human being requires interaction with other people” (p.38). Gawande cites examples of the cruelty and desperation that derives from extreme cases of isolation from groups such as long distance solo sailors, astronauts, hostages held in solitary confinement and research conducted on both primate and human infants (in experiments that were at times cruel and are now prohibited) to demonstrate that long periods of isolation not only lead to psychological problems but also brain abnormalities (2009). Gawande states that “Without sustained social interaction, the human brain may become as impaired as one that has incurred a traumatic injury” (2009).

A recent survey of Canadians revealed that Canadian adults living with epilepsy faced many obstacles in their day-to-day lives (CNW, 2012). Among the top barriers needing to be addressed included

the stigma, lack of independence, and the difficulties with entering the workforce and other social opportunities. Across the country people living with epilepsy shared insight into their stigma, their experience of discrimination, the overt challenges they faced, and the general lack of awareness of epilepsy within their communities. Approximately 38% of the respondents reported these factors as having a negative effect on their life. Furthermore, adult PWE voiced the challenge of maintaining employment with more than half reporting their job choices were restricted. Respondents from St. John's to Victoria invariably reported the same obstacles including the social impacts associated with having epilepsy, the limited treatment options, and the limited access to specialized care (2012).

On account of seizure frequency, PWE lose their drivers licenses increasing their isolation and dependence on others leading to feelings of frustration, and guilt associated with feeling like a burden on others (Comprehensive Epilepsy Centre, 2011). While public transit is an option for many individuals, not having a drivers license can lead to further economic hardship as many employers can require employees to have a class five drivers license to maintain employment. In Alberta, employers can legally ask if individuals have a class five drivers license as a standard question on an application, disqualifying anyone with epilepsy from applying (2011).

Myth and stigma persistently contribute to the marginalization and isolation of PWE. However, the result for PWE losing even more control over their lives than the already felt loss of control experienced by living with unpredictable seizures such as losing their drivers license, restrictions on employment choices, or in extreme cases, the loss of employment when epilepsy is revealed, can be felt in the form of isolation. The psychological conditions that exist for PWE further exacerbate their risk for marginalization and isolation from communities and being an active member of society. To eradicate the aforementioned conditions associated with epilepsy the importance of community is examined in the following Section. Research has determined that community is an essential element to an individual's quality of life. The ways in which community is being utilized currently by Western society is assessed as well as the specific community opportunities that exist for PWE are examined to determine whether there is a need for more community opportunities or alternative communities.

# SECTION THREE: The Importance of 'Community' on Individuals Marginalized by Illness

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The research on the connection between individuals to their communities and the effects on one's health and wellbeing is remarkable, unveiling a rich history that consistently indicates that individuals with the absence of a sense of community in their lives have higher incidences of illnesses in such maladies as common colds, strokes, depression, heart attacks and various forms of cancer (Putman, 2000). Durkheim, a nineteenth century sociologist, first observed the connection that people who were more connected to their families and community were far less likely to commit suicide (2000). Berkman, also identified that in an absence of community individuals may experience loneliness, and that loneliness is a chronically stressful condition to which humans respond to by aging faster (Putman, 2000).

This section defines community, from its historical background to the forms of community that individuals living in Western societies currently use today. The level of importance that community has on an individual's wellbeing is analyzed with consideration of Maslow's hierarchy of needs and finally the opportunities currently available for people living with epilepsy in Calgary are assessed.

## 3.1 Communities

Defining community is challenging, as there are a number of factors that influence its development. These include its geographic location, size, social environment, and the support, interest and commitment of the individuals collectively involved. On account of these factors, researchers have never been so bold as to stake claim to a definitive overarching definition. For the interest of this report, Galbraith's (1990) definition will be adopted stating that community is "the combination and interrelationships of geographic, locational, and non-locational units, systems, and characteristics that provide relevance and growth to individuals, groups, and organizations (p.5). Galbraith's definition best suits the characteristics of online communities, which will be considered below.

During the pre-industrial period, groupings of people lived together and their relationships were characterized by face-to-face interactions (Brown, 2008). More recent definitions of community illustrate three of its general forms: geographic, functional or attribute, and interest (Lee, 1992). A geographic community is a group of people who are living in the same physical location or meet regularly in a specified location. A functional or attribute community is a group of people who share a commonality such as gender, race, religion, or socio-economic status. An interest community is a group of people who are joined through a common interest or concern that they wish to address, an example of this could be a social-action (Brown, 2008).

Contemporary variations of community that exist in Western society are constructed by the very same principles found in the past including geographic, functional or attribute, and interest communities. Some simple examples of how individuals are currently participating in these various forms of community include:

**Community halls** – Physical structures that are geographically localized, community halls serve as a space for a variety of groups to meet regularly and serve the various interests of community members. The groups that meet at a community hall are geographic communities and the many groups that utilize the hall may be interest or functional or attribute communities depending on their interests and purpose.

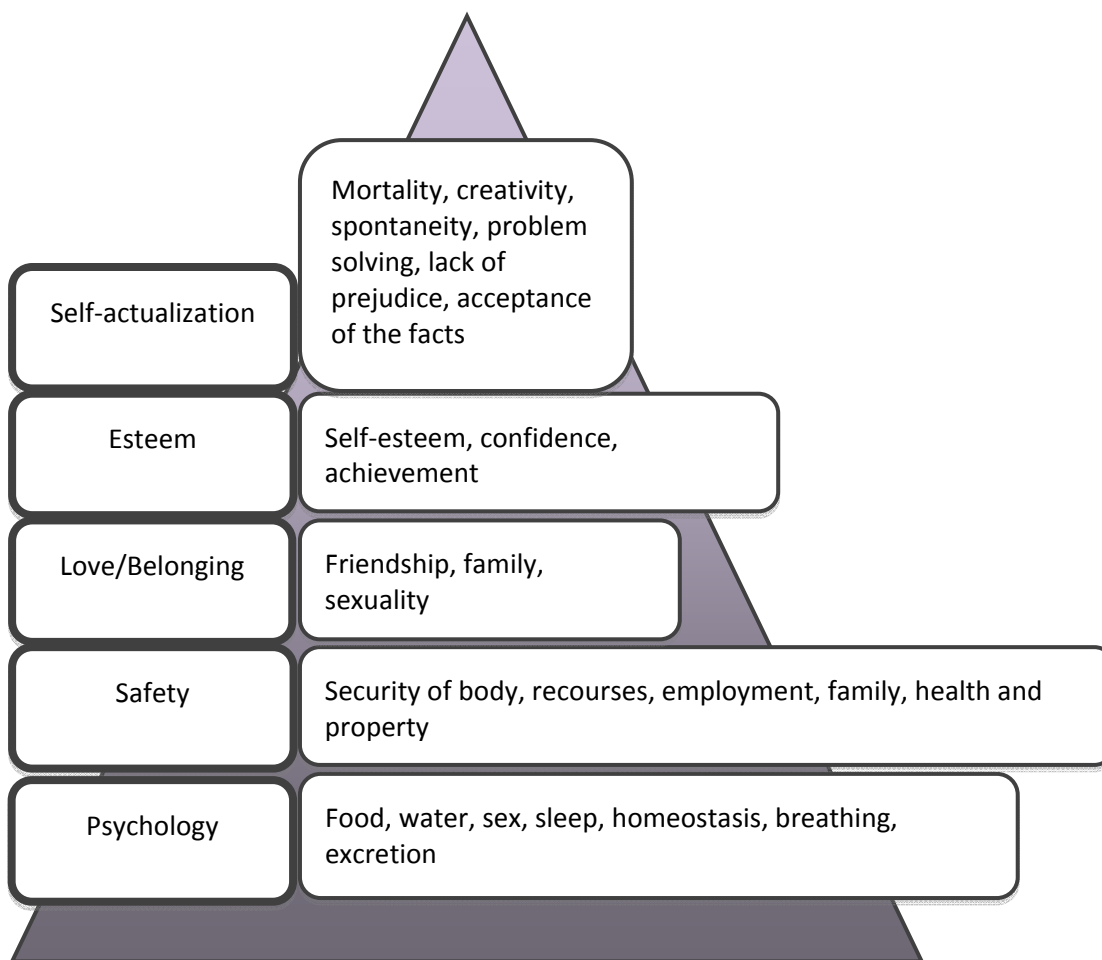
**Church groups** – Church groups are functional or attribute communities based on the participants shared commonality of their religion.

**Meetups** – Meetups (2013) take many forms from new entrepreneurs congregating to share business ideas and build a network to women's only hiking groups. Whatever the reason a group has for creating a Meetup group they are interest communities based on a shared common interest.

Communities have transformed over the decades, as has the modern Western family. The mounting pressures on Western families to maintain an aspirational lifestyle is driving them away from family and community and towards an unachievable existence resulting in individuals being alone (Brown, 2008). Due to the financial pressures of Western society at the end of the day people are often far too exhausted to nurture their community networks (Brown, 2008). Researchers have discovered that individuals search for acceptance and belonging from their immediate family, yet less frequently are these relationships being fulfilled appropriately due to the work commitment of the parents. This issue worsens for parents who have one or two jobs. The Western society lifestyle is not only affecting the immediate family but also the extended family members who experience the effects in the form of mental illnesses such as depression due to loneliness (p.3). Ultimately if a community or family is inadequately bonded, either by lack of participation, or the issue that initially connected the group has deteriorated, then subsequently the individuals of the community or family will weaken or lose their resolve and ability to contribute (2008).

In the 1940's, Maslow (1943) proposed a theory of psychological health that described a hierarchy of human needs that progressively need to be met as an individual moves from the most fundamental needs, such as food and water, toward self-actualization. Known as Maslow's hierarchy of needs, this progression is depicted in Figure 2. He believed that humans have an instinctive need to stay connected to one another, and before they can experience full self esteem, confidence or a sense of achievement, the needs associated with a sense of belonging first have to be met including feeling safe and supported by a group (Kim, 2000). Socializing is an important need for human beings as, according to Maslow, self-esteem is built through the skills developed in relationships and through the security and safety that come from being a part of a community (2000).

