Territory Building
Supporting small communities in assembling and making sense of online information
Abstract
I introduce the concept of **Territory Building** – a social media application approach that intends to guide and support sufferers of rare diseases in the process of “making sense” of online information.

Similar to approaches that emphasize the sharing of web resources – such as social bookmarking sites - user interaction in regards to web resources is at the centre of this concept. The idea of **Territory Building** is built on a geographical metaphor, guiding a community in assembling a “virtual territory”, consisting of existing web resources related to the community’s domain of interest, along with user-generated information pertaining to these resources. As users build up this **Territory**, claiming new resources for it, charting out the place of this information in the context of the existing **Territory**, finally colonizing these resources by interacting, discussing, rating the information, they participate in a process that should help both the individual and the community as a whole in “making sense” of this information. The “added value” generated through the contributions and engagement of the userbase as a whole becomes more accessible to the individual, and individuals in turn have a more immediate means of contributing to the existing knowledge.

Paying close attention to the needs of the intended target group, I designed and implemented a prototype web-application based on the **Territory Building** approach, and deployed it for use by persons suffering from the rare disease Trigeminal Neuralgia. I observed how this audience made use of the approach, and how implementation details were received.

80 users registered in the prototype system, 31 web resources were contributed by users. The findings suggest that the Territory Building concept can address a genuine need in regards to assembling and engaging with available online information, and that patients are interested in making use of this approach for the purpose of disseminating information resources to their peers. Lessons learned also indicate that the approach can potentially support those affected by rare diseases in “making sense” of the information available to them, and that means of accessing and creating user-generated knowledge in the context of existing web-resources can increase the potential of users to benefit from the collaborative knowledge-generating processes of their peers.

Keywords
rare diseases, social media, sensemaking, patient online communities

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1 Introduction

I introduce an approach called “Territory Building”, which is aimed at supporting rare disease online communities in regards to constructively engaging with online content. Territory Building focusses on supporting and guiding a collaborative process for these communities, which often have to “make do” with few members and limited resources. Based on a geographical metaphor, it describes a process where members can “claim” existing web content for their community, “chart” it by furnishing it with relevant metadata, and then “colonise” it by engaging with this content - through means such as discussions and “helpfulness ratings” - with the ultimate goal of making sense of the contained information in a collaborative manner.

The main objective of this work is testing the applicability and usefulness of this approach by developing an implementation and employing it in a “real-world” scenario. The findings of this work can potentially also be applied to other communities in a similar situation - with few users collaborating to make sense of online information.

1.1 Online Communities and e-health

The web is home to a vast range of communities, which often provide significant benefits to their members or the wider online audience at large. Examples such as Wikipedia demonstrate the value that can be created through the collaborative efforts of individuals, demonstrating the “power of the crowd”.

Even when small in scale, communities can provide significant value to their members. Numerous small-scale communities concerned with specific topics are active on the web. Whether these may be specific common interests such as hobbies, professional interests, or people being affected by the same specific health condition. Users can collaborate in much of the same way as in larger contexts, but some aspects and challenges are particular to these small-scale communities. Fewer members mean fewer individuals that can contribute to community efforts, and for specific topics of interest information related to these topics may be not as commonplace as other kinds.

Health-care plays a major role on the web, and numerous approaches and services are concerned with providing health information and connecting consumers (Sarasohn-Kahn, 2008). Services providing medical information, along with communities that allow patients to share coping advice with their peers have emerged, and enjoy significant popularity.

The opportunities for participation, even for laypeople, have led to a somewhat shifted role in the “traditional” patient-doctor-dynamic (See “Shifting Roles”).

Today’s patients often have significant amounts of information available at their fingertips, and are aware of the experiences and recommendations of their peers - which allows them to take more informed decisions regarding their own health care. A patient constantly researching aspects of their own condition might accumulate significant knowledge regarding this specific domain, a wealth of practical advice that a medical professional might not be able to supply in a comparable fashion (Wilson et al; 2007). Being able to get involved in one’s own health-care to a greater extend, to no longer be only on the “receiving end” of all aspects regarding their own health care, is very beneficial for the well-being of patients (World Health Organization, 2006). The patient becomes “empowered” (See “Benefits”).
In the following section I am providing a short overview of the specific case of online communities for rare diseases, and the unique challenges these face. I then elaborate on the Territory Building approach, and how I seek to apply this approach within that domain. This will set the stage for defining the ultimate purpose and goals of this work, and the definition of the research questions I seek to address.

1.2 Problems and Challenges Within the Domain of Rare Diseases
Some conditions occur only in very small parts of a population. These rare diseases - defined in 2004 by the European Commission as “life-threatening or chronically debilitating diseases” affecting “less than 5 per 10,000 in the community”, come with unique challenges in regards to appropriate care and treatment.

Experts knowledgeable in a specific rare condition tend to be few, data and research on conditions tends to be limited, and a patient is unlikely to find peers that provide much needed support and coping advice in their geographical vicinity (Aymé et al; 2008). In particular the latter - being unable to find support from peers or domain experts in their immediate geographic vicinity, has led many rare disease sufferers to seek out online solutions.

Online Rare Disease communities aim to address the needs of patients seeking to engage with their peers. As social support and coping are significant factors for the success of a patient’s treatment, and for their quality of life in general, they address a strong need (Aymé et al; 2008). Patients (as well as other interested parties, such as care-providers, relatives or even researchers) can share experiences, advice, or refer to information resources. However, there are some unique challenges these communities face.

**Few potential contributors**
Typically, only a fairly limited amount of users actively participates in a community, performing activities such as creating or sharing content (Sun et al; 2014). Combined with a community that has fairly few members to begin with, this can be a significantly limiting factor for any collaborative efforts such a community wishes to undertake.

**Lack of information flow between “island approaches”**
Many online communities tend to be rather “self-contained”. Community members interact on a certain platform, and knowledge is being shared within the bounds of this platform. Information is not frequently exchanged between communities, and this can mean that discussions of similar topics may happen again and again, valuable knowledge, experiences and insights may not reach all the parties that share an interest in a certain subject (Sarasohn-Kahn, 2008).

**Lacking means for capturing the "Body of Knowledge"**
The “Body of Knowledge” of a community is a term that describes information that a community has gathered, or generated through collaborative processes. This information can exist within discussions, within assembled lists, posts, wikis - any number of places. By having this information spread out in a manner that makes it hard to see as a whole, it can become difficult to make use of this information (Faraj et al; 2011).

By “making use” I mean aspects such as understanding what has been generated, surveying it, or to contribute to ongoing discourse. A newcomer to a community, for example, will have to go through an extensive process of researching and evaluating
available information, seeking out what other community members may have made of it, and what role it may play in the context of the wider landscape of information that is available. Similarly, a researcher or other professional interested in obtaining an overview of the knowledge online users have assembled, and the advice that is being given based on it, will have a very significant task ahead of her.

**Existing models don’t always reflect the trend for patient-owned information**

In the current model employed by online communities, there may for example be a central information storage, such as a list of curated links, provided by moderators and selected contributors. The communities at rareconnect.org for example tend to be hosted by patient communities, which take the roles of information providers. There exists a certain hierarchy of moderators and power-users providing information, and other users consuming it (Wilson et al; 2007). While users are given the option to share information, this usually happens in the form of discussions - they may not necessarily act in the same way as the power/expert-users, and the flow of information and interaction may still resemble models of traditional healthcare, where the patient has little say in regards to her interaction with medical experts and her treatment in general. (This aspect is further addressed in the literature review on “Shifting Roles”).

**Risks of accessing medical information without context or means of "making sense"**

Especially when it comes to information of medical nature, topics of context and sense-making are of particular importance. Information that has been misunderstood, is incomplete, or was taken out of context, can have quite literal health consequences to consumers. When community efforts for purposes such as discussing, accumulating, and processing information therefore are spread over various places, out of the reach of novice users browsing the available information, the situation isn’t ideal.

The value added by communities, in particular in regards to preparing information for novice users (users that have limited knowledge within the topic domain), is an integral part of what online health communities can offer to the individual, and aforementioned challenges of navigating this collective work of the community can negatively affect the value, in particular to practical application of the information, which the user can obtain (Eysenbach et al; 2004).

**Unique requirements**

Some of the symptoms experienced by sufferers of rare diseases can have a direct effect on their use of online media, and their general online usage patterns. Aspects such as cognitive or physical impairments, differences in the way social situations are experienced and handled, or simple demographic aspects related to a disease (e.g. the disease commonly occurs for persons of a specific age or gender) mean that crowds of rare disease sufferers cannot always be compared to a “crowd of web users” in general, and may also have significant differences between them. Accordingly, online interaction patterns and community structures may differ significantly from condition to condition, and specific solutions catering to specific conditions may need to be designed with these differences in mind.

1.3 Territory Building in the Domain of Rare Diseases

I am introducing the concept of Territory Building in the domain of rare diseases.
While the Territory Building concept on a general level can be used for any type of small online community, it is particularly interesting for the use within online communities that cover the topic of specific rare diseases.

Rare Disease communities have a particular need for taking control of the Body of Knowledge related to their condition, as the information assembled and shared by other community members can positively affect their means of coping with a condition, and the quality of their health care (This is further explored in the Literature Review sections on Social Media for e-health and Rare Diseases Online).

Exploring the approach within the Trigeminal Neuralgia community
I am exploring this approach in an implementation aimed at people suffering from (or otherwise interested in) the rare disease “Trigeminal Neuralgia” (TN).
A short definition of TN is the following:

“Trigeminal neuralgia (TN), also known as tic douloureux, is a distinctive facial pain syndrome that may become recurrent and chronic. It is characterized by unilateral pain following the sensory distribution of cranial nerve V (typically radiating to the maxillary or mandibular area in 35% of affected patients) and is often accompanied by a brief facial spasm or tic.” - Singh, 2014

Basically, TN is a chronic pain condition where the Trigeminal Nerve is affected (See Figure 1 for an illustration), leading to significant facial pain, and with limited available options regarding treatment. Many factors of the condition are unknown, research into treatment options is ongoing (NINDS, 2015).
Pain and pain medication play a significant role, and these directly affect the daily lives of patients. People with TN also gather in numerous other online places, such as groups on Facebook, networks of Twitter users, as well as some forums/sub-forums on other websites, notably the discussion forums of the Trigeminal Neuralgia Foundation.1
I am describing my considerations for choosing this community in the background section “Case Study: the community "living with TN".”