**Figure 2 – Maslow’s hierarchy of needs**



### *3.1.1 Community opportunities available to individuals living with epilepsy in Calgary Alberta, Canada*

To help answer the Epilepsy Association of Calgary’s (EACs) question: *Can marginalized individuals living with epilepsy benefit from online communities?* It was essential to assess the community opportunities currently available to people living with epilepsy in Calgary to learn whether there is indeed a need for further programs or alternative community opportunities.

### *Seizure Monitoring Unit*

The Foothills Hospital is Calgary's largest and most advanced medical facility, which houses the Seizure Monitoring Unit (SMU), a specialized four-bed inpatient unit designed to evaluate, diagnose, and treat seizures and understand "seizure like spells" in adult patients (Clinical Neuro Sciences, 2014). This unit is run by a multidisciplinary team of trained nurses and technical personnel trained to observe four patients 24 hours a day via video and EEG recordings. This recording allows epileptologists to characterize the type of spells, pinpoint the area in the brain where the seizures begin, and exclude non-epileptic seizures from the diagnosis. Each patient receives a customized treatment plan, which may conclude for some patients in surgery, psychological treatment, medications or a combination of all three (2013). The SMU is a treatment alternative for some PWE, however it is only offered to patients with severe seizure conditions and is not an option for the vast majority of PWE.

The SMU becomes a form of community for the patients who attend the unit as they typically must stay for long periods of time ranging from a week up to two months. Relationships between staff and patients are developed during the SMU experience, and the SMU patients can develop relationships with each other as they share in the experience of being taken off their medication and enduring various treatments intended to provoke seizures.

### *Accessible Housing Society*

The Accessible Housing Society (AHS), is a non-profit organization with a mandate to generate opportunities for safe, affordable, barrier-free housing for persons with mobility issues (Accessible Housing Society Calgary, 2013). Developed in 1974 by a woman who had a brother with epilepsy, she dreamed of creating an organization that would house people with disabilities who could not otherwise live independently (2013). Though the mandate for AHS is open to anyone with mobility issues, if a PWE has uncontrolled seizures and desires to live independently, they are welcome to apply to the AHS (2013).

This is a community opportunity for PWE, who have an chance to live independently perhaps for the first time. The AHS homes are safe and are arranged together so that the occupants ultimately become a community. Independence is an important aspect for individuals living with disability as the restrictions can be overwhelming on their lives. To have the control to live with minimal assistance can be very empowering.

### *Epilepsy Association of Calgary*

Calgary's central source of community for the epilepsy population is the EAC. Incorporated in 1955 by twelve PWE, the EAC is a charitable, social service agency governed by a voluntary board of directors with a mandate to support independence, quality of life and community participation for those with and affected by epilepsy (Epilepsy Association of Calgary, 2012).

The EAC has monthly face-to-face discussion groups geared toward supporting adults with epilepsy (Epilepsy Association of Calgary, 2012). These groups help to increase knowledge and understanding about epilepsy, help participants gain new skills, and strengthen support and social connectivity throughout the community (2012). They offer a monthly *parent network* support group for parents and caregivers with children living with epilepsy offering face-to-face support, information, and a sense of community (2012).

Specialized support groups offered through the EAC have been designed for individuals who are ready to examine the effects that epilepsy has on their lives. They allow participants to learn the skills necessary for minimizing the negative impact epilepsy can have on their lives and helps them work toward an optimal level of health and wellbeing (Epilepsy Calgary, 2012). This program takes into account PWEs entire physical, emotional, social, and spiritual state and develops a twelve step program which will lead to a better understanding of epilepsy and the many factors that can lead to seizures. Most importantly, this program will help individuals understand their seizure triggers and auras in effort to improve seizure control to give them more power over their lives (2012).

The EAC offers regular events and fundraisers to raise awareness and educate the community about epilepsy, which also contributes to a sense of community for the participating staff and volunteers of the EAC (Epilepsy Calgary, 2012). Opportunities to engage epilepsy community for PWE can offer medical support, education on epilepsy, treatment options, social support and an over all sense of wellbeing. However, for individuals suffering with depression, anxiety, isolation, or all of the above, participating in monthly meetings or community events may be impossible. Equitably addressed alternatives such as online communities that would meet PWEs requirements must be assessed as a form of opportunity to alleviate this need.

Even with the extensive programs the EAC offers and the introduction of their Facebook page, it still does not mitigate all of the challenges that marginalized and isolated individuals face on account of their epilepsy. PWE who lack the mobility to leave their homes or are experiencing long hospital stays may turn to Facebook as a means of keeping up to date with friends and abreast of current events. However for a vulnerable community dealing with illness, an alternative structure for an OC should be developed taking in account all the factors specific to marginalization, psychological conditions and dealing with illness. Alternative approaches and how they will mitigate any potential challenges unique to this marginalized population will be further explored in Sections 4 and 5.



# SECTION FOUR: Online Communities

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In the previous section the importance of community specifically for individuals marginalized by illness was reviewed. While traditional communities have historically been limited by geography, online communities (OCs) use the Internet to establish relationships that circumvent the geographic barrier. Unlike traditional communities, which are place-based, OCs are fluid and operate without formal boundaries (Squire & Johnson, 2000). Similar to traditional forms of community, OCs are organized around activities, and are formed when a need arises (Squire & Johnson, 2000). While relatively new, they are already proving to be successful alternatives to traditional communities in developing relationships between members. Researchers have reported that participants involved in OC have expressed improved health, self-esteem, and overall wellbeing (Chen & Rodgers, 2006).

This section reviews the pervasiveness of the Internet and how the basic tools for developing OCs are now readily accessible and can easily be used by almost anyone. Furthermore this section will detail the existing forms of OCs such as groups, instant messaging, blogs, and popular forms of social media; and will assess the strengths and weaknesses of each and how they ultimately affect the people that use them.

## 4.1 Online Community

Today it would be difficult to imagine life without access to the Internet, yet it has a relatively short history from its modest functional origins to the all pervasive nature and affect it now has on our contemporary world. The Internet and the possibilities it houses have forever changed how individuals communicate with one another. Starting initially as inter-networked computers used to enable communication between researchers, the Internet rapidly evolved over the last 30 years to the ubiquitous entity it is today. The early literature of the Internet regarded it as revolutionary in both its technical innovation as well as its social and political suggestions (Benedikt, 1991, Gore, 1991, Negroponte, 1995). In a computer savvy world where many North Americans have more than one computer operated device within reach at all times, face-to-face interaction is no longer the first and only means of conversing. This rapidly spreading and increasing rate of usage meant that the Internet was more than a remarkable technological phenomenon, it was the single greatest phenomenon to affect humanity, having introduced the greatest and most pervasive 'change' to global society (Plant, R. 2004). The Internet revolution changed communication drastically as by early 2012 it was estimated that there were over seven billion regular users of the Internet viewing and sharing information around the globe (Internet World Stats, 2014).

The introduction of OCs began in the late 1990's (Online Community Directory, 2008), creating groups of individuals who may be separated geographically but still assemble due to their shared beliefs and common interests (Brown & Dugguid, 2001; Wasko & Faraj, 2005). Some of these groups are open to the public where anyone can follow or join in on the conversation, while others are private groups,

limited to a select membership. There are groups set up for schools or businesses, and blogs where members can check in to get the latest information relevant to their community. Some OCs focus on para-social interactions where members want to learn specific personal skills such as cooking, gardening or sewing (Ballantine, 2002). OCs can take many different forms all of which are centered in an online arena.

Researchers have long recognized the importance between humans and their community (Lee, 1992) yet for individuals who are marginalized due to medical illness including people with epilepsy (PWE), OCs can be a viable solution. Due to the high level of depression, anxiety and suicidal ideation associated with people with epilepsy (PWE) caused from either their seizures, medication, or a combination of both (Epilepsy Toronto, 2013) it can be a struggle to maintain offline relationships (Yang & Tan, 2010), so OCs allow them a community otherwise not possible (Wasko, *et. al.*, 2013). OCs offer members with emotional support and self-development, unlike the support from family and friends (Molm *et al.*, 2000, 2007; Wasko & Faraj, 2005). OC participants offer a renewable source of support due to shared experience and the understanding associated with fighting the same medical condition (2005).

Scholarly literature has been debated as to whether or not Internet mediated communication within a group, naming itself an OC, is in fact real or imagined community (Bordieu, 1991). The debate explores whether communication online is capable of creating the same nature as traditional face-to-face groupings known as communities (Wilson, 2002). He questions whether online arenas for meeting to discuss, chat, and meet-up in the virtual sense can compare to a meeting in a physical setting. However, with the advent of online communication done by way of email, instant messaging, instant bulletin boards and blogs (Conhaim, 2002) it forever transformed online interaction providing an alternative method for individuals to build a sense of community. No longer was community limited to face-to-face interaction and in 1983 the definition of *community* was challenged making room for OC (Anderson, 1983).

#### 4.1.1 *Common platforms of online communities*

Determining the structure and development of an OC requires many factors, however one that should never be ignored is humans need to communicate (Maslow, 1943). Therefore when implementing an OC utilizing a variety of platforms of communication is essential, allowing member's a choice in how they converse with the other participants. The following describes a list of popular forms of OC platforms, which would be suitable options for isolated and marginalized individuals dealing with illness.

##### *Message boards*

OC can have central arenas that act as message boards where people congregate to address daily news, share issues, and stay up to date with what is happening in their direct 'community' (Inversoft, 2012). Message boards are an asynchronous type of interaction meaning that participants do not have to be present at the same time to virtually carry on the conversation. Conversations do not happen in 'real' time and may have gaps between them. Message boards are public forms of OC where the communication is readily available on the Internet to anyone unless the administrator implements a password protection or invitation policy. Message boards are good for question and answer arenas and

are spaces that members can read about the community's history and learn about the group's interests (Putman, 2000). They are a great resource for finding answers to frequent questions, which can then in turn be used to create FAQ sections within the community.

### *Mailing lists*

Mailing lists are tools that allow the sending and receiving of emails between users. First a list is created by the administrator who then gives the list an address (ID), which is used to send out an email message to everyone. All participants who voluntarily register on the email list will receive the same email from the administrator and once they reply to that email it activates their use to the mailing list. Mailing lists are private arenas and the communication is kept between the invited members of the group. A mailing list is a tool used for small OCs or when organizations need to spread information such as newsletters or upcoming events (Putman, 2000). There are different formats of mailings list such as discussions and announcements (Burns-Millyard, 2014). Discussion lists are email only mailing list that offers communication for participants around the world. The discussion is on a given topic, which elicits comments to that topic from the subscribers on the list (2014). Announcement mailing lists offer product information in the form of coupons, product announcements holiday specials and discount incentives all aimed at the community's topic or concern (2014).

### *Instant messaging*

Instant messaging is exactly like what it sounds like as conversations happen in 'real' time instantaneously. Different from face-to-face interactions, instant messaging allows members from different geographic locations to have conversations. This form of communication is private, meaning the communication is only seen between members conversing. The messaging can occur in small groups, one on one, or within subgroups, which can function independently from the main OC. This type of synchronous interaction, meaning people in different locations are communication in real time, is as close to real life interactions as online can get (Putman, 2000).

### *Blogs*

Evidence has shown that individuals wish to create their own unique identity online, designing personal pages that house photos, bios and information on their current personal experiences. For some participating online a goal of reaching a broader market and gaining an audience is appealing, and creating their own blog page can do this. Blogs are used for a multitude of purposes allowing the blogs producer to express their opinions on topics such as cooking, sewing, gardening, politics, fashion or pop culture. Recent studies estimates the total number of people publishing blogs to be between 500,000 and 1 million compared to the 23 web logs reported by blogging historian, Blood, less than 15 years ago (Blood, 2000). For individuals dealing with health issues blogs are proven useful tools for individuals to share their health experiences in an anonymous communication to a vast audience (Rains, 2013).

## *Listserve*

Listserve are an alternative to traditional mailing lists in that they contain external addresses making them public or open, which allows anyone to join the conversation, search archived messages and leave questions (Roy, 2012). Users of a Listserve site receive a daily email message updating them on information from a randomly selected member of that Listserve. The email may contain a selection of information ranging from what that individual did that morning to a photo or a political statement and the content may be sent publicly or anonymously from within that Listserve group (2012). To protect anonymity the chosen email sender has the option of sending their message from his or her own email address or from the Listserve email address. Listserve staff members assure the material is appropriate for the group members prior to it being sent out (2012).

## *Social networking sites*

Social networking sites provide a method of communication done through personal web pages which can include any or all of these components: personal status updates, photos, video, audio recordings, blogs, message boards, instant messaging, and links to other websites (Safety & Security Centre, 2014). Facebook, LinkedIn, MySpace and Twitter are four commonly used forms of social networking sites (2014).

### *4.1.2 How online communities are developed, organized and structured*

OCs can easily be built by anyone in a matter of minutes using various software, which all aim to help make it simple to have an online site up and running quickly (Microsoft SharePoint, 2014). Many OCs have public areas housed on the home page where individuals can instant chat with one another. These central areas allow members to congregate and get up to speed on current events pertaining to the group (King, 2012). This central lobby environment is public therefore it is not an arena to share concerns on private matters. An OC may have a main page with a public home page offering options for members to join smaller groups. Many individuals prefer to choose a group or sub-group that are more focused on a subject allowing members to connect on a more intimate setting (2012). More specific still are private chat areas offered on many OC sites for individuals to speak one on one with each other. This allows closer relationship building and a higher level of honesty between members (2012).

An example of a popular OC that utilizes public, private and group structures is Facebook (Hughes, *et. al.*, 2012). Facebook is a social network site developed for users to stay connected with friends and family from any location in the world (Hughes, *et. al.*, 2012). The popularity and growth of Facebook has been expansive from 5.5 million users in 2005 to approximately 1 billion in 2011 (Facebook, 2011). Facebook allows individuals to create personal profiles where they can upload biographical information such as employment, marital status and educational history, personal preferences known as 'likes', images and status updates. Once a profile has been created users can connect with 'friends' and begin posting links, send messages, upload pictures and videos, or just observe other user profiles. Facebook

also offers instant messaging between friends, and group fan pages. The group pages allow users access to information on material relevant to the group, however, this access also allows said ‘group page’ access to the users profile (2012).

While individuals use Facebook for personal use, there is a staggering growth in popularity for community groups, organizations, teams and clubs, which are opening pages for self promotion, camaraderie and staying connected. Facebook allows the administrator of the page the option of making the page public or private, meaning that it can be open to anyone with a Facebook profile to join or closed for invitation only (Facebook, 2014). Facebook pages offer members to learn more about each other through observing their profiles. The group pages work well to keep members abreast of local news and to advertise group member’s successes, birthdays and important life events that may be overlooked in regular community meetings. Facebook is an open transparent OC, meaning that the information a user shares is publicly shared and accessible through the Internet indefinitely (2014). On account of the lack of privacy of the overall site, Facebook should not be used for communicating personal information between members on the main page.

Table 2 below compares the different forms of OC platforms (i.e. Message boards, Mailing lists, Instant messaging, Blogs, Listserve, Facebook). OCs must be clear with what types of platforms they want to incorporate in the structure of their OC. Platforms of an OC should be easy for the members to use and the community should be mindful of the costs associated with each platform as they require maintenance, which takes time and money (Millington, 2013). An online community should also include diversity in their platforms so that members have options that suit their communication preferences and be made aware as to whether the platform is public or private (2013).

**Table 2 - Benefits and tradeoffs of online community platforms**

	<b>Benefits</b>	<b>Tradeoffs</b>
<b>Message boards</b>	<p>Conversations between members continue regardless of participant’s online status, meaning that they are able to leave the conversation and return at their convenience (Suler, 2004).</p> <p>Acts as a resource for archived conversations as all information is publicly accessible later (Inversoft, 2012).</p>	<p>Requires staff to maintain the constant activity (Inversoft, 2012).</p> <p>Staff must be forward thinking to drive conversations and promote the site (2012).</p> <p>All material submitted on the message board is visible (2012).</p>
<b>Mailing list</b>	<p>They are private arenas and the communication is kept between the invited members of the group (Putman, 2000).</p> <p>A tool used to spread information such as newsletters or upcoming events (2000).</p>	<p>Can be demanding for members as people check their email frequently (Putman, 2000).</p> <p>Communication is private and is limited to the size of the email list (Miller School of Medicine University of Miami, 2008).</p>

<b>Instant messaging</b>	<b>Benefits</b>	<b>Tradeoffs</b>
	<p>Conversations happen in ‘real time’ (Putman, 2000).          Ability to keep up to date with people from all around the world with short conversations (2000).</p>	<p>There is no time to review the message before sending it like you can with email (Putman, 2000).          Difficult to gauge emotion of the sender of the message (2000).          Difficult to know that the person you are talking to is actually who they say they are (2000).</p>
<b>Blogs</b>	<b>Benefits</b>	<b>Tradeoffs</b>
	<p>Shares up to date content (Blood, 2000).          Good arena for members to share personal information about themselves that can be therapeutic (Rains, 2013).          Useful tools for sharing health experiences in an anonymous communication to a vast audience (2013).</p>	<p>Not all members feel comfortable commenting or contributing to blogs and instead observe quietly (Blood, 2000).</p>
<b>Listserv</b>	<b>Benefits</b>	<b>Tradeoffs</b>
	<p>Can contain external addresses making them public or open, allowing anyone to join the conversation, search archived messages, and leave questions (Listerv, 2014).          Being public generates heavy traffic (2014).          Members have the ability to remove themselves on his or her own without the administrator’s authority (2014).</p>	<p>Someone is responsible for managing the list and defining the rules and policies (Listserv, 2014).</p>
<b>Facebook</b>	<b>Benefits</b>	<b>Tradeoffs</b>
	<p>Good method to spread information (Pro/Con List, 2013).          Helps individuals build relationships (2013).          Can improve individual’s lives by being part of a community (2013).          They can educate the public and disarm stigma and myths (2013).</p>	<p>Some material can be false if not monitored (Pro/Con List, 2013).          Lack of privacy allows personal information to be readily available (2013).          In some instances they can entice people to spend less time in face-to-face communication (2013).          They are susceptible to viral attacks and hackers (2013).</p>

When developing an OC it is important for the developer to understand the main objective, mission and vision so that they can make the correct decisions on how they launch the site. Relying on existing public platforms such as Facebook may not be an appropriate choice for organizations dealing with marginalized individuals, rather a private invitation only OC should be considered. To assist in making imperative decisions early in the development stage observing the *lifecycle* approach can be an effective method to ensure all of the groups needs will be adequately met. The lifecycle approach was devised by a group of community minded thinkers who wanted to create a formulaic outline of what they believed were the necessary considerations for structuring and developing a successful OC (Cambridge, Kaplan, & Suter 2005).

### 4.1.3 Utilizing the Lifecycle approach for developing a successful online community

The collaborated efforts of the National Learning Infrastructure Initiative at EDUCAUSE, the American Association for Higher Education, and iCoHere who shared their experiences in operating communities in an online arena, resulted in the step-by-step guide for designing and cultivating communities of practice (Cambridge, Kaplan, & Suter 2005). This guide provides the tools to design, launch and grow a successful OC. Understanding that communities experience a *lifecycle* where they emerge and grow experiencing a life span (p.1) is the first step in developing the structure for an OC.

As Cambridge, Kaplan, and Suter suggest, a clear purpose is paramount throughout an OCs evolution along the lifecycle. Conducting a needs assessment using interviews, surveys or focus groups will define the audience, domain, purpose, goals and projected outcomes that the community wishes to achieve (2005). As each community is unique with its own goals and needs, when structuring an OC the design therefore should be driven by a well-defined purpose. The most successful way to frame the OCs purpose is to identify how the OC purports to benefit its stakeholders and then address how those benefits will be met (2005). By having the purpose set, it focuses on participants, aiding in the success both in immediate and future goals.