![Figure 1: The three branches of the Trigeminal nerve, and the facial regions to which they correspond. Image: Baptist Health South Florida](http://fpa-support.org)

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1 [http://fpa-support.org](http://fpa-support.org)
1.4 A Short Overview of Territory Building

I developed the concept of “Territory Building” as a potential means of supporting online communities of small size in the process of making the most of the potential benefits provided by their access to online information resources. This section provides a short introduction to the concept. Additional considerations are described in the later chapter called “Territory Building”.

As members of a community which revolves around a specific topic work with information - gathering it, discussing it, putting it into context of other information - they add value. This product of a community’s collaborative work can be described as their “Body of Knowledge” (I will further detail this concept in the literature review section “User contributions and the "Wisdom of Crowds"”). A new user seeking to learn more about this topic can benefit from this sort of work, understand what primary information sources they may want to seek out, and how other, potentially more experienced users view this information. This “Body of Knowledge” is not explicitly owned by any authority, organisation, or individual - but is the “property” of the community as a whole.

**Territory Building as a tangible means of capturing the Body of Knowledge**

I am introducing the term “Territory” as part of a metaphor that seeks to describe an approach for managing this Body of Knowledge. It is therefore meant as a tangible collection of information that represents this abstract concept.

The Territory can be understood as a set of web resources that are of concern to a specific target community, along with related information and knowledge that has been created or assembled by the community due to engaging with it through discussions, recommendations, or other means of interaction. Territory Building describes my approach for supporting a community in assembling, extending, and maintaining the information described under the Territory term. By providing a tangible context for this information, it seeks to support users in regards to obtaining information and benefiting from the community’s work.

The idea of this approach is to exist alongside other social networks or communities, primarily acting as a solution catering to the specific needs of users in regards to assembling and engaging with existing information.

**The idea of Social Layering**

The base concept of Territory Building builds on the idea of Social Layering by Östlund (2015). In general terms, Social Layering is about the idea of taking “something social”, and applying it in a disassociated manner – a “Layer” – “on top” of existing web content. Content and social functionality are separated. Within this “Layer” users can become visible towards each other, and interact across the domains of the websites they are visiting, not bound by the functionalities these particular websites are offering.

I further explain Social Layering in the section “Social Layering” of my detailed explanation of the Territory Building concept.

**The Territory Building Steps**

The idea of Territory Building spans three main steps, as illustrated in Figure 2. In accordance with the geographic metaphor, I call these steps the “claiming”, “charting” and “colonising” of a web resource. These steps are discussed in more detail in the section “The Territory Building steps” of my detailed explanation of the concept.
This process is a continuous one, referring to the stages a single piece of uniquely identifiable web content goes through. The entity that represents such a piece of online content, along with any accompanying data that gets generated throughout the process, will be referred to as a *Resource* from here on.

**Interaction in context - “Zero Degrees of Separation”**

The idea of incorporating a *Resource* into the *Territory* through this process lends itself towards the question of how this would be accomplished. The idea here is to allow such functionality to happen “in place” - to provide one location where users may view web content, and make this very same location the one where any of the other interaction happens - such as providing additional data to a resource, or discussing it. I call this concept “Zero Degrees of Separation”.

1.5 Purpose

The purpose of this work is to examine the use of the *Territory Building* concept for the ultimate aim of making sense of online information. As *Territory Building* is a novel concept which I am explicitly introducing within this thesis, I intend to explore how the underlying ideas fare when the concept is transferred into a practical implementation, and the ways in which the ideals of guiding and supporting this process of building a “virtual territory”, containing the assembled wisdom of the community, can be implemented in practice.

1.6 Goals

The over-arching goals of this project are to:

- Design a system based on the *Territory Building* concept
- Implement this design in the form of a prototype
- Obtain information from the intended target community regarding their perception of the design, and observe it in action.
- Identify challenges emerging throughout the process, and explore strategies for overcoming them

The goal of this work therefore is to take the abstract idea of *Territory Building* towards a feasible design of an online service, implement a usable version of such an online service. Once it is made available to the audience of my specific target group - users
interested in information related to the rare disease Trigeminal Neuralgia – I evaluate how this service is perceived, as well as what usage models can be observed.

1.7 Research Questions
I wish to explore this Territory Building idea, and investigate the means by which it can be of help for any scenarios where small online communities encounter content in the wider context of the World Wide Web. For this purpose, I defined the following research questions:

1. In what ways can the approach of “Territory Building” guide and support the process of assembling and deriving meaning from web content for a small special interest online community?
2. How can the idea of “zero degrees of separation” influence the way users interact with the system?
3. How can the Territory Building approach fit into the existing landscape of social media solutions?

“Zero degrees of separation”, as described in the section on “1.4 - A Short Overview of Territory Building”, refers to a means of presenting user-data and related interactive functionality simultaneously with existing web resources.

1.8 Limitations
A number of aspects can limit the applicability of this work:

**Limited time, interaction may not fully emerge**
A main restriction of this approach is the limited amount of time available for setting up a community website, and for observing community patterns as the system sees use. As the approach is aimed at allowing a community to gradually build up something they collectively own, and for the community to exist based on user engagement, patterns may be difficult to observe when there is not a lot of time available for this kind of interaction to emerge.

**Requirements of other use cases may differ from the tested one**
I test the idea only within the context of one specific condition - every condition may bring some specific restrictions and conditions with it, may target different demographics, users may have different privacy needs etc. This means, requirements that I have identified may not be universally applicable, and other communities will have requirements that were not obvious in the context of this work.

**Limited scope of implementation**
I’m not developing the prototype to its greatest extend. Some features specified in the design cannot be fully developed for the purpose of the prototype implementation, as the development effort would exceed the scope appropriate for this thesis. The absence of such functionality may elicit different user responses compared to a more fully fleshed-out, more “mature” web service.
2 Background

This chapter lays out the background for this work - starting from a review of the relevant literature, a description of the problem domain, to a discussion of approaches that are conceptually similar to the Territory Building approach. I will furthermore discuss the case study of a particular community, which also acts as the target audience for the later implementation of the approach.

2.1 Literature Review

In reviewing relevant literature, I am focusing on three main areas:
- Social media & sharing
- Social media for e-health
- Rare Diseases Online

As this thesis describes an approach which falls into the domain of Social Media - by addressing users interacting with one another on the web - I explore the greater landscape of social media, along with common approaches and practices that relate to "sharing". This will allow me to position the approach within this landscape, defining the ways in which it is similar, or in which it differs from other services and approaches. I then further explore the domain of e-health, explaining how aforementioned ideas and practices of social media come into place within this domain, and finally I introduce the specific domain within which I intend to employ my approach – online communities for rare diseases.

2.1.1 Social Media and Sharing

In order to position the ideas described in this work within the “greater context” of social media, this section addresses the various types of social media, a means of differentiating approaches, and illustrates the popularity of approaches related to the activity of “sharing”.

The ability for communities or groups of users – “crowds” – to create substantial value is an important aspect being investigated in the domain of social media. As this potential is what the Territory Building concepts aims to harness, it is also introduced here.

2.1.1.1 The social media landscape

The social media landscape is diverse, constantly changing, and spans a wide number of models and approaches. Within this thesis, I am particularly interested in online communities, as the ideas discusses herein specifically concern community-based approaches.

General purpose and special-interest communities

The spectrum of online communities ranges from large “general purpose” communities intent on attracting a wide user base, to intentionally more specific approaches and communities focused on common interests (Boyd & Ellison, 2007). General topics such as cars or video games may unite a large amount of users, and consist of a great number of "sub-communities". Typical forms of more specialised communities may be web forums, or groups that form as part of a "broader" social network, such as topic-specific groups on Facebook.
Social Networks

Social Networks are a specific kind of social media. Typically, a social network is defined by providing the possibility for establishing links between users—such as “friends” on Facebook, “contacts” on LinkedIn or “followers” on Twitter (Boyd & Ellison, 2007). Establishing such links is not essential in order for an approach to be social - YouTube for example does not support any such connections (unless one counts the ability to “subscribe” to channels), and would not fall under the definition of Social Network I am using. An online social network would therefore fall into the domain of social media, but social media includes more than social networks.

2.1.1.2 The honeycomb of social media

As there are many approaches that can be classified as “social media”, and the field is constantly changing, it can be difficult to pinpoint the exact role of specific approaches within this domain. I am discussing one approach that attempts to offer a general means for classifying social media approaches based on the functionalities they offer.

![Honeycomb of Social Media](image)

Figure 3: “The honeycomb of social media”, Kietzmann et al. (2011)

Functionalities of social media approaches can be roughly associated with specific aspects that are common within the field. One means for the purpose of comparing social media approaches based on these aspects was developed by Kietzmann et al. (2011). They identified a number of “functional blocks” that typically make up social media approaches. These can be mapped to a “honeycomb” model (See Figure 3) for the purpose of classifying social media approaches, and comparing them on a general level.

Within this model, different social media approaches can be indexed according to the degrees to which they may (or may not) emphasise these different facets. As an example (shown in Figure 4), Facebook most prominently emphasises the “Relationships” block,
while Presence, Identity, Reputation and Conversations also play elevated roles. In contrast, LinkedIn most prominently emphasises “Identity”, with “Relationships” and “Reputation” playing important roles as well.

Figure 4: Applying the honeycomb model to some existing sites (Kietzmann et al; 2011)
Figure 5: The Territory Building approach according to the honeycomb model

**Territory Building according to this model**
The Territory Building approach, when analysed based on these blocks, could be categorised as following (illustrated in Figure 5) - some details that are referenced here are discussed in more detail in the dedicated “Territory Building” chapter:

- **Presence** - Does not play an important role. The approach does not explicitly emphasise synchronous communication or other functionalities that would require users to be aware of each other’s presence.
- **Sharing** - This is the main idea of the approach. By adding knowledge resources, and by contributing own opinions and information, people actively share knowledge within the Territory Building process.
- **Identity** - Quite purposefully, identity is not emphasised within the Territory Building approach. This is in order to avoid issues of ownership - users are encouraged to contribute, but not to get defensive about “their” content. The use of pseudonyms allows each user to decide to what degree they’d build their identity, of whether to reveal their real-world one.
- **Relationships** - In contrast to a defining feature of online social networks, relationships (like “friends” on Facebook or “contacts” on LinkedIn) are not modelled within this approach. This is because the focus is on what the community builds as a whole, and because the approach is not intended to replace other, specialised approaches that cater to relationship building.
- **Conversations** - Conversations, after sharing, are the second major aspect of this approach. The system encourages users to engage in discussions regarding the content of resources gathered within the system. These are a major tool in regards to “making sense” of content, and the “Colonising” step in general.
- **Reputation** - There is no implementation of a reputation system for users, and for similar reasons as in the case of identity, this aspect is not emphasised. The focus is on information resources, and on building an environment that is different from real-world scenarios, where reputation makes engagement in discussions very difficult for some. When viewing information resources that are part of the Territory though, the user opinions on content helpfulness, the “voting”, can be understood as a content-specific reputation system.
• **Groups** - As the approach is intended for small, narrow-focus online communities, there is no focus on further sub-dividing the community. The assumption is that users are guided by a common interest in a very specific issue, and therefore already are members of a narrow sub-group of general web users.

The above categorisation applies to the *Territory Building* approach and its implementation described in this work. An emphasis on functionalities that require presence indication (synchronous communication, e.g. live chats) or provide means for establishing relationships, are not excluded per se. Functionality that wasn’t pursued for the implementation is described in Appendix G: *Features not included in the implementation*, and the Discussion part of the thesis will further address potential adjustments and extensions to the approach.

### 2.1.1.3 Sharing Information

Sharing web resources is an integral part of web interaction, and most services counting as “social media” support some degree of sharing activities (John, 2012). Certain services, however, are specialised for the purpose.

Services with a strong sharing emphasis - as defined in Kietzmann’s honeycomb model - would for example be YouTube or Flickr. A common aspect in these kinds of sites is that certain objects are the focus of sharing activities - videos in the case of YouTube, or photos on Flickr, and any interaction relates to such objects.

Sharing does not necessarily have to be related to such specific objects, though. Different services encourage different sharing patterns. Users of a micro-blogging service are much more likely to share personal, “dynamic” information (generating multiple conversations among its consumers), while a wiki for example includes larger amounts of “static” information (mainly intended to provide information, without an opportunity to gather responses or reactions to the information shared) (Osatuyi, 2013).

User’s motivations to share knowledge with others include personal attachment, commitment to online relationships, and to a large part altruistic reasons as well. In particular in social media environments aimed at particular common interests, altruism is an important motivation for contribution (Ma & Chan, 2014) - users are willing to contribute without explicit reciprocity.

### 2.1.1.4 User Contributions and the "Wisdom of Crowds"

Users acting together, as communities, have the potential to “add value” to content they interact with and share. Information created by communities in relation to existing information - such as semantic classifications, discussions, or recommendations - provide additional means for interacting with such information, potentially supporting an individual’s process of “making sense” of it.

Numerous approaches enjoy great success by harnessing “the power of the crowd”. The combined efforts of interested contributors have shown to accomplish substantial tasks, as illustrated by the success of examples such as Wikipedia³, or the approach of monetising this potential in the form of Amazon’s Mechanical Turk⁴. Making use of the potential of approaches where numerous users - crowds - collaboratively create

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⁴ [https://www.mturk.com/mturk/welcome](https://www.mturk.com/mturk/welcome)
“something bigger”, has been an important topic in research and development in the area of social media over the last several years (Doan et al; 2011). For the purpose of this work, I restrict myself to the added value in the form of knowledge.

The “Wisdom of Crowds”
Zettsu & Kiyoki (2006), describing the idea of the “wisdom of crowds”, state

“Large groups of people are remarkably intelligent, and are often smarter than the smartest people in them. Even if most of the people within a group are not especially well-informed or rational, the group can still reach a collectively wise decision. Our basic idea [related to developing a concept of knowledge management] is to exploit the collective intelligence of Web users, or “the wisdom of crowds”, as the basis of knowledge.”

Crowds may establish significant collections of information (such as Wikis) out of the sheer drive for social recognition and a will to contribute to a topic they have a particular relationship to, or interest in. Even users that are not explicitly experts on a certain domain have the potential to contribute value.

A community’s “Body of Knowledge”
Regarding the power of web communities in regards to knowledge generation, Zettsu & Kiyoki (2006) state:

“From a sociological perspective, knowledge is considered to be socially constructed. Social processes influence the processes of generating and applying knowledge. As a consequence, knowledge cannot be described as objective truth, but as what a social system considers to be true. In this sense, the collective intelligence of Web users can be viewed as a common (or shared) understanding between people, which is the type of knowledge that people tend to take for granted.”

The authors describe the process of a community accumulating knowledge as “Bottom-up consensus”. This does not necessarily need to be the express intent of community members, as “Users pursuing their own selfish interests build collective value as an automatic byproduct”.

While there are active means of enhancing information, such as creating semantic classifications by means of social tagging (Choy & Lui, 2006), often also called the creation of “Folksonomies”, there is plenty of valuable data being produced by users “only” browsing resources. Passive use - seeking out information, consuming, but not actively producing content - should not be seen as inherently negative (Nonnecke et al; 2006). It provides valuable information on the popularity of content, and such passive users tend to be driven by different needs than active participants.

The value being created by users can be described as the community’s Body of Knowledge - a somewhat abstract concept encompassing not only information, but the wisdom and knowledge that the community collects or generates in relation to this information.

A related aspect is the generation of culture. As a community interacts, values, norms and customs regarding such interactions emerge - all part of the community’s specific interaction culture. These aspects can explicitly guide and support the process by which
a community assembles and creates additional knowledge, and may influence the way a community-driven approach may take significantly. (Boyd & Ellison, 2007)

By taking available online information, aggregating it, and collaboratively building concepts and understandings of this information, a community as a whole can go through a “sensemaking” process. Figure 6 provides an overview of the process how understanding is derived from information on the web - where specific networks or communities, building from various knowledge bases, reach a degree of common understanding.

![Figure 6: “Generic framework for developing collective intelligence of Web users” by Zettsu & Kiyoki (2006)](image)

### 2.1.2 Social Media for e-health

E-health is an important domain in which social media approaches, particularly in the form of patient communities, enjoy great popularity. Many increasingly patient-centric approaches are symptomatic for a “shift in power” between patients and health care professionals, crowd-centric approaches provide users with the possibility to actively engage with their health condition and care. The benefits found within such approaches, and the means of achieving them, are what Territory Building aims to further support.

#### 2.1.2.1 Health and the web

The topic of e-health is becoming increasingly interesting to researchers, and for patients it is becoming commonplace to access health information on the web. The easy availability of health information, as well as means of networking with one’s peers, provides plenty of unique opportunities.
“Top-down” and “peer-to-peer” approaches
Online health services come in different forms, run by (medical) professionals or interested amateurs, focused on merely providing information, or encouraging discussion and information exchange (Sarasohn-Kahn, 2008). Generally speaking, these services can be divided into “Professional” or “top-down” services on the one hand, and “patient-to-patient” services on the other. The former includes information assembled by health-care professionals or similar sources, like WebMD, government websites, or special services such as electronic health records. These services typically offer little to no “social” functionality.

The latter includes solutions such as forums and other community platforms - social approaches that can include practical advice on coping with a condition, opinions and experiences with treatment strategies and medications. Some of these peer-to-peer services have developed “organically” - emerging when patients, interest groups and others used various communication means in order to address needs such as social interaction, support, and the exchange of information.

An additional category, e-health services such as electronic patient records, typically includes approaches that are aimed at direct patient-to-professional interaction. As this is generally “one-to-one” communication, I do not count it as social, and will not further elaborate on these kinds of services here.

For the purpose of this work I restrict myself to social, web-based approaches. This means any kinds of online services and communities that allow a degree of interaction between users.

2.1.2.2 Patient Online Communities
Patient online communities - often run by patients themselves, or by specific patient organisations - offer a place where patients may interact with one another, providing support and opportunities for the exchange of advice. They can act much like a “traditional”, physical self-help group, but with the potential of greater geographical reach, means of disseminating information, and other general benefits of online collaboration, as discussed earlier.

A body of research exists on the general effectiveness of online patient communities, and the effects peer-to-peer online communication can have on the individual patient (Eysenbach et al., 2004; Leimeister et al., 2008). This research however tends to be focused on measuring immediate health benefits resulting from the participation in such communities - not as much on the less tangible benefits of a patient’s well-being that such interaction may produce.

Such communities are facing a certain shift. Edenius & Åberg-Wennerholm (2005) argue that many "traditional" patient communities undergo transformations in the era of ICT, where patients are relying on single communities to a lesser extent, but rather make use of the wide variety of resources and communication possibilities to be found on the web. They further argue that information is typically no longer "belonging to" a certain patient community, but instead is possessed by the individual patients. This means that such “traditional” communities would have to adapt their approaches to this situation.
2.1.2.3 Shifting Roles

Just like the role of patient communities sees a shift in recent years, the role of individual patients in regards to their health care is changing.

"The role of the patient is starting to shift from being a minimally-informed advice recipient to an active participant, instigating collaborator, information sharer, peer leader and self-tracker engaged in participative medicine; a transition is underway from paternalistic health care to partnership models." - Swan, 2009

The increased agency of patients, the increased availability of information, are symptomatic for a general shift in the patient-doctor dynamics. First-hand information related to day-to-day living is something that is of great value to patients, but something for which medical professionals might not always be the best source. Having a space where one can exchange information, learn about the situations of others, discuss experiences with practitioners etc. is perceived as very valuable by many patients (Edenius & Åberg-Wennerholm, 2005).

![Figure 7: “A new model of health and health care” (Swan, 2009)](image)

Figure 7 details how current and upcoming services prioritise the individual, and involve elements that are initiated by, or otherwise related to, the patient him/herself. The individual acts pro-actively, from means of improving their quality-of-life, preventing medical conditions and living with existing ones, to informing themselves about current research and available research options. Information collected by the patient, or by using various logging devices, can also be used when engaging with peers or medical professionals. The patient acts as an informed participant, not a passive user in regards to their own health care.