Once the purpose of the OC is identified the next steps are to frame the infrastructure or platform used to develop the site (Microsoft SharePoint, 2014) and create the language of inquiry (methods to measure success) that the community will use to understand and document its success (Cambridge, Kaplan, & Suter 2005). Properly documenting the OCs successes will aid in achieving purpose, meeting the communities goals, responding to its needs, and making future decisions (p.2). The purpose, goals and results will be measured through consistent inquiry, interviews, surveys and focus groups to assess operations (p.6).

## 4.2 Health Care Online Communities – A Platform Focused on Health Care, Education and Individual Support During Illness

There are many factors to consider when developing an online community OC, yet when individuals experiencing life crisis or illness form them on their own, it raises the importance of other issues pertaining to safety and additional guidelines needed when protecting vulnerable populations (Jones, 2012). These issues concern how participants interact as well as what information is disclosed in the building of online relationship (Walther, 1992). An example of drug treatment sharing is examined as well as the available opportunities of removing those risks.

Health care OCs offer individuals not only relevant information to their health concerns, but also a community of participants to support and offer emotional assistance, and an arena to build confidence (Samoocha *et al.*, 2010). Participating in a health care OC (HCOC) members feel supported from the community psychologically through shared success stories from other members or through the

relationships developed with other members (Wasko, *et. al.*, 2013). Patients become empowered when they can understand and influence their own health status (Samoocha *et al.*, 2010). To that end, for PWE, managing one's personal healthcare can be overwhelming, juggling the new challenges that come with dealing with illness. Sunderland, Beekhuyzen, Kendall, & Walski (2013) have identified a number of emotional challenges that can compound one's wellbeing which include: a general lack of knowledge about their illness, lack of a thorough or comprehensible explanation of the medical condition, and the perceived and actual emotional and physical losses associated with their medical condition (2013). Various online tools and resources now offer individuals help in managing their healthcare and deepen their understanding of their condition. These tools further contribute to an individual's ability to seek out alternative approaches and treatments as well as the ability to connect with others who share the same medical condition (2013).

There are complexities that exist in HCOC that are not present in other OCs as for some participants with certain health conditions any miscalculated advice available in the HCOC has the potential to result in death (Wasko, *et. al.*, 2013). The ramifications inherent to the information available within HCOCs, therefore, can be extremely serious. Information sharing is a central objective of OCs, but with health related conditions there are often other factors that can limit this objective. There may be social stigma associated with acute and chronic conditions such as those perceived to be associated with HIV/AIDS or mental illness, for example, that may make participants reluctant to share (2013). Community participation provides members with access to unique benefits that exists only within a specific OC. The information participants receive can increase in accordance with the individual's level of involvement to the OC. This knowledge allows the participant to value the information and tailor it to suit their personal situation (2013). Participants want to feel like they are making informed decisions and having the information to do so is an important factor. Citing all the information presented within an OC encourages participants to make informed decisions and to take responsibility for their actions (Kouzes & Posner, 1987). Within the healthcare sector, OCs are established to support members by providing a means for empowering patients dealing with difficult health related issues (Rohrer *et al.*, 2008). Allowing participants of an HCOC to access information concerning specific information on obscure treatments and insights presents a unique opportunity for HCOCs to promote health care and wellbeing (Thackeray, Neiger, Hanson, & McKenzie, 2008).

*Examples of health care online communities successfully benefiting participants marginalized by medical illness:*

- *SickKids*

Currently in Toronto, Canada, there is a program called SickKids which is an online social network specially designed for young patients that have to stay in the hospital (SickKids, 2012). Patients who would not otherwise be able to connect with each other on account of their illnesses are now able to connect via the Internet. SickKids focuses on connecting young patients through a program called Upopolis, which is a service that offers each patient the opportunity to create online personal profiles, an option to create a blog, instant chat and child friendly games.



Upopolis is a password-protected social network utilizing content-filtering tools and pre-consented contacts, which acts within a protected atmosphere allowing patients to communicate (2012).

Upopolis provides patients with homework sites to keep them up to date with schoolwork, child friendly sites offering wellness information, and connections to other children with similar health challenges. This OC offers patients tools in dealing with emotional issues associated with being in the hospital, combating isolation and communicating their feelings (2012). The relationships between the members of this HCOC are forged through the connections made between their shared experience and the empowerment of one's own healthcare management.

- *PatchWorx*

A California non-profit organization created an OC called PatchWorx designed to assist young people facing illness and disability (Hillan, 2003). The founder and president of PatchWorx believes creating an online computer mediated form of communication helps children develop skills to better cope with their illness and provides access to the tools they need to practice seeking online information so that they may be proactive in finding "social support" (2003). On account of the young age of PatchWorx members, the OC requires parental permission to join and is facilitated by adult volunteers that monitor the site.

In the United States, more than a half a million children between the ages of 5 and 18 suffer from illness or disability. The isolation from either extended hospital stays or being restricted by being homebound is a challenge. Participating in an OC can allow members to communicate feelings, concerns, and become more active in their own healthcare (2003).

Middleton explains the mission and purpose of PatchWorx, "Many children facing critical illness feel alone, and are lacking social and peer support. This is particularly true these days when many family and youth-related support systems are weakening...We designed PatchWorx to help these kids reach each others across the barriers of distance and disability and, through developing friendships, find new ways to deal with their challenges" (2003).

Below, Table 3 depicts the use of the lifecycle (Cambridge, Kaplan, & Suter 2005) approach, which offers guidance to organizations like SickKids and PatchWorx to understand their audience, purpose, goals and methods that they will use to measure successes.

**Table 3 - Utilizing aspects of the lifecycle approach to assess examples of online communities**

	<b>SickKids</b>	<b>PatchWorx</b>
<b>Who is the audience?</b>	Patients staying at SickKids for long periods of time (SickKids, 2012).	Children facing illness and or disability (PatchWorx, 2003).
<b>What is the purpose?</b>	Offering a community for the children patients staying at SickKids by supplying online school programs, child appropriate games, ways to interact with other patients and relevant information allowing them to gain a sense of control over their health care treatment (SickKids, 2012).	To develop an OC for the youth facing illness and disability that houses opportunities to improve their skills in dealing with their illness (PatchWorx, 2003).
<b>What are the main goals to be achieved?</b>	To have a safe OC for the patients aiding them in dealing with their illness and long hospital stay (SickKids, 2012). Offer a feeling of community for the child patients who are unable to leave their beds (2012). Allow the patients to keep up with their school work while dealing with their illness (2012).	Offering the members of the OC support while dealing with their illness or disability (PatchWorx, 2003). Create a community enriched in material and resources specific to their needs (2003).
<b>How will success be measured?</b>	The staff of SickKids must decide what methods that they will use to measure the purpose and goals of the OC such as interviews, discussions, surveys and focus groups. By measuring the successes it will ultimately create forward thinking and future goals for the OC.	The staff of PatchWorx must decide what methods that they will use to measure the purpose and goals of the OC such as interviews, discussions, surveys and focus groups. By measuring the successes it will ultimately create forward thinking and future goals for the OC.

Gathering the aforementioned information helps communities, groups, and organizations focus their attention on their purpose, ultimately aiding in achieving their goals thereby creating a future of successes. For a more detailed example of the lifecycle, a chart is available in Appendix A (p.58).

# SECTION FIVE: Examples of Strengths and Challenges of Online Communities for Participants Marginalized by Illness

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This Section discusses both strengths and potential weaknesses of online communities (OCs) specific to how they would affect participants marginalized due to illness. In certain cases a weakness for one OC may be a strength for another, thus it is imperative to understand the communities needs, purpose, and goals early in the development stage to avoid any potential challenges.

## 5.1 Examples of Strengths/Challenges that Exists with Popular Forms of Online Community

A challenge to one OC may be seen as a strength to another as no one OC is the same. Therefore this section lists challenges common to OC as defined by researchers and how they may be potential strengths to an OC developed for marginalized members due to illness.

### *Participation inequality*

In some instances an OC encourages silent participation, meaning when individuals observe but do not comment or participate (Nielsen, 2006), this is called “lurking”. Lurking or *participation inequality*, which was first studied in the early 1990’s (2006) can be a concern for participants of OCs marginalized by medical illness if the sensitive information being shared between the members does not remain private through a password protection service. Persistent peripheral participation (lurking) may be seen as a threat to an OC as they can undermine the community’s collective efforts “and lurkers may draw on the knowledge of others without contributing anything in return”(Wasko et al 2005, pg. 37). Alternatively, researchers have agreed that lurkers act as members to OCs through their observation, and this act is in fact participation (Lave et al. 1991). Lurking can also be a period of time that should be provided to inexperienced members to prepare for their entry into participation (1991).

Nielsen believes that there are no viable means to overcome participation inequality, however, size may contribute to the inequality ratio therefore by creating password protected groups with a 50 members or less policy may encourage member participation through the safety of the intimate arena. For the individuals who require time to participate and lurk on the site, they would not be considered a threat to the members of the general site if proper provisions were enacted such as invitation only policies for specific groups.

### *Power of anonymity and disinhibition effect*

Researchers have recognized an effect, which can happen to individuals when online called the disinhibition effect of Cyberspace (Suler, 2004). Suler identified that certain individuals will do and say things that they would never do in the “face-to-face world” (2004). The act of hiding ones identity and disconnecting from their actions is considered dissociation anonymity (2004). The combination of having anonymity and being invisible online adds to the disinhibition effect as a person does not need to worry about the usual body language that may stop them from being open about themselves (2004). Researchers say that in normal face-to face conversations people often avoid eye contact when discussing personal issues making it easier to be vulnerable. Online it can be that much easier to express personal issues with newly made relationships (2004).

OCs create a level playing field which is very important for individuals who are experiencing losses in their life associated with their health and adapting to a life with a disability. People have reported feeling like their “true self” online, by using their cyber identity it allows them to feel like the person they want to present to the world (2004). Anonymity and the disinhibition effect is considered positive for persons who struggle with anxiety and depressive disorders. Individuals who are generally shy in face-to-face communications are able to open up in the cyber world and have a community of people with whom they can share and connect (Suler, 2004). The disinhibition effect can eliminate the surroundings of the home environment, allowing individuals to communicate a story of a life and community that is more desirable than the life of their disability. For individuals living with extreme disabilities or homebound due to illness, this can be of great comfort (2004).