2.1.2.4 Benefits of these approaches

These approaches, and the increased role of patients in their own care, can bring some unique benefits to the field of health care.

**Empowerment**

An important keyword when discussing trends in health care and online communities is "empowerment". The availability of knowledge, the increased possibilities for patients
to become domain experts (patients possessing domain-specific knowledge that is valuable to other patients), tends to be seen as symptomatic for the aforementioned “shift in roles”. Patients are able to enjoy and exercise more freedom in regards to their own health care, and this development is commonly seen in a very positive light.

The World Health Organization (2006) describes empowerment as a "prerequisite for health”. An empowered patient possesses knowledge, and can use this knowledge to take action. Being informed allows a patient to be involved in decisions regarding their treatment, in actively inquiring and engaging with the treatment strategies laid out by medical professionals. Edenius & Åberg-Wenerholm (2005), discussing the future of patient communities and the role of ICT, note that “without information, the patient can neither economically nor legally act, either as patient or as consumer.” They also state "Empowerment from our point of departure means helping patients feel that they have power over significant and important aspects of their lives; to let the patient be empowered is to let them be involved, committed and hopefully also willing to perform independently and with responsibility."

While individual definitions of empowerment can somewhat differ, a common theme that clearly emerges is the role of the patient as an active participant in her own care and treatment strategy. This covers researching treatment options, engaging in discussions with health-care professionals, allowing patients to make choices regarding their health with the knowledge that these choices are informed.

The Long Tail - catering even to small audiences
Web-based health approaches make it more feasible to address a larger portion of patients, even those with uncommon conditions (Swan, 2009). This is comparable to the scenario where large online retailers may cater to a more diverse range of customers than traditional “brick and mortar” stores, as carrying a wider selection implies significantly less overhead for such online retailers. In a similar fashion, online services can cater to audiences that are few in number, geographically wide spread, and where local, physical approaches such as self-help groups are not feasible. Community-run services without intent to “turn a profit”, without organisational overheads, can have a focus that for other institutions would not be viable.

Making sense of information
Online communities have the potential to aid users in understanding, making sense of online health information as they profit from the understanding of their peers - the community-generated knowledge (Johnson & Ambrose, 2006). Related to the earlier introduced concept of the Wisdom of Crowds (see “User Contributions and the "Wisdom of Crowds"”), I am discussing another keyword describing the value derived from collaboratively engaging with information: sensemaking.

Swan (2009), states that “A key step may be missing from the current translational medicine process that expert patients and health social network researchers could help with, the enumeration of the specific functionalities or capabilities of the research findings in a context such that non-scientists who are knowledgeable in the area can more easily see what solutions those capabilities could generate, the “productizing” of the research findings.”

Discussing means for interacting with such data, she concludes that
“at some websites, individuals creating or interacting with the data can help to stratify it with relevancy and abstraction layers by actively engaging in collaborative filtering, tagging, voting and other standard Internet community data management techniques or passively, by having their attention recorded as page views.”

Online information, in the context of the interaction means afforded by different social media approaches, can be enriched by these aspects. The user does not simply consume the information, but is provided with contextual information - how it is received by peers, which sort of other information is relevant for the context, whether there are some aspects that are widely seen critical, or receive strong support. In similar ways as the interaction and exchange with peers provides a very different quality of information and advice than merely consuming a book, as information is complemented with practical experiences and opinions, this sort of contextual information complements the actual information source.

This is relevant in particular considering the aforementioned Long Tail - as these possibilities for sense-making, for complementing information, are made available to a wider range of consumers than could realistically be reached by traditional, “physical world” approaches.

Paul & Reddy (2010) summarise the main points in sensemaking literature as “First, sensemaking is about meaning generation and understanding. It is a cognitive activity that is part of, but distinct from, other cognitive activities like decision-making, problem-solving, comprehension, creativity, mental modeling, and awareness. [it] is an important aspect of information seeking tasks. Most of the models and theories of sensemaking have described it in the context of finding, understanding, and using information. [...]it] has mostly been viewed as an individual cognitive activity consisting of iteratively finding information based on an initial framework; organizing information into frameworks or representations; refining the representations used based on new information found; and changing representations or frameworks in use to fit new information”

In their work, sensemaking is defined as “a social and interactional activity that takes place between multiple people”, and explored in the context of Collaborative Information Seeking. The main activities of sensemaking include the prioritisation of relevant information (“Making relevance judgments on information found is an important aspect of the individual information retrieval process. As people find information pertaining to their information need, they make a judgment about how important that information is for fulfilling their information need.”), and sharing based on what group members deem most relevant.

2.1.2.5 Examples of e-health web services

I am introducing three health related web services in order to provide a glimpse in the diverse range of health-related and community-based online solutions.

Patientslikeme

Patientslikeme allows patients to share their personal health data, with the intent of helping other patients, as well as medical practitioners and medical research in general.

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5 https://www.patientslikeme.com
Patients can log a wide array of data that can be relevant to their condition. The user-supplied data can be beneficial for the purpose of exploring patterns and in order to learn things that would otherwise only be acquirable through extensive trials. This allows insights even for patients themselves, as the data on their condition is publicly available. The service is very data-centric, though discussions regarding specific health topics are supported as well.

**Smartpatients**

Smartpatients\(^6\) is aimed at helping patients understand latest clinical trials, to network with other patients, offering and receiving advice, and to generally expand their knowledge, fostering “patient experts” with significant domain knowledge regarding their own disease. Discussions and sharing in like-minded communities are prominently encouraged, a feed of discussions is the main focus of the website. Patients, medical professionals and researchers are supposed to learn from each other by networking with one another. The idea of patients that become experts on their own disease and subsequently support other patients by sharing their knowledge is explicitly emphasised. The website does not emphasise sharing external web resources, though they may be referenced within discussions.

**Inspire**

Inspire\(^7\) offers sub-communities run by specific organisations, such as patient organisations. Health communities target specific diseases and conditions - they act mainly as forums, providing a place to discuss. These allow both patients and medical professionals to connect and support each other. Patients may maintain individual journals, network with others and share information on themselves and their condition in their profile.

### 2.1.3 Rare Diseases Online

Several online services and communities cater to sufferers of specific rare diseases, acting in lieu of physical support groups, and offering information and social support to their members. Members accumulating knowledge often provide information to their peers, supplemental to what health care professionals might offer. This knowledge found within the community is what Territory Building aims to make more tangible and accessible.

#### 2.1.3.1 Online Rare Disease Communities

In the case of rare diseases, online communities are of particular importance. People suffering from rare diseases may find it hard to find local support groups for their condition, and even the medical experts they frequently interact with tend to only have a limited amount of information available - no doctor knows every condition by heart, and the next expert on a disease that only strikes a small fraction of the population may be far away. General practitioners in particular don’t likely possess much specialist knowledge that could be of use for specific, rare, conditions. Approaches such as social media services, the advice of other experiences patients, and more, are therefore important when it comes to helping patients in regards to navigating the available information body (Swan, 2009). Particularly when such a condition is

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\(^6\) https://www.smartpatients.com/
\(^7\) https://www.inspire.com/
chronic, the interaction with other patients, who often acquire significant knowledge on the domain of their own condition as they live with it day after day, is extremely valuable.

Numerous approaches and communities catering specifically to the topic of rare diseases do exist. The research in the field of online rare disease communities, however, is limited. Besides investigation into therapeutical effects of social support in some specific scenarios, patterns of online interaction of rare disease suffers have not been widely researched.

2.1.3.2 Community Structures

Peer-to-peer information exchange and social support are of particular importance within these communities, where patients come together to discuss topics, typically in bulletin-board like discussion threads. Discussions as well as the exchange of experiences and advice can support a patient in testing their logic in regards to “sensemaking of one's illness and the situation one is facing”. (Josefsson, 2005)

Some communities are hosted by interested individuals, while others may also be coordinated by organisations such as the National Organization for Rare Disorders (NORD)\(^8\), or can be formed as groups within other social media services, for example in the form of Facebook Groups. These communities tend to be separate, self-contained communities, not relying on existing "multi-purpose" social networking services such as Facebook. While a community's members may make use of a wide array of web resources and online services, "social functionality" is typically constrained to the bounds of a particular online community’s website.

Exchange and assembly of Advice

Practical coping advice, information resources and the like are important resources being shared within patient online communities. Users can engage in discussions about information, deliberating its validity, practical use or effects on other, related pieces of knowledge and wisdom. Communities may maintain repositories of accumulated knowledge resources, or, more commonly, embed information within everyday discussions and interactions. This means information is primarily conveyed user-to-user in the context of specific conversations, and less commonly as a list/repository of knowledge.

2.1.3.3 Expert patients

People living with chronic rare diseases tend to accumulate significant knowledge on living and coping with their specific condition, information that can be very valuable to other patients. These patients may be referred to as “expert patients” or “e-patients” (Swan, 2009, Ferguson & Frydman, 2004). Such expert patients may for example provide practical advice on day-to-day living with a specific condition - something that can be beneficial to other patients, even if they have access to advice from medical professionals.

Expert patients may also gather knowledge usually in the domain of medical experts, such as available and upcoming potential treatment options as well as ongoing medical research. As there are few medical professionals that engage with specific rare diseases, there is a distinct lack of such information from professional sources, making the role of

\(^8\) http://www.rarediseases.org
these domain experts particularly valuable. While an expert patient can’t be expected to have a level of medical expertise comparable to a medical professional, advice on dealing with symptoms, of adapting living conditions and of courses of action that can benefit the patient’s treatment can supplement medical advice in a unique fashion.

2.1.3.4 Examples of Rare Disease Communities

The following are examples of rare-disease specific online communities, providing an idea of the different types of such communities that are available.

**Ben’s Friends**

Ben’s Friends\(^9\) is a collection of rare-disease-specific online communities. The organisation provides support in regards to setting up and administrating an online community, but the actual day-to-day administration is handled by engaged community members themselves. These individual communities provide a space where members can maintain individual profiles, network with other users, and engage in discussions. The “heart” of a typical Ben’s Friends community is the forum section, where members share advice, discuss, and provide support. The community platform provides features similar to what is found in a “typical” online social network - discussions, messaging, personal profiles, sharing. The ways in which such functionality is used is up to the users. Ben’s Friends communities operate independently from other online social networks, such as Facebook. As of January 2015, there have been 36 communities launched by Ben’s Friends.

**Crohnology**

Crohnology\(^10\) is a community intended specifically for sufferers of Crohn’s Disease. A focus within this community is the free sharing of patient information, so that such information may benefit other patients (similar to the principles behind PatientsLikeMe). Users are encouraged to freely share their experiences in regard to treatments, changes in regards to live-style or similar aspects that affect (or are suspected of affecting) disease symptoms and the patient’s quality of life. This allows assembling data on a scope and over a time period that would be hard to accomplish in traditional medical trials, and may therefore potentially provide new practical insights for sufferers of the disease.

**Rareconnect.org**

Rareconnect.org\(^11\) is a place for numerous rare disease communities. It is a joined offer by the European Rare Disease Organization (EURORDIS) and National Organization for Rare Disorders (NORD). The provided service emphasises the three points “Understand”, “Meet”, and “Learn” - meaning for each of the “supported” rare diseases there is a list of available information resources (and partnering patient organisations), as well as means for patients to create profiles, to interact with each other and to engage in discussions. “Patient stories”, testimonies, and references to disease-specific support organisations help a patient with understanding the condition, as well as with understanding the intricacies and challenges of living with it. FAQs, published articles and more provide additional learning and information resources for a better understanding of the condition.

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\(^9\) [http://www.bensfriends.org](http://www.bensfriends.org)

\(^10\) [https://crohnology.com](https://crohnology.com)

\(^11\) [http://www.rareconnect.org](http://www.rareconnect.org)
2.2 Conceptually Similar Approaches

Approaches that are close to the intended Territory Building approach, similarly emphasising aspects such as sharing of web resources, and generating additional user data in regards to these, are the concept of Social Bookmarking and concepts that can be seen as evolutions of the Social Bookmarking idea.

2.2.1 Social Bookmarking, example of Delicious

Web resources can universally be identified by their Uniform Resource Locator (URL). When one treats this identifier as an object, storing it for example with a descriptive name, it becomes a Bookmark. Social Bookmarking is an approach aimed at sharing bookmarks, using different social media functionality for the purpose of augmenting the process.

This additional functionality typically allows the community to furnish these links with some additional data, such as tags/classifications, by making them part of special lists/collections, or by offering comment functionalities. Typical social bookmarking approaches tend to have a more “cataloguing”-oriented approach - without, or with limited commenting functionality - instead focusing on categorising and sorting bookmarks by popularity, using voting mechanisms. A traditional social bookmarking service, such as Delicious, allows users to submit links to web resources, which can then be added to various collections, based on semantic classifications (tags).

Delicious

Delicious was a major contributor to popularising the field of "Social Bookmarking". In 2008 the service had 5.3 million active users. The service allows users to submit and collect bookmarks from over the web, which can then be organised in groups as well as classified using user-assigned tags. A focus of the service is the idea of explicitly emphasising the sharing of these bookmarks with the wider community. Organising bookmarks using tags allows users to gather web resources that concern a specific topic, though they cannot be gathered in specific collections (this was a temporary feature). This process of collaboratively building an index of resources related to specific keywords, the creation of a “Taxonomy” which assists in providing a semantic structure to the web resources being indexed, is one of the main appeals that made the service popular. Functionalities for discussing resources are not available, and while the service recently focused on increasing its "social component" by implementing sharing functionalities, social networking is not a functionality offered by Delicious.

2.2.2 Evolution of Social Bookmarking, example of Reddit

Other approaches had success by modifying certain social bookmarking functionality, and, for example, adding a temporal dimension as well as advanced ranking algorithms.

In the case of Reddit, default views prioritise submissions\(^\text{12}\) using a proprietary algorithm. By default it is aimed at keeping content “fresh”: Resources have a relatively short span during which they are active and being discussed, then they disappear from the front-page views. While older content is not removed, archiving and building collections are not main priorities of the service. Submissions always relate to a specific “sub-reddit”, and users may filter what they view by subscribing to specific “sub-redds”. Tag-based classification and similar meta-data do not exist. Instead, submission-specific discussion threads tend to be the main attracting feature for users.

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\(^{12}\) Text-based submissions that don’t refer to external web resources are also supported, but are not the focus of this discussion
The approach is known as “Social News” (Kietzmann et al; 2011), and should not be understood as a replacement of the Social Bookmarking model. Rather, Reddit can be viewed as an evolitional development of the idea of “self-organised” frameworks dealing with web content (Zhang et al; 2006).

The ideas here relate to “arbitration” of information, using the community to identify such information that is potentially worth further engaging with. In his work on the potential and risks for approaches like Reddit, Mills (2011) describes this concept as

“Distributed moderation and filtering (or DM) systems appear to offer a unique, people-powered, approach to the problem of Information Overload. The principle behind these systems is that some dimension of user activity is taken as a measure of an item’s quality or relevance; this measure being used to rank and sort items, with those items which rank more highly being placed in positions of greater visibility.”

### 2.2.3 Comparison of Territory Building and similar approaches

Table 1 illustrates the differences between the Territory Building approach, and three previously discussed existing web approaches - Reddit, the Social News website, Delicious as an example of social bookmarking, and Ben’s Friends, host of numerous rare disease communities. The approaches are compared based on the aspects defined in “The honeycomb of social media”, and the comparison is intended to provide a general idea of the different focusses these approaches have.

<table>
<thead>
<tr>
<th>Feature</th>
<th>Territory Building</th>
<th>Reddit</th>
<th>Delicious</th>
<th>Ben's Friends Community</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SHARING</strong></td>
<td>Sharing information resources is central feature.</td>
<td>Sharing information resources is central feature.</td>
<td>Sharing web resources in the main focus of this service</td>
<td>Sharing is important, no explicit feature.</td>
</tr>
<tr>
<td>PRESENCE</td>
<td>User presence isn’t indicated</td>
<td>User presence isn’t indicated</td>
<td>User presence isn’t indicated</td>
<td>Users can choose to indicate presence</td>
</tr>
<tr>
<td>RELATIONSHIPS</td>
<td>Not supported</td>
<td>Not supported, users may communicate privately though</td>
<td>Users may “follow” one another</td>
<td>Social Networking-style relationships are supported</td>
</tr>
<tr>
<td>IDENTITY</td>
<td>Users choose name, rudimental user profiles</td>
<td>Wide-spread use of pseudonyms, rudimental user profiles</td>
<td>Rudimentary profiles, not essential</td>
<td>Social Networking-style User profiles</td>
</tr>
</tbody>
</table>
2.3 Case Study: The Community "living with TN"

For the purpose of illustrating the aspects of an existing rare disease community, I studied the case of the “living with TN” community, a community hosted at Ben’s Friends.

2.3.1 Choosing a Sample Community

For the purpose of identifying a specific rare-disease centric community, from which I could understand the habits and customs that govern their interactions, I examined existing communities hosted at “Ben’s Friends”. Ben's Friends is large conglomerate of individual communities focused on rare diseases. Each community populates their own installation of “Ning”, a service that allows hosting one's own special-interest social networking service. The individual communities are maintained and moderated by engaged volunteers, typically people themselves suffering from the disease in question. As bensfriends.org offers an overview along with usage data on the scope of these communities, I decided to search within the most popular ones found there.

Patient Community - “Living with TN”

The community which is the focus of this case study (and from which the domain of the implementation of my approach was derived), is called “living with TN”.

The community is one of the most active communities at Ben’s Friends, with more than 6,000 members (June 2015), allowing for in-depth observation of interaction and communication habits within this community.

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13 http://www.ning.com
14 http://www.bensfriends.org/communities/
15 http://www.livingwithtn.org
By establishing contact with one particular moderator and expert on the community there,\textsuperscript{16} who has his own research interest regarding aspects such as the demographics of the community (Lawhern, 2012a & 2012b), I was able to obtain detailed insights into the day-to-day of “Living with TN”.

\subsection*{2.3.2 Opinions of a Community Expert}

In a series of e-mails I asked this moderator and “resident research analyst” several questions, regarding his views and experiences on a number of topics.

Regarding the composition of the community, and their individual situations, he stated

“[… ] our member audience is highly non-homogeneous. Some have significant cognitive, attention, or stamina issues due to either their primary disorders or the effects of medical treatment. Needs vary between people who are just starting to learn about their disorders versus those who have been suffering for 20 years or more.” - Richard Lawhern, Personal Communication, 25.02.2014

He emphasised the effects that the specific condition along with related treatments can have on patients, and how it may affect their performance. Cognitive issues, such as shortened attention spans or stamina issues, significantly limit their potential to maintain high levels of engagement with online content, and put special requirements on the ways that content is presented. He also pointed out the differences between user types, e.g. those that lived with the condition for a long period of time, or those that newly arrive and search for some initial information and orientation.

“We already list resource sites in one of our menu entries, but few of our members make use of those resources” - Richard Lawhern, Personal Communication, 28.02.2014

Existing information resources offered on the website, maintained by community managers based on suggestions by members as well as themselves, did not see much use.

“One of the more frequent scenarios where our moderators tend to get involved, is with patients advocating for controversial or unproven treatment protocols, out of desperation for help.” - Richard Lawhern, Personal Communication, 28.02.2014

He pointed out the role of moderators, and how these typically take care of pointing out unreliable resources and unproven claims.

“TN patients generally operate with high levels of anxiety and possible side effects of medications. That can make assessments of source credibility or usefulness quite problematic for patients themselves. Likewise, rather large numbers of medical professionals either do not believe they have time to participate in Internet search/source-validation, or lack the personal desire to reexamine their own assumptions and training.” - Richard Lawhern, Personal Communication, 04.06.2014

\textsuperscript{16} Richard Lawhern acts as “Resident Research Analyst and Senior Moderator” of livingwithtn.org, acted as “webmaster and a member of the Board at the US Trigeminal Neuralgia Association in 1998-2001”, and “authored and coordinated physician validation for the most recently published version of the Trigeminal Neuralgia Fact Sheet at the US National Institutes for Neurological Disorder and Stroke.”
He pointed out the anxiety and side-effects of medication which affect the typical community member. This contributes to challenges with assessing source credibility and usefulness. Involvement in online communities by medical professionals seems to be very limited in general.