### *Privacy protection of personal information*

There are many different forms of OCs, some with open concept and others with closed invitation only policies. Due to the fact that community members living with epilepsy who may experience uncontrolled seizures have higher levels of depression, anxiety, and suicidal ideation (Epilepsy Toronto, 2013) a health care online community (HCOC) would be an appropriate structure for this group (Wasko, *et. al.*, 2013). An administrator should create a comfortable environment for new members by first having an introduction to the OC that walks each member through the OC and allows them to answer any questions. The administrator will introduce the members to individuals or specific groups to connect with, all while heavily monitoring the site for any nefarious activity (bullying, threatening language, or inappropriate medication sharing) and responding to it when necessary. HCOC have physician’s who frequent the site to share relevant content associated with member’s health condition (Samoocha *et al.*, 2010). The physician’s can observe the site, however, they maintain members privacy as they may have chronic conditions that can carry social stigmas such as those associated with mental illness (Wasko, *et. al.*, 2013). The approach of a HCOC supports its members by empowering them, by giving them the tools to begin managing their own health care and the space to communicate with other individuals in the hope of developing positive relationships, which are fundamental to the overall wellbeing of each participant (Rohrer *et al.*, 2008).

HCOC typically use central lobbies, allowing participants to post questions and to revisit the response at their convenience, creating asynchronous communication (Suler, 2004). These central lobbies are arenas that act much like a coffee room in a face-to-face environment, where members can share information, distribute local and international information relevant to the community and have open conversations. An OC that uses this central lobby in the form of spreading useful information about health related issues is MedHelp (MeHelp, 2012). MedHelp is a large scale HCOC offering expert advice in weight loss, mental health advice, specific disease questions, and forums discussing countless medical concerns. MedHelp and other large scale HCOC are educational tools designed for individuals suffering with medical illness as well as their family members dealing with the patient (2012).

These educational OCs should not be confused with an OC that is aimed at building and forging relationships between members. A HCOC such as MedHelp offers individuals wanting to visit and gain knowledge about a subject with a wide range of information; however, it may not be the suitable OC for participants marginalized due to illness who are specifically seeking a community to belong to and a group to connect with. MedHelp's primary concern is information sharing, not membership relationship building.

To protect the personal information offered by the members marginalized by illness such as intimate stories of their life experiences living with their condition, it is recommended using a service similar to Upopolis (SickKids, 2012). Upopolis is a social network service with an objective to maintain an OCs content confidentiality, password access settings, and to protect member's privacy (2012). Members will be expected to offer their personal information to the OC administrator to obtain a password and login in capability, however, the information will be restricted from any other user unless members choose to share. Protecting privacy for HCOC is vital especially to vulnerable communities, as divulging personal stories about ones self can be very intimidating and requires a safe environment. It has been noted that in extreme cases, if privacy concerns are not properly managed, it can create or exacerbate life and death situations for vulnerable members (Wasko, *et. al.*, 2013).

*Developing an online community to act as a traditional community (So members feel deeply connected to one another and connected to the purpose of the community)*

OCs are developed for a multitude of groups to support individuals with issues such as alcoholism, eating disorders, dating, and other psychological conditions (Wuthnow, 1998). The OCs are created to provide care for one another, share intimate issues, and act as platforms for the individuals to communicate with a small group in a safe and supported environment (1998). As Robert Wuthnow (1998) emphasizes, "this is not an accurate real life community as it once was in the past". He continues "it is built to support the individual in a safe place and does not create a life to live together, the social contract binding the members together asserts only the weakest of obligations; come if you are able, participate if you wish to, and leave if you are dissatisfied" (p, 70). However, when individuals are dealing with loss, or a new medical illness, a support group can offer resources, answer health related questions, listen to and support individuals, and be a necessary community to that individual going through a difficult experience (1998). It has been noted by Wuthnow that challenges exist in developing OCs that act as a traditional

communities (meaning; consistent meetings, regular events, relationships between members, etc.). However, there are methods to create camaraderie and sense of purpose and belonging among members, which include:

- Sharing stories personal and otherwise helps members find connections, understand one another on a deeper level and to build trust
- Regular fundraising events work to build camaraderie among the members and enhance group dynamics
- Creating ideas as a group to educate the public about their communities purpose
- Celebrate member's important life events, i.e. birthdays, new babies, graduations
- Keeping members abreast on important local events related to the community
- Keep the homepage current with positive affirmations and imagery; remembering that some members are homebound
- Develop ideas on upcoming event as a group, i.e. themes, dates, perhaps meeting offline for certain projects (this can be a turning point for certain members)
- When fundraising moneys are donated notify all members on the home page to keep morale up and to keep minds focused on future goals
- Most importantly is keeping the conversation going, a quiet page is a lonely day for members who can not leave their home (Thorpe, 2011).

### *Story Sharing and Blogging*

Sharing personal stories is a useful method for human beings to communicate their present, past, and future and to build relationships (Thorpe, 2011). Communicating online faces the challenge of not having the ability of seeing others participant's body language, hearing the tone in their voice, or energy levels, which are contexts that are relied upon in face-to-face communications. Storytelling is a method of communication that breaks through the aforementioned barriers and connects individuals on a deeper level, connecting groups on a higher level, building strong social ties and group resilience (2011). Through sharing of stories, individuals in turn learn a great deal about themselves in the process. Storytelling is often used as a tool to discuss issues between individuals and share problems, as a way of inspiring one another and learning from each other's experiences (2011).

Blogs are proven useful tools for individuals to share their health experiences in an anonymous communication to a vast audience (Rains, 2013). Individuals who may be embarrassed by their illness or have become stigmatized due to the illness itself achieve a sense of freedom from discussing it by way of an electronic journal (2013). When 113 individuals were assessed through their blogs about their health experiences over an 8 week period what was revealed was the positive associations between the amount of disclosure and beneficial outcomes related to physical health (2013). Additionally participants who talked to another participant reported a lower perceived stress indicating that communication was a valuable tool in health related disclosure and coping (2013). Rains and Keating (2011) reported positive results in participants who blogged more frequently or supported others through reading their blog posts.

Research found that women with breast cancer who founded an OC and who have been consistently participating online in blog forums offer insight into their feelings and experiences through time (Chen & Rodgers, 2006). Research looked into how many women seek support, and interviews of 178 breast cancer patients revealed that as many as 42% use the Internet for medical health issues (2006). Looking at the psychosocial benefits, the results showed that many of the woman who turned to OC for support were more isolated from their families and were feeling distressed (Fogel, 2004). The overall results of research into woman with breast cancer who turned to OC for support was a greater optimism towards cancer, better skills to cope with the disease, improved mood, decreased psychological suffering, and newly developed coping methods to deal with stress (Chen & Rodgers, 2006). The benefits gained from the sharing of life stories through blogs contributed to empowerment for the women as well as providing the researchers a rich context of data that they could read to understand how OC affected the women over time (2006).

Medication and the distribution of treatment plans are at times shared between members of health OCs, this is partly due to members learning about others illness through personal story sharing in the form of blogs and comparing others personal situation to their own. However, there are ramifications that can develop as has been identified between members of breast cancer OCs who share information about the anti depressant treatments and medications for anti-nausea (Chen & Rodgers, 2006), leading members to then make personal changes to the course of their treatment that can be detrimental and life threatening. Sharing drug treatment in OCs can be dangerous, so it is good practice for physicians to spend time on OC to provide “expert” information to debunk myths (2006).

As previously discussed individuals suffering from marginalization and isolation due to epilepsy often experience emotional and psychological conditions related to their condition. These psychological conditions come in the form of anxiety, perhaps due to the unpredictable nature of living with epilepsy or depression possibly developed from the seizures or medications used to treat the disorder. These factors must be addressed when a community is in the initial stages of structuring and developing their OC. Methods of communication for vulnerable communities should be determined based on the ease of use, privacy of member’s personal information, and the desired ability of achieving a high rate of participation and involvement from it’s members.

### *5.1.1 An Example of How the Online Community will be Structured*

This example explains how an OC should be developed for participants marginalized due to illness. The following explores the roles of staff members, the platforms of communication and methods of protecting member’s privacy.

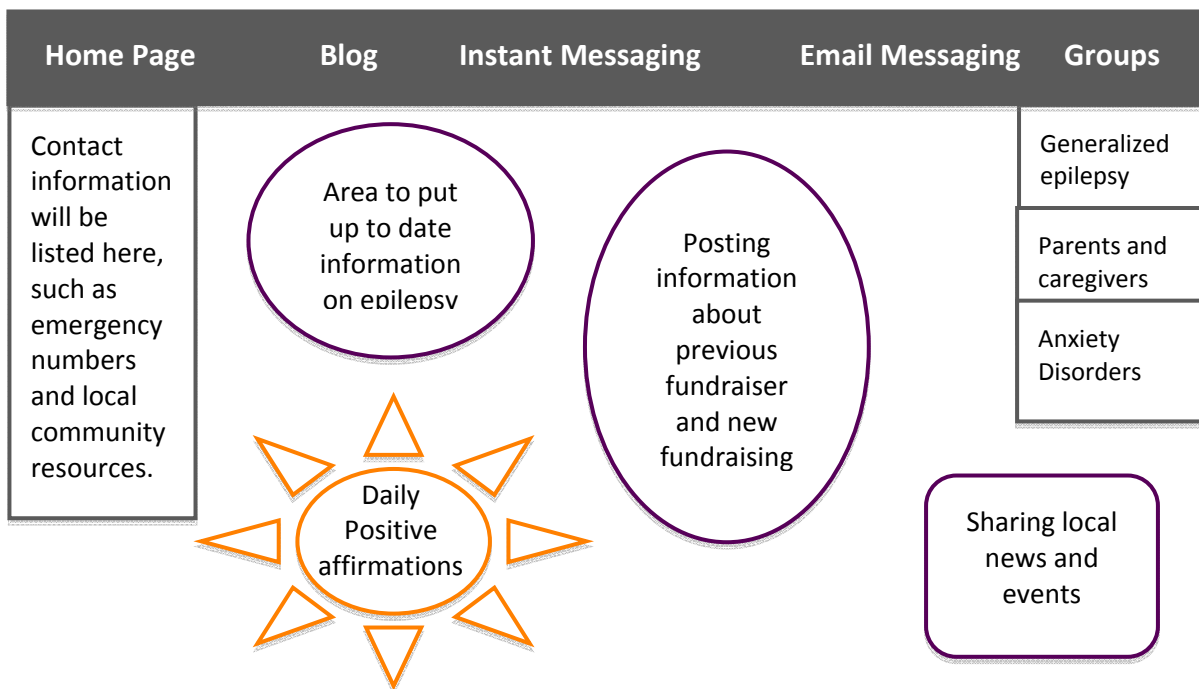
Employing an administrator, monitor and the presence of a Neurologist or Psychologist observing the material submitted by group members will ensure the OC is safe and the information is accurate. The monitor of the groups is armed with the skills to observe nefarious behaviour (members using harmful language, bullying, or inappropriate sharing of medial treatments) and then has the authority to remove