2.3.3 Focus of Discussions
In order to understand the kind of topics discussed within the community, I indexed all forum discussions that were created over the course of one week within the LivingWithTN community (these forums are shared by all ~6000 members of the community). Users created 35 new discussion threads, with threads receiving between 1 and 39 replies, and between 16 to 873 views. The full results can be found in Appendix A: One-week sample of livingwithtn.org discussions. This allowed identifying some main topics and themes that frequently occurred.

The majority of conversations within the sample related to treatment options in one way or the other, seeking peer advice on options such as medication or surgery. Generally, patients have a significant need to share experiences and maintain social connections (this applies to most online health communities), to obtain support both in the form of general as well as practical advice on aspects such as coping with the disease, treatment options, recommendations regarding specialised medical experts and news on ongoing research efforts.

2.3.4 Special Considerations
One requirement that became clear through community observations and discussions with the community expert, was that sufferers of Trigeminal Neuralgia are likely to be suffering from specific effects that may affect the way they interact with online information. TN can appear in the form of sudden painful attacks, as well as more constant sensations, often triggered by various events throughout the day. The condition can become debilitating, and affect patient’s everyday lives (NINDS, 2015). The effects of pain and pain medication can have negative effects on the user’s attention spans and general ability to focus and engage with content at an intensive level - a situation often referred to as “Brain Fog”17 (Lawhern, 2012a).

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3 Territory Building

As described in “A Short Overview of Territory Building”, Territory Building refers to a concept that supports small online communities in the process of taking charge of the Body of Knowledge relevant to the domain of their interest. It encompasses a three-step strategy based on a geographical metaphor, which describes the process of adding web resources to the Territory, providing them with a context and place within this Territory, and allows interacting with them, creating further knowledge and meaning.

Ultimately, the goal is to create a “virtual territory”, in which to focus and bundle resources that otherwise are widely dispersed and disassociated. Navigating the information contained therein can be a significant challenge. The idea of offering additional social functionality “on top” of existing web content is based on “Social Layering”.

3.1 Social Layering

Social Layering is about “Populating the web by making netizens visible and approachable to one another” - Östlund, 2015

In his ongoing research, Martin Östlund is investigating a concept called “Social Layering” along with approaches related to it. The Social Layering idea describes that “something social” - such as interactive commenting or highlighting functionalities - can be superimposed over existing web content. Such functionalities would not have to rely on being implemented by the provider of web content, but users of the Social Layer would nonetheless be able to profit from them, as they view the web content overlaid by this layer - it is “added on”. The explicit focus of such a Layer is on a social purpose, and in decoupling related aspects and functionalities from the domain of existing web content.

Practically speaking, a layer of interactive features could be displayed on top of a web page (as illustrated in Figure 8), and on a wider scale as social interaction functionality spanning across domains (Figure 9). A community acting within the Social Layer would not be defined by any relations or cooperation between the domains of content they are interacting with. Approaches working with the concept have explored different means of interaction and usage scenarios, but have not yet explicitly targeted user communities organising within the social layer.
Figure 8: Illustrating a “layer” of social functionality on top of another “layer” of pre-existing web content (Östlund, 2015)

Figure 9: The Social Layer allowing the separation between content and social interaction, spanning across content domains (Östlund, 2015)
3.2 The Territory Building steps

*Territory Building*, in line with the geographic metaphor employed, can be split into three distinctive steps: Claim, Chart and Colonise (illustrated in Figure 2\(^{18}\)). These steps refer to the stages an individual piece of web content (a *Resource*) goes through.

![Diagram of the three main steps of Territory Building](image)

Figure 2: The three main steps of Territory Building

**What a Resource is**

Within the definition of *Territory Building*, a piece of web content (identified by a unique URL) is called a *Resource* when it has been added to the system (the “claiming” step). In this “claiming” step, at the very least, a name will be associated with the URL. From thereon out, *Resource* refers to the original web content as well as any additional related data that has been created throughout the *Territory Building* process.

**Claiming a Resource for the Territory**

When an interested community member comes across, or otherwise becomes aware of web content that can be of potential interest to the community, they may “claim” this *Resource* - wherever it may be located. This does not mean to actually take ownership of the *Resource*, but rather designating it as being of (potential) interest for the community per se. This marks the *Resource* for other community members, identifying it as part of the sub-set of the web that is of particular interest to the community.

**Charting the Resource and determining its place in the Territory**

Putting information in context, and making it findable/accessible, is important in order to make good use of it. In this step interested members of the community (this must not necessarily include the same individual that originally *claimed* the *Resource*) can put the information contained within in the wider context of the *Territory*. This covers categorisation of the information, as well as preparing summaries of the contained information, so that it becomes easier to navigate for other community members.

**Colonising the Resource, integrating it into the Territory**

The ultimate step in this metaphor is the “colonisation” of information resources. In this step, the community works with the information, through activities such as discussing it, or otherwise interacting with and processing it. The community as a whole decides on the relevance/importance of the information, the use and placement within the relevant information landscape becomes clearer. This

\(^{18}\) This figure is the same as in the “short overview” chapter, placed here for the sake of convenience.
means that any party interested in the available information on the subject in question will benefit from learning things such as how this information integrates into the greater Body of Knowledge available, how others perceive it, or how it may be supplemented and in which ways it may come short. Instead of benefiting from the information alone, the user benefits from what others have made of this information.

The source is not affected
A limitation to the metaphor is that, differing from the actual act of colonisation, the Resource remains untouched. What the community does with the information, within the context of their Territory, does not affect what others do with it, as in no step the actual source data is manipulated. The original context of any content remains, and it is merely viewed from within an additional context within the Territory Building process.

3.3 Bridging Contexts / Overcoming the "Cognitive Hurdle"
Interacting with information in one, and related discussions and other activities in another place (tab, browser window), requires the user to work in two different information contexts. Such “cognitive hurdles” can significantly impact the flow of a user’s experience, as working memory, attention and similar factors are limited (Pearrow, 2007).

In the research of Radvansky (2012), he describes the disrupting effects that crossing of “event boundaries” can have on memory. These findings are described as “walking through a doorway causes forgetting” - these doorways do not have to be physical ones though, as switching between events in virtual environments showed similar effects. When viewing the reading and parsing of web information, and then additional interaction such as commenting on this information as separate “events”, I’d expect similar effects on the user’s memory and focus.

“Zero degrees of separation”: Bridging the information access and community discussion context
Typically, information contained in a web resource tends to be at least “one step” removed from any community activities that relate to it, such as a forum discussion thread concerning a certain article. In a practical context, this one step would be the separation of a certain tab or browsing window holding the information in question, and a different one for the discussion thread.

Within the Territory Building approach, I intend to offer functionality that enables users to interact with the Resources in a manner that does not require switching between contexts of accessing existing web content, and means of value-generating activities within the community, such as discussing their content. I refer to this idea as “zero degrees of separation”. This removes the aforementioned “cognitive hurdle”, which may seem small in practice, but could potentially be significant when it comes to the interaction of online communities and web resources at a larger scale.

3.4 Addressing Small Communities
The approach purposefully targets communities that are small in size, meaning they consist of few members, and which are of narrow focus - they are concerned with a particular topic of interest. Many regular online communities fare well with situations where only a small number of its members are actively creating content or contributing in a similar fashion. The smaller the scale of the community, the more difficult it becomes to sustain a community on that model. It is therefore of value to investigate
approaches which guide and support as many community members as possible in terms of increasing their engagement.

In the context of a small community, the amount of information with which the community is concerned tends to be restricted, which means aiming to build a comprehensive overview of existing information material is within the realm of feasibility, while in cases of other, more generic topics this may not be possible.

3.5 Community Norms Govern Collaboration Processes

The described concept has no explicitly “built-in” means to address aspects such as the distribution of information that may be factually incorrect, requires further contextual information, or may even be malicious or otherwise harmful. The idea is to allow the community to develop the strategies for addressing such challenges.

Example of Wikipedia

An efficient means of governing the collaborative process of its community can be seen in the example of (the English-language version of) Wikipedia: Community “norms”, policies and guidelines govern the majority of user interaction. In the interest of neutrality users are expected to work in accordance to these norms that have been created by the community itself, with powerful institutions such as moderators/administrators only taking action if members repeatedly demonstrate an unwillingness to adhere to these norms. When it comes to vetting information there typically is no definitive authority - it is expected that contributors list sources that adhere to certain quality standards (which again are community-defined), and that quality will be ensured as long as users adhere to these standards.

Applying norms in the Territory Building Approach

An important difference between the described Territory Building approach and Wikipedia (apart from scale), is that the system does not require consensus to be reached, as it merely refers to information resources - users may discuss their factual validity and similar aspects in the associated comments and discussions, and differing viewpoints may coexist. The only place where definitive statements are made are in the case of supplying short descriptions of the content, along with the choices of how to categorise the content. Here, users are expected to supply neutral viewpoints (which can be reached through iterative editing processes), and to act according to community-defined norms in case conflicts emerge. These norms and regulations also ensure quality: While everyone can contribute, the clear set of rules and norms ensures that content of low quality can relatively easily be identified as such, and removed/improved.

3.6 Examples of Norms and Culture

This sections addresses a number of issues that could fall under the domain of a community’s culture - the norms, rules and customs that are established. The aspects addressed in this section should therefore be seen as general discussions on these subjects, as suggestions for points of departure - and may change as an individual culture emerges within a community employing this approach.

Determining Value

In particular when it comes to medical information, questions of validity and value are very important. Providing a structure where medical experts assess information, however, would be neither feasible for such a small-scale community-driven approach, nor would it reflect the expressed intent of keeping the power in the hand of patients. It is therefore up to the users to determine the value of content - and to define such information that is not supported by sufficient evidence, or may even be harmful. Once again, inspiration can be found at Wikipedia - where information can reach a high level of quality, without a requirement for contributors to hold specific credentials. Norms and rules regarding source quality, along with deliberation processes, are the established means of ensuring quality. In the Territory Building approach, it would similarly be up to the community to handle these aspects.