that individual from the group. By implementing a social network service similar to Upopolis (SickKids, 2012) that will provide strict privacy control over the groups assures members that their personal information remains private. With the addition of privacy protection, the presence of physicians and a group monitor allows members to feel safe to share their personal stories with other members, helping to build trust and contributes to their own improved self-esteem. Developing an OC that incorporates many platforms of communication such as blog, groups, instant messaging, or private chat is imperative to allowing members the choice to what best suits their individual needs. The following is a list of factors to include:

- Developing an OC that is diverse, incorporating formats such as blog, groups that address varied issues on the related illness, instant messaging, or private chat, Facebook links etc.
- Having an administrator create an ‘invitation only policy’ for the groups of the OC
- Implement a monitor to oversee the groups
- The monitor has the skills to observe negative behavior and the authority to remove members acting inappropriately
- Implementing a social network services similar to Upopolis (SickKids, 2012), providing privacy protection for the OC

An example of how an OC that would operate successfully for the Epilepsy Association of Calgary (EAC) and beyond would incorporate a multitude of platforms of communication that the members may choose from, a place of knowledge gathering, groups, and both public or private areas to comment or post a blog. The following is a rudimentary example of how this structure of OC would appear online:

### Example of the Epilepsy Association of Calgary Online Community





At the top of the OC example is a listing of options available for members such as home page, blog, instant messaging, email messaging and groups. The members can scroll over the headings to pull down further options. If a member scrolls over *Home page* as an example, they will have access to the local resources available to them for services such as, mental health, emergency, the EAC contact information, and email contacts for EAC members etc. When a member scrolls over *Group* as an example, they have options such as the types of epilepsy groups, parents and caregiver groups, and anxiety disorder groups; this offers an intimate setting for specific conversation organized around that topic. The members joining the specific groups must request an invitation from the administrator of the OC, which can be done simply by sending a request to the administrator. In certain circumstances a perspective member may be recommended to join a specific group by his or her physician, in which case an email request can be sent directly from the physician to the administrator. The new member will then receive an email from the administrator with an invitation to the group. *Groups* do not all have to operate so rigidly, however, as in certain circumstances having a group designed for members with specific needs is recommended. The *Blog* pages will have many different topics depending on who has posted that week, and members are free to post and add comments to the blog to keep the conversation flowing. The blog page is an open public space. The *Instant messaging*, and *Email messaging* pages are private pages and like the group pages, requires a password.

The following Section produces a breakdown of the literature reviewed throughout this report. Furthermore recommendations are offered to the EAC on whether there is a need for developing an alternative approach for community for the individuals in Calgary living with epilepsy that have become isolated or marginalized due to their condition.

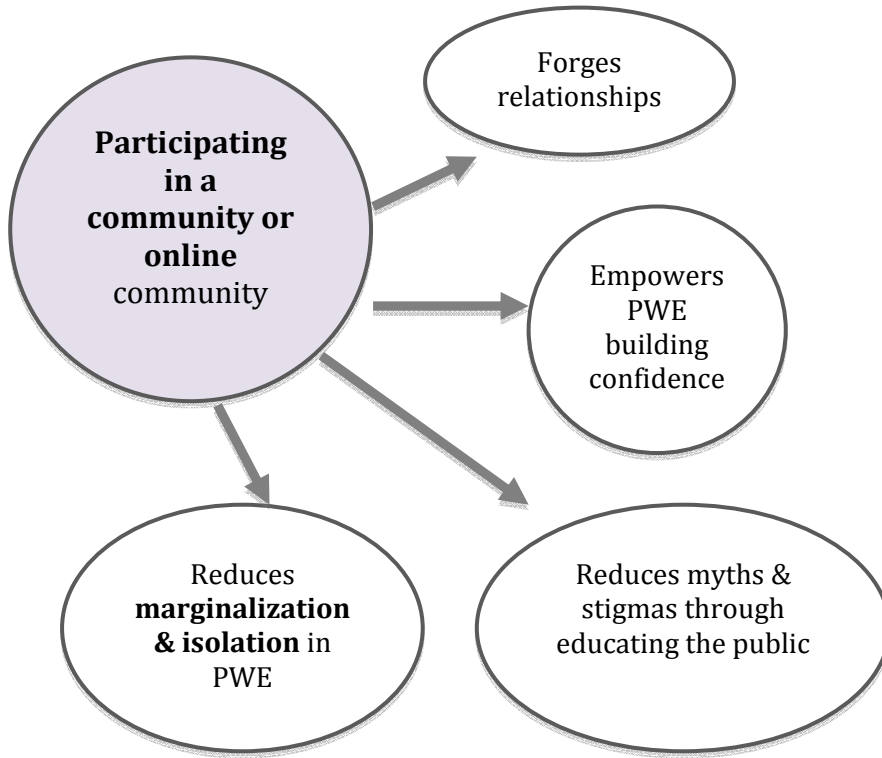
# SECTION SIX: Recommendations for the Epilepsy Association of Calgary

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On account of the evidence found in the literature proving that community is a fundamental part of human nature (Kim, 2000); it is strongly recommended that the Epilepsy Association of Calgary (EAC) develop an online community (OC) specific to the marginalized Calgarians living with epilepsy who do not have access to traditional forms of community. The particular circumstances that limit a person with epilepsy's (PWEs) opportunity to connect meaningfully to traditional communities can range from the condition of epilepsy itself including the frequency of seizures as well the unpredictable nature of the disorder, the emotional conditions associated with epilepsy such as depression and anxiety, the lack of treatment options, the resulting side effects of current medicinal treatment options, and the social stigma of epilepsy that impacts their overall wellbeing. Whatever the reasons an individual becomes marginalized and isolated from society, the lack of community and belonging to a group can negatively impact that person's life both physically and emotionally (Feist, 2013). The development of an OC for members of the EAC and other Calgarians affected by epilepsy is recommended as an alternative to the current traditional community opportunities. This report examined the importance of community for individuals and how it serves to fulfill an important basic human need (Kim, 2000). Individuals who have become isolated on account of their epilepsy require alternative methods of community which can be accomplished to varying degrees through an online setting as seen with examples of other health related OCs, including SickKids (SickKids, 2012) and PatchWorx (PatchWorx, 2003), two organizations with a mandate of creating a sense of community for children facing illness and disability. OCs offer a wealth of possibilities for the improvement of participants wellbeing through increased insight into their own treatment and care, relationship building, opportunities for improving self-esteem, and by assisting in effectively dealing with their marginalization by taking steps to regain their independence and become active participants in their communities.

Research has shown that individuals suffering from medical illness who take part in a community for support have positive results in the form of empowerment and an overall sense of wellbeing (Chen & Rodgers, 2006). Figure 4, depicts the results that occur when isolated and marginalized individuals participate in community.

**Figure 4 – Online communities reducing isolation and marginalization**



This Section will show that by developing an OC for the marginalized and isolated individuals living with epilepsy will not only support those individuals but also will work towards educating the public about the facts of epilepsy in an effort to diminish the myths and stigmas. The following are recommendations towards developing an OC specific to the EAC.

### **6.1 Recommendations Toward Building an Online Community**

This goal of this report was to answer the question: *Can marginalized individuals living with epilepsy benefit from online communities?* The spectrum of mental and emotional conditions that co-exist with the disorder of epilepsy contributing to isolation and marginalization was assessed to learn if an OC would benefit individuals living with epilepsy. In response to the literature on the importance of community on a person’s quality of life and the evidence proving that the psychological conditions associated with epilepsy can contribute to isolation and marginalization from society, it is strongly recommended that an OC be developed for the EAC. The structure of the OC should be built around alleviating the isolation brought on by the emotional conditions associated with epilepsy. Furthermore the OCs should be goal driven towards eradicating the persistent myths and stigma of epilepsy through education and

community involvement. The following are the recommendations for developing, structuring and launching such an OC for the EAC:

It is recommended that the OC model be based on a health care approach. There are potential challenges when using OCs for participants marginalized due to illness as alternatives to traditional communities, health care online communities (HCOC) can mitigate these potential challenges when structured properly. HCOC offer support otherwise not possible (Wasko, *et. al.*, 2013) such as: physicians sharing relevant information associated with their health condition (Samoocha *et al.*, 2010), keeping all information relevant and up to date, and maintaining privacy as the members may have chronic conditions that can carry social stigmas associated with mental illness (Wasko, *et. al.*, 2013). The approach of a HCOC supports its members by empowering them, promoting health care and contributing to the development of an overall sense of wellbeing all within an arena that offers privacy protected areas for its members (Rohrer et al., 2008).

It is strongly recommended using aspects of the *lifecycle* approach, a guide that provides the tools to design, launch and grow a successful OC (Cambridge, Kaplan, & Suter, 2005). The collaborated efforts of the National Learning Infrastructure Initiative at EDUCAUSE, the American Association for Higher Education, and iCohere who shared their experiences in operating community in an online arena, resulted in a step-by-step guide for designing and cultivating communities of practice (2005).

The following identifies the six lifecycle phases:

- **Inquire:** This is the phase of identifying the audience, purpose, goals, and vision for the community. This process can be conducted through a process of exploration and inquiry.
- **Design:** Defining the activities, group processes, and roles that will support the community's main objectives.
- **Prototype:** Select a group of stakeholders who will test the OC and offer opinions to refine and establish a successful outcome.
- **Launch:** Expose the OC to a broader audience, welcoming new members.
- **Grow:** Engage the members in collaborative learning, sharing activities, group projects and networking events to help increase participation and contribution.
- **Sustain:** Cultivate the OC by implementing new strategies, goals, activities, roles, and be forward thinking (p.2)

The pertinent questions involved in the development and structuring of the OC using the lifecycle approach can be found in Appendix A.

The OC should implement many platforms of communication such as message boards, mailing lists, instant messages, blogs, listserves, and social network services such as Facebook, Twitter and LinkedIn (2014). Having many options of communication allows the member's choice in how they converse with the other participants.

**Table 4 - Recommendations for building an online community**

<b>Recommendation:</b>	<b>Possible Activities:</b>	<b>Benefits Addressed:</b>
Employ a health care OC approach to the structure and development of the OC	Share relevant information associated with epilepsy (Samoocha et al., 2010). Keep all content relevant and up to date through the approval of physicians (2010). Maintain the privacy of the member’s personal information (Rohrer et al., 2008).	Alleviate social stigmas associated with epilepsy and psychological conditions (Wasko, et. al., 2013). Allows member’s to make educated decisions about their health condition (Samoocha <i>et al.</i> , 2010). Allows member to feel comfortable to share personal information about their illness, developing an overall sense of well being (Rohrer et al., 2008).
Utilize a Lifecycle approach to the structure and development of the OC (Cambridge, Kaplan, & Suter, 2005).	The EAC staff should do a needs assessment answering the lifecycle chart (found in Appendix A) prior to developing and structuring the OC	The knowledge gathered from the lifecycle assessment will focus the OC identifying the audience, purpose, goals, and vision for the community (Cambridge, Kaplan, & Suter, 2005).
Utilize many platforms of communication on the OC	Offer message boards, mailing lists, instant messaging, blogs, Listserves, Facebook (2010) links, LinkedIn (2014) links and other community links and resources to the OC	Offers members a choice in how they wish to communicate with other members on the OC

## **6.2 Recommendations for Building Member Participation**

It is recommended that all tools used on the OC should encourage ‘story sharing’ as a method of empowering members, to break down barriers, and to help forge relationships. The main objective of any OC is participation and a consistent flow of information and action on the site, therefore offering many forms of communication will offer members options for participation. To help improve the lives of individuals with epilepsy who have been isolated from society the method of story sharing will be strongly recommended by the administrator and monitor of the OC. Story sharing is an effective tool that allows individuals to communicate their present, past, and future (Thorpe, 2011). Utilizing online story sharing mitigates the challenges of not having the capacity of seeing other participant’s body language, hearing their voice tones, and observing energy levels, which are contexts that are relied upon in the face-to-face communication. Recommending story sharing as a method of communication will break down the

aforementioned barriers and connect individuals on a deeper level, connecting groups on a higher level, building strong social ties and group resilience (2011). When dealing with members marginalized and isolated from traditional forms of community, utilizing story sharing as a method to bridge relationships will enable individuals to construct their own identity (Hall, 1996), share their illness, express emotions, and share experiences in their own narrative (Chen & Rodgers, 2006). The strength of story sharing and participating in an OC empowers individuals online as well as offline (Preece, 2005). In addition to members using story sharing, instant messaging and emailing between members in groups, it is also recommended that member's successes be shared on the home page as a means of inspiring and motivating members to increase participation.

It is recommended that the OC have relevant and meaningful content readily available to its member's. Physicians must approve the content posted on the sites home page in order to maintain its accuracy. Having the physicians cite all information that they post is important as members need to know they are making correct and informed decisions over their own healthcare management (Wasko, *et. al.*, 2013). By hosting a site about epilepsy rich in content assists in the challenge of eradicating myths and stigma.

### *Defining roles*

- *Architects*

The architects of the OC must develop a site sensitive to the needs of its members. Certain members of the OC who are vulnerable due to high levels of depression, anxiety and suicidal ideation associated with their epilepsy require more specific privacy controls. Therefore, the architect's should implement a service that will serve to protect the privacy for its members as well as the content provided on the site. It is essential that the structure of the OC include privacy controls as researchers have noted that OCs that remain completely open to the public offer a lower threshold for participation (Booth, 2011).

For the OC to properly protect privacy of its members it is recommended using a service similar to Upopolis (SickKids, 2012). Upopolis is a social network service used by SickKids, the hospital program working to connect child patients together offering education out of school programs, and implementing child safe games that work to build a sense of community for the members during extended hospital stays. The architect's main objective is maintaining the OCs confidentiality, password setting safety, and the protection of member's privacy. By eradicating any potential challenges typical to most OCs it creates a safe environment for the members to express themselves openly. The site should create a strong sense of community and include member's photos, indicating when members are online (Booth, 2011).

- *Administrator*

The role of the administrator or manager of the OC is to oversee the sites membership

policies including accepting new members, recruiting new members, achieving activities and goals, organizing the groups, protecting membership privacy and assisting members who require more assistance. The overarching position of the administrator should be to assess the OC operations and decipher any irregularities or weakness. The administrator will enact an invitation only policy to the individual groups, offering a safe environment for members to share freely. They should help keep conversations and participation active, entering comments to blogs or discussions, assuring that the site never stays quiet.

- *Monitor*

The monitor is a role filled by an individual who has the skills to identify nefarious activities occurring on the OC and then reacts appropriately to mitigate those issues. The groups on health care OC are specific to individuals needs and will all operate in a closed environment, meaning that they should be password protected and invitation only. The monitor has the ability to observe the conversations and activities occurring in these groups and can interject if they notice any negative behaviour or member's displaying signs of high levels of depression, anxiety or suicidal ideation. The monitor will offer Neurologist, Psychologist or other professional resources to members who require assistance. The monitor should highlight successes relevant to the community on the home page on a regular basis to engage member's participation.

- *Neurologist and Psychologist*

Neurologists and Psychologists will have access to the OC and all of the private groups enabling them to assess the content of the OC maintaining its relevance and accuracy. Their role in the OC is to do regular check-ins to observe that members are not showing signs of emotional or psychological issues or participating in the sharing of treatment ideas and or medication changes. When the monitor has detected any questionable activity they will notify the Neurologists and Psychologist immediately.

### *Activities*

- *Fundraising events*

Traditional community groups create regular fundraising events to develop camaraderie amongst the collective, these events come in a many forms from bake sales, to dances, bottle drives, mail outs, soliciting the general public for money or national campaigns and awareness weeks. It is recommended that the OC utilize these traditional forms of community fundraising approaches among online participants as well as social media campaigns. An example of a social media campaign could be testing the general public's ability to go one week without driving their vehicle as PWE commonly lose their license due to their condition. This could be a great opportunity for raising funds and raising epilepsy awareness. The purpose of fundraising will not only connect members, it will raise public awareness, working towards diminishing stigmas and

myths about epilepsy which is an imperative component in working toward eliminating the marginalization of individuals who suffer from uncontrolled seizures.

It is recommended that the OC contribute money raised toward furthering epilepsy research, medical advancements and community projects, for the growing need of epilepsy patients. Developing a grant dedicated to epilepsy research is a great tool for increasing awareness and aiding in the development medical advancements for epilepsy. The main goal of fundraising being to raise awareness on the important issue of educating the public about epilepsy and diminishing any stigmas and myths.

- Volunteer section

Developing a volunteer section in the website that allows PWE willing to share their stories and to become community media contacts with the goal of educating the public is a tool that could represent epilepsy in a positive perspective.

**Table 5 - Recommendations for participation**

<b>Recommendation:</b>	<b>Possible Activities:</b>	<b>Benefits Addressed:</b>
Utilizing 'story sharing' as a method to engage the members	Create a blog area on the site specific to the sharing of personal stories related to their epilepsy (private and public)	Help reduce the number of individuals suffering from isolation due to lack of skills in communication and relationship building
Define the roles of OC staff	<ul style="list-style-type: none"> <li>• Architect</li> </ul> Develop a site sensitive to the needs of its members, with higher levels of privacy controls	Give a sense of safety for members to share personal stories about their illness
	<ul style="list-style-type: none"> <li>• Administrator</li> </ul> Oversees the sites membership policies Accepting new members Recruiting new members Achieving activities and goals Organize the groups Assisting members who require more assistance	Create a well organized site open to generate new members, able to support members who require more assistance
	<ul style="list-style-type: none"> <li>• Monitor</li> </ul> Identify nefarious activities occurring React appropriately to mitigate those issues	Maintain a site safe from negative activity so members can be open and honest about their illness



	<ul style="list-style-type: none"> <li>• Neurologist and Psychologist</li> </ul> <p>Maintaining the OCs content is relevant and accurate Do regular check-ins to observe that members are not showing signs of emotional or psychological issues Make sure there are no signs of sharing of treatment ideas and or medication changes.</p>	Maintain the accuracy of the content on the site while protecting the most vulnerable members with physician supervision
Define the activities and goals of the OC	<ul style="list-style-type: none"> <li>• Fundraising events</li> </ul>	Develop group camaraderie while raising funds that can go towards epilepsy awareness, educating the public to help diminish myths and stigma
	<ul style="list-style-type: none"> <li>• Volunteer section</li> </ul>	PWE can share their stories about living with epilepsy to become community media contacts. To spread facts about epilepsy helping to diminish myths and stigma

### 6.3 Recommendation to conduct further research into the legal frameworks pertaining to privacy and ethics

It is suggested that while the Epilepsy Association of Calgary (EAC) conducts a needs assessment to determine fundamental requirements for the OC that they also consider making strategic partnerships with other similar organizations operating in the same capacity who are currently using OC or consider it an asset to their organization. By sharing experiences with other community minded organizations the EAC will not only expand their current understanding of OC, its benefits and challenges, they will also have the opportunity of amalgamating ideas with these organizations with a goal of benefiting individuals living with epilepsy. An example of an organization that the EAC may connect with is the Epilepsy Association of Edmonton (2010) (EAE) who currently has a general website and Facebook page. Through sharing experiences, ideas, fears, goals and merging ideas, it can be beneficial in the initial stages of developing an OC for the EAC. Connecting with organizations who are community minded and driven to help individuals with illness or disability widens the EAC’s audience, creating new opportunities for fund development.