Within a starting phase of employing this approach, prior to reliable processes emerging, it can be worthwhile to have a person specifically vet such information until appropriate norms have emerged.

Ownership

As the idea is to capture the Body of Knowledge of the community, focussing on their combined efforts, no user can proclaim “ownership” of a resource, or in any way dictate in which ways the community interacts with it. They may be the actual author of the web resource in question, but this does not imply they get to dictate the discussion within the scope of the Territory Building concept.

While this could be handled differently - individuals even could be encouraged to take charge of “their” resources - in this concept the deliberate choice of not emphasising individual ownership supports the concept of the community as a whole “owning” information. The intent is to avoid issues where users may act in a defensive manner if they perceive that someone may challenge “their” interpretation of certain information. In Wikipedia, this is treated in a similar manner.20

The moderator role

In certain online communities there are roles for “policing” content (in lieu of editorial staff / expert consultancy), for example moderators that review information, or systems that may only allow specific, vetted-for users to actually contribute. Within the Territory Building concept, users rule - and aren’t dependant on any governing entity.

For the sake of combating certain unwanted and destructive behaviour - spamming and other malicious actions, or community members that are unwilling to participate in civilised discourse - a mechanism for addressing such issues should be present. A moderator role should therefore be imposed. Not as an authority to determine rules, but as an executive force for enacting the community’s will, when community deliberation concludes an individual is acting in a malicious or destructive manner. This is once again inspired by the aforementioned customs of Wikipedia.

This of course requires well-established means of dealing with such cases, and a young community cannot be expected to establish such processes from the get-go. For a starting phase, therefore, the role of moderating can be filled in by site owners or developers, but any such activity should very deliberately be kept to a minimum.

Neutrality and differing opinions
As the amount and diversity of information that is available online can be overwhelming, understanding how information is received within the community context is an important aspect.
Contrasting to Wikipedia, *Territory Building* does not require to identify a specific view-point that will be presented as intrinsically true. Differing views may be voiced side-by-side. The community and the discussion patterns that emerge therefore will influence what kind of information and view-points are available in the system. It is up to the users to develop strategies which guide sense-making while at the same time not excessively marginalising minority opinions (By coming up with *Norms* that govern these processes, as described previously).

“Voting” and exposure of content
The approach, intrinsically, is “biased” towards resources that support view-points shared by the majority of users, simply due to the *helpfulness* rating system acting as a quasi-democratic voting system.
In the context of Reddit, similar concerns are raised in regards to the attention content receives on the front page, where submissions only remain for relative short durations of time. While increasing the visibility of certain content through voting mechanisms frequently raises concerns regarding a “hive mentality” where minority opinions are suppressed, Mills’ (2011) analysis has shown that community norms and members that are in favour of neutrality can prevent such opinions from being marginalised. Community members in favour of neutrality or opposing viewpoints can get differing opinions heard, and in the cases that were examined, view-points differing from the most popular one did also receive significant community exposure.

Equality of users
Community members, no matter whether they are patients, interested persons, or medical professionals, are treated equal in so far that no one’s opinion is “weighted” more. Each user may rate each *Resource’s* helpfulness, engage in the discussion, and adjust the related meta-data to a similar extend. This means patients can make their voices heard to a much greater extent as they may be able in other, more “traditional” settings. They become an active collaborator, rather than a “recipient”. This does not mean there are no risks, and that the validity of medical information should be up for a vote. It is vital that potentially harmful information is identified, and users are made aware of such risks. It is up to the community, however, to establish the appropriate norms for this.

3.7 Summary
The definition of *Territory Building* in this chapter describes the concept I had devised as a potential means of supporting rare disease online communities in their process of assembling information, working with it, with the ultimate goal of making greater “sense” of it. The following method chapter covers how I went about developing a design and implementation from this approach, with the goal of testing it within the specific domain of Trigeminal Neuralgia.
4 Method

This chapter motivates and explains my process of answering the Research Questions, spanning from initial design activities, development and testing with user involvement, along with evaluation steps during and after deployment of a working prototype. Specifics of the design and implementation process are addressed in the following chapter, “Design and Implementation”.

4.1 Method Steps

The work performed for this thesis is split into several steps:

- Identification of a condition and related communities as context for my further work and testing of the approach.
- Identification of needs and requirements of members within the community.
- Design of a prototype solution based on these requirements (not to the full extend specified in the design)
- Testing, and iterative revisions of the design and implementation
- Observation of use of the system by the target audience.

By involving community members from an early stage, I intend to ensure a design that addresses user needs and concerns as closely as possible. As Kushniruk & Patel (2004) state

“The understanding of how complex information technologies can be successfully integrated into the process of human decision making and practical day-to-day use is critically important in increasing the likelihood of acceptability. Information from usability testing regarding user problems, preferences, suggestions and work practices is applied not only towards the end of system development (to ensure that systems are effective, efficient and sufficiently enjoyable to achieve acceptance), but throughout the development cycle to ensure that the development process leads to effective end products.”

Territory Building depends on being used and employed by users, and therefore methods that explicitly cater to user needs are important when transferring the concept into practice.

The entire process was frequently informed and influenced by user feedback and tests, in regards to usability as well as general user feedback, informing the iterative development of a design and implementation, in line with common standards of iterative software development. The general process of such an iterative approach is illustrated in Figure 10.
The means I chose for the purpose of conducting this work aim at examining the *Territory Building* approach during a design and development process with subsequent evaluation – though I could also have focussed on more specifically examining perceptions of the concepts from a user’s perspective, without extensive implementation work. This, however, would make it difficult to judge how such an approach could look in practice – and since it is intended to be integrated into existing “ecosystems”, obtaining a more realistic perspective seemed to be the more appropriate choice.

4.2 Identification of the Condition Trigeminal Neuralgia as the Domain

For the purpose of examining the applicability of the *Territory Building* concept in a real-world scenario, being used for a specific purpose, I sought out to test it in the context of a specific rare disease. Such observation in a “real-world” scenario, alongside existing communities and services, would help with identifying aspects relevant to my third research question: “How can the *Territory Building* approach fit into the existing landscape of social media solutions?”

As described in the *Case Study: the Community "living with TN"*, I analysed an existing rare disease community called “living with TN”. The community is one of the most active Ben’s Friends communities, and one of their resident moderators has his own research interests in the group, which meant that for example a paper on the groups’ demographic composition was readily available (Lawhern, 2012b). While observations from this community, and input from one of its moderators informed the initial design, the subsequently designed and developed prototype was aimed at people interested in TN in general - not just members of the specific “living with TN” community. By involving actual users from a specific domain, I hoped to obtain more
valuable insights in regards to how the specifics of the Territory Building approach can support the day-to-day information management tasks faced by rare disease sufferers.

4.3 Automated Analysis via “Link Crawler”

In order to address issues of starting a community without explicitly influencing users in regards to how they should interact with the system, I decided to base the initial extent of the Territory based on what already existed in the wider Trigeminal Neuralgia community. The use of this information is further addressed in the section “The honeypot effect” in “Building the initial Territory”.

Apart from my observations and interactions with the target community, I analysed the types of web resources that were discussed in the community’s forums. Using a web-crawler I developed for this purpose, I gathered the URLs that were most frequently mentioned in forum discussions over the cause of a year, during the time span of April 2013 to April 2014. Based on these, I then proceeded to assemble a sample set of content, containing resources that had been mentioned most often, and appeared representative of the types of content that gets discussed in these forums. The purpose of selecting these initial resources by these means was to identify a “starting set” of resources that are likely of interest to users, and to avoid influencing the future development of the community by suggesting a certain type of resource ought to be favoured. The initial set, along with motivations for selecting these specific resources, can be found in Appendix B: Initial starting set of resources.

4.4 Design and Implementation Process

This section outlines my choices regarding the design and subsequent implementation of a prototype. Specifics of my choices regarding both design and implementation are described in the dedicated chapter “Design and Implementation”.

For the sake of clarity, I am describing the identification of needs and requirements, the design, and the implementation of the approach in a sequential manner. In practice, due to the user-centred focus of the process, adjustments to the design and implementation were a continuous process, in particular after the point where a small number of users was first exposed to an initial version of the system.

Definition of Needs and Requirements

Based on the information gained during the initial case study of “Living with TN” (see Case Study: the Community "living with TN"), I gathered the needs in regards to online approaches that target this community. From these, I derived a list of requirements (described in “Definition of Needs and Requirements”), which then informed the subsequent design process.

Design

I developed an initial design, along with interface mock-ups (see Appendix C: Mock-ups) detailing how this approach could behave in an implemented form. During this “pen and paper”-centric initial design phase I collected further feedback from the community expert, in order to ensure the functionality adequately addresses the needs of users from the target community.

Implementation

I then developed an initial, functional, prototype version of the design. Additional usability tests (discussed in “Usability tests”) validated the design decisions there, and I

21 http://www.livingwithtn.org/forum
tested a first working prototype with a handful of users from within the target community, which volunteered to test this initial version (discussed in “Initial small-scale tests with target audience”). Based on what I learned from this feedback, I further refined the design, adjusted the implementation, finally launching a test version to a wider audience of users.

4.5 Launch and Fostering Awareness
After developing a working version of the system, the next step was to introduce this prototype to the intended target audience, to get it started, and to get users engaged. Starting up, and then maintaining and fostering this engagement was an important aspect, as without sufficient user engagement it would be hard to evaluate the approach, to observe user interactions and behaviour.

**Honeypot effect**
In the field of HCI, researchers discuss a strategy for overcoming this “start-up” challenge under the term of “Honeypot effect” (Hornecker et al; 2007). A critical number of “bees” need to be present and active in order for others to come by and check out “what’s the buzz”. In a physical space, this may mean placing a few initial actors interacting with an object, prompting others to observe and investigate. In a virtual space, similarly, this means ensuring some initial engagement in order to drive further activities. This has to be weighed against the risk of influencing the ways in which interaction may take off from this starting point, though. If the idea - as in the case of Territory Building - is to provide a tool with comparatively large degrees of freedom, and the intent of having users decide on how they make use of it, it is important not to guide their engagement in a certain way.