Furthermore it is suggested that during the needs assessment of the OC that the EAC consider how the OC fits within legal, professional ethics, and moral frameworks, particularly as they relate to privacy

and security of information. This will be of great importance while they are working with a vulnerable community who may be sharing information that holds social stigma. The EAC will want legalities in place to maintain member's privacy is not jeopardized as well as to protect the Association itself who ultimately carries responsibility of its members.

# SECTION SEVEN: Conclusion

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This report has examined human's basic need for community. Individual's congregating in groups for the sole purpose of supporting one another fulfills a need as does being part of a community (Sunderland, Beekhuizen, Kendall, & Walski 2013). When individuals become marginalized due to an illness their ability of meeting the fundamental basic human need of social bonding is lost, resulting in isolation that further exacerbates that very illness. Research into OCs has unveiled strengths for marginalized individuals, proving that the necessity for this alternative form of community is compulsory for individuals isolated from society.

On account of the evidence found in the literature proving that community is a fundamental part of human nature; it is strongly recommended that the Epilepsy Association of Calgary develop an OC specific to the marginalized individuals of Calgary living with uncontrolled epilepsy who do not have access to traditional forms of community. The OC should be developed using a health care OC (HCOC) model merged with the lifecycle approach (Cambridge, Kaplan, & Suter, 2005). These two methods will work to drive the Epilepsy Association of Calgary's (EACs) overall focus by uncovering their purpose, main stakeholders and overall goals and objectives, while utilizing a platform that is sensitive to the needs of a vulnerable community.

The development of an EAC OC will create opportunities for marginalized member's in Calgary living with epilepsy and the epilepsy community as a whole offering opportunities that educate, offer specific resources about epilepsy, create options for communication such as blogs, instant messaging, email lists, and groups. The EAC OC has a main objective of serving the marginalized and isolated individuals with epilepsy and educating the public about the myths of epilepsy to contribute to the reduction to the most damaging characteristic of epilepsy, its stigma enabling members to live happier lives.

## SECTION EIGHT: References

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## Appendix A

**Table 6 – Using the lifecycle to organize and structure an online community**

This chart is inspired from the collaborated efforts of the National Learning Infrastructure Initiative at EDUCAUSE, the American Association for Higher Education, and iCoHere who shared their experiences in operating community in an online arena, resulted in a step-by-step guide for designing and cultivating communities of practice (Cambridge, Kaplan, & Suter, 2005).

<b>1. Inquire</b>	
Who is the audience? What is our purpose, goals, and vision for the online community?	
<b>Main questions to explore</b>	<b>Supporting Activities</b>
<p><b>Audience:</b> Who is the OC to be developed for?</p> <p><b>Domain:</b> Understanding the audience of the OC. What are the main issues and needs to be addressed?</p> <p><b>Purpose, goals and outcomes:</b> Given the audience and domain, what is the main purpose of the OC? How do the members benefit? What specific needs will the community meet? (p. 4).</p>	<ol style="list-style-type: none"> <li>1. Conduct a needs assessment through informal discussions, interviews, surveys and focus groups.</li> <li>2. Define the benefits of the OC; its stakeholders, members, and the community as a whole.</li> <li>3. Develop a mission and vision statement for the OC.</li> <li>4. Identify the most important content relevant to the OC.</li> <li>5. Estimate the cost for developing the OC.</li> <li>6. Recruit individuals who will represent the OC members as a core team decisions (p. 4).</li> </ol>
<b>2. Design</b>	
Define the group processes, activities, and roles that will support the OCs objectives.	
<b>Main questions to explore</b>	<b>Supporting Activities</b>
<p><b>Activities:</b> What kinds of activities will the OC use to generate support and participation?</p> <p><b>Communication:</b> What form of communication will the OC use to accomplish its purpose and goals?</p> <p><b>Interaction:</b> What forms of interaction will produce community energy and engagement?</p> <p><b>Learning:</b> What goals for learning does the OC have and how will they be achieved?</p> <p><b>Knowledge sharing:</b> What resources will support the development of the OC during the initial phase?</p> <p><b>Collaboration:</b> How will OC members collaborate together to achieve goals?</p> <p><b>Defining Roles:</b> How will the roles be defined and who will fill the positions (p. 4)?</p>	<ol style="list-style-type: none"> <li>1. Identify the key responsibilities the members of the OC will want from the community.</li> <li>2. Identify opportunities for the members of the OC to communicate like face-to-face communities.</li> <li>3. Develop a timeline of how long it will take to create the OC.</li> <li>4. Develop a system for organizing the discussions, documents and resources of the OC.</li> <li>5. Determine the roles for the OC (p. 4).</li> </ol>

<b>3. Prototype</b>	
How will the OC develop a team to test ideas, refine the strategy and establish a successful community?	
<b>Main questions to explore</b>	<b>Supporting Activities</b>
<ul style="list-style-type: none"> <li>• What are the pilot OCs short-term goals?</li> <li>• What technologies will support the pilot OCs core activities?</li> <li>• What image does the pilot OC want to project, considering their audience, domain, purpose and method of operation?</li> <li>• What image and activities do the monitors/facilitators want to project?</li> <li>• How will the OC identity be shared to the public and participants?</li> <li>• How will success of the OC be measured and how will this information be communicated to the stakeholders (p. 5)?</li> </ul>	<ol style="list-style-type: none"> <li>1. Choose technology features that support the OCs goals for the pilot.</li> <li>2. Post design of the OCs environment have a test group run through scenarios on the site.</li> <li>3. Conclude what community image is desired and how it will be communicated through the community's appearance.</li> <li>4. Implement the pilot OC and have the core group act as its audience</li> <li>5. Add the content to the pilot OC</li> <li>6. Measure the success through the response from the test groups and reports this to the stakeholders (p. 5).</li> </ol>
<b>4. Launch</b>	
Launch the OC to a broader audience in ways that engage new members and deliver instant benefits.	
<b>Main questions to explore</b>	<b>Supporting Activities</b>
<ul style="list-style-type: none"> <li>• What benefits does this OC offer its members?</li> <li>• What is the business model of the OC?</li> <li>• How can new members learn about the OC?</li> <li>• What are the norms for behaviour for the OC?</li> <li>• When new members join how do they get orientated with the OC?</li> <li>• Based on the test conducted with the pilot OC, what activities engage the members and generate the most support of community presence (activities, interaction, sharing of knowledge, learning, collaboration, and roles)?</li> <li>• How will the roles and social structure be defined, based on the pilot OC?</li> <li>• How will the OC measure success (p. 5)?</li> </ul>	<ol style="list-style-type: none"> <li>1. Utilizing the information gathered from pilot OC, design the OC environment (include; graphics, predefined content, links, etc.).</li> <li>2. Create the OCs mission, vision, goals, and members norms and agreements.</li> <li>3. Define the OCs roles.</li> <li>4. Create the marketing and communication plans.</li> <li>5. Recruit new members.</li> <li>6. Create new members accounts, self-joining members and group sign-ins.</li> <li>7. Enable a greeting for all new members when they log in.</li> <li>8. Complete the OCs calendar of events.</li> <li>9. Create synchronous and asynchronous community activities (p. 5).</li> </ol>
<b>5. Grow</b>	
Engage members in collaborative learning, knowledge sharing activities, group projects, and networking events that meet the group's needs while increasing participation.	
<b>Main questions to explore</b>	<b>Supporting Activities</b>
<ul style="list-style-type: none"> <li>• What are the benefits the OC offers its members, groups, stakeholders and entire</li> </ul>	<ol style="list-style-type: none"> <li>1. Proceed with implementing the OC including the monitors and communication.</li> </ol>

<p>community?</p> <ul style="list-style-type: none"> <li>• What are the different options for groups of the OC for its members?</li> <li>• How do members create their own identity on the OC?</li> <li>• What are the most important elements of the OC that should be highlighted in its policies as well as in the online environment (p. 6).</li> </ul>	<ol style="list-style-type: none"> <li>2. Share the OCs success stories to create a positive energy and motivate members.</li> <li>3. Conduct a resource inventory to keep content fresh and relevant.</li> <li>4. When designing activities attach rewards to motivate the members and encourage participation.</li> <li>5. Conduct focus groups, interviews, surveys and other forms of data collection to measure the success of the OC.</li> <li>6. Create discussions about the community itself to motivate participation from members (p.6).</li> </ol>
<p><b>6. Sustain</b>  Assess the learning, knowledge, and products created by the OC that inform new goals, activities, roles, technologies, and a business model for the future.</p>	
<p><b>Main questions to explore</b></p>	<p><b>Supporting Activities</b></p>
<ul style="list-style-type: none"> <li>• What practices will keep members participating?</li> <li>• How does the OC support its members?</li> <li>• How will new roles be identified and supported by the OC?</li> <li>• How is the OC serving its audience and accomplishing its purpose and goals?</li> <li>• From the perspective of the OC as a whole what is the perceived return on participation (p. 7)?</li> </ul>	<ol style="list-style-type: none"> <li>1. Develop a recognition program for the roles of the OC.</li> <li>2. Maintain the procedures, practices and technology support the sharing of data.</li> <li>3. Develop policies and processes for the sharing of information outside the online arena.</li> <li>4. Encourage publication on the OC to share the projects and activities.</li> <li>5. Assess the activity reports and members surveys for participation.</li> <li>6. Review the audience, purpose, goals and domain for the OC regularly to observe any shifts in expectations and needs (p. 7).</li> </ol>