4.5.1 Building the initial Territory
Initially, I required a sufficiently attractive starting point from which any further user-generated collaboration could happen. A “blank slate” would give initial users little from which to judge the idea of the concept.
I introduced a starting set of resources to the system - an “initial Territory”. These were based on a number of links gathered by scanning the forums during my earlier preparations (see “Automated Analysis via “Link Crawler””). A concern was not to over-load the system with a large amount of content, which would make it increasingly hard for users to find own content they could add, therefore discouraging involvement.

The initial feedback from the limited tests however quickly made clear that the availability of useful content from the get go was a vital factor in attracting and engaging users. The initial content set was therefore expanded by adding 25 additional resources from a manually compiled list maintained by an existing community. This is a list of resources that were considered of specific importance to TN sufferers, based on the list author’s experience as a community leader for several years.

4.5.2 Initial small-scale tests with target audience
For the purpose of evaluating the prototype at a small scale, before making it available to the “wider public”, I invited users to participate in a round of initial evaluation. These users were recruited from a TN-related Facebook group, where I asked for volunteers willing to explore and provide feedback on a prototype version of my approach. In total,

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22 http://www.livingwithtn.org/page/member-resources
9 people expressed their interest, and received a link to the prototype, along with the instructions to explore it at their own will, based on their interest in the topic of TN.

**Strong preference for individual conversations**

Soliciting feedback proved challenging, as the users invited for this test demonstrated a clear preference for individual communication, only sharing their thoughts regarding the concept when prompted in individual conversations. They had the option to provide feedback through a Facebook group created for the tests, a “Feedback” button directly on the page, by email, or by Facebook conversation. All favoured individual Facebook conversations, though.

While my initial intent was to ask users a series of questions related to different aspects of the prototype, this proved difficult due to the low level of engagement of the participants. I restricted the probing to their initial perceptions, or any obvious flaws with the design.

**My role during the test phase**

In order not to influence the means of initial interaction, I initially restricted myself to a passive observer role. It later became clear that I had to actively contribute resources to the website though, in order to compensate for lacking user submissions.

**Results**

Quotes with the individual feedback from these users can be found in Appendix G: Feedback from initial user tests. The main complaint of users was a lack of already available resources, which led me to adapting a more pro-active role in obtaining resources through own research and observation of discussions in social media. The structure of the navigation page, described as “confusing”, was streamlined, and a separate landing page (as described in “Portal / ‘Landing’ Page”) was added prior to the official “launch”.

**4.5.3 Awareness Strategy**

High drop-off rates and low engagement indicated that the starting set was still not quite sufficient. For the public launch I decided on a strategy where I would periodically add new content, based on what was shared on social media, or what I discovered in own searches. Acting as an initiator for user engagement, my intent was to further expand the initial content in order to make the offering more appealing, and to demonstrate that the page represents a living, expanding community, instead of a rather static list of very limited scope.

The launch was accompanied by the creation of Facebook and Twitter accounts, used to regularly disseminate updates regarding the system and the resources to be found there, and with the intent of hopefully attracting further interested users that were motivated to contribute to the web service. From these accounts, I interacted with other active users related to TN, shared resources, and also went looking for content being discussed, which could then be made available within my system as well. At a later point I created a Google AdWords online ad (See Figure 1) specifically targeted at people researching TN (using keywords such as “trigeminal neuralgia” or “facial nerve pain”) - in hopes of immediately reaching the relevant target audience. The effect of this ad is described in “Traffic sources”.
4.6 Feedback and Observations

After launching the prototype, making it available for a wider audience, I observed interaction manually, through data generated by the system, and through activity measurements performed using Google Analytics. Visitors were encouraged to provide further feedback in written form.

By observing the means by which users were making use of the system, and by inquiring users regarding their opinions of the approach, I aimed to gain insights that would be particularly relevant for addressing my first research question, “In what ways can the approach of “Territory Building” guide and support the process of assembling and deriving meaning from web content for a small special interest online community?”.

Secondly, observing user interaction by means of Google Analytics would help evaluating the impact of the idea of “zero degrees of separation”. This idea explicitly influenced the development of the “Browsing view”, and observing the use of this functionality would therefore be valuable in indicating the ways in which it could influence user interaction with the system.

**Individual user feedback**

After the page went “public”, the means of providing feedback as described in “Initial small-scale tests with target audience” remained, and I further encouraged users to provide additional feedback in a greeting message on the website. This individual user feedback is listed in the Findings section “Feedback after the public launch”.

**Observations and system-generated data**

Simultaneously, I observed user interaction on the page, capturing the activity of users by means of observing system logs, and through direct insights into the database. The data from the latter is described in the Findings section “User Interaction in Numbers”.

**Google Analytics**

Using Google Analytics, I recorded data such as the duration users stayed on the page (session length), where they came from, or their patterns of interacting with the website. This was combined with manual observation of the website and user interactions with the system (such as comments created, “helpfulness” votes and similar actions). Such information can give a clear indication regarding the degree to which users interact with a service, and in what ways adjustment to the service may affect user engagement. Particularly in this community-driven approach this level of user engagement is an important factor for the purpose of examining patterns of user interaction and collaboration.

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23 [http://www.google.com/analytics/](http://www.google.com/analytics/)
5 Design and Implementation

This chapter describes the implementation of the prototype, and the design considerations that led to these implementation choices. Chronologically, of course, the system was designed prior to its implementation. Due to the user-centric nature of the development process, observations and feedback after the launch led to subsequent adjustments. For the sake of clarity though I will first explain aspects of the implementation in its finished state, and afterwards elaborate on the design decisions that led up to these implementation choices.

5.1 Implementation of the Design

The implemented prototype being discussed here - “TN Community Navigator” - can be accessed online at [http://tncommunitynavigator.com](http://tncommunitynavigator.com)

This section describes the implemented version of the design from a user’s perspective. This means it points out the functionality presented, and how interaction is structured. Technical aspects of the implementation are described in Appendix F: Technical Implementation Details.

Technically, the approach is built based on standard web technologies and current development frameworks (Laravel as a backend PHP-Framework, Boostrap as a Frontend HTML5/CSS3 framework). This allowed for swift development and production of a usable version of this approach, so that it could then be actually used and employed by end users.

The service is accessible as a standard web-site within the browser, not requiring special plugins or clients on the user’s side.

There are three main “views” of the system:

- The Landing Page serves as the point of entry to the system - this was added after the prototype had been launched, and based on user feedback and initial usability tests that indicated that the “Navigation Page” was not an appropriate point of entry.
- The Navigation Page is more focused on the task of exploring available content, allowing searching or filtering by means of free-text search, user-assigned tags, or target-audience classifications.
- The Browsing View presents any Resource within the system, making use of an “in-context” means of viewing and editing user-generated additional data alongside external web content.

5.1.1 Portal / Landing Page

The “portal”, or “landing page”, is the entry point to the system, greeting anyone visiting the website. Figure 1 is a screenshot of this page. This page includes a brief statement of the purpose of the website, a prompt to log in or create a new account in order to participate, and, most prominently, showcases a selection of content available.
"Jumbotron” and bold structural components
The page contains a clear description of what the service offers, and emphasises the types of information the user can expect on the page. Essential information is communicated within a short moment of accessing the website, with the intent of reducing “bounces” - users leaving the website after a short duration without engaging with content, as the purpose of the service was not clear.

Emphasis on community and user contribution
The prominent “sign-up” box, and the clarification that sample resources are “Most popular”, emphasise that the service is aimed at user contributions and community engagement. When scrolling down, a further call to action encourages users to sign up and participate.

Showcase
Several popular resources within the four prominent categories are showcased, so that a user may quickly identify actual content when exploring the page. Interaction is encouraged, and the user is invited to explore the additional features within the “browsing view”, accessible after clicking on some of the available content. The tool for showcasing content is split up in four categories: “What is TN?”, “Living and coping with TN”, “Medication and surgical treatments” and “Support communities and organizations”. This structure reflects the way information tends to be structured in other, comparable websites - intended to be immediately clear and familiar to the user. Each category showcases a few web resources in a “minimal” view, along with essential information such as the short description, thumbnail and amount of comments received.

A novice user accessing the website in search of information therefore is immediately greeted by a selection, prompting them to stay and interact with the page, exploring it, rather than immediately leave (“bounce”) in case the page appears not to cater to what they were looking for.
5.1.2 Navigation Page
The navigation page allows exploring the Territory, as well as to search/filter for specific content.

![The navigation page of TN Community Navigator](image)

Figure 13: The navigation page of TN Community Navigator

**Filters for different user types**
Through the use of simple filter controls, different types of users are served simultaneously. A user without specific medical knowledge, for example, may choose only content targeted at “patients”, therefore filtering out other material that may not suit their interests as clearly.
Filtering by associated tags, as well as the free-text search, further support the users in identifying the types of content they are most interested in, reducing time needed for browsing, and therefore addressing issues of reduced attention span. Any filter choices are instantaneously updated using Ajax, meaning the user immediately sees how their choices may influence the result list.

**Detailed overviews**
For each of the resources listed in the results, the most relevant information is presented in a condensed manner. Users may quickly see what kind of additional information has been added by community members, and how the helpfulness of content has been received. This gives a more detailed view than for example the results list on most common search engines, and in particular provides a set of more relevant contextual information.

**Simple Navigation**
The controls are designed to be very straight-forward, with a clear highlighting of how selections in the left-hand navigation menu influence the result list on the right-hand
side. This will support users in navigating the “sea of information” in an easy as possible manner, by filtering the information in meaningful ways.

5.1.3 Browsing View
Whenever a user clicks on a Resource within the system, she is taken to the Browsing View. This view, as shown in Figure 14, provides a view of external web content, along with a bar at the top of the screen, allowing access to system functionality. This simultaneous presentation addresses the previously discussed concept of Zero degrees of Separation (see “Bridging Contexts / Overcoming the "Cognitive Hurdle"”)

Figure 14: The “browsing bar view” of TN Community Navigator

By being present even when the user is viewing an external resource, the browsing bar supports the user in evaluating the information on offer within the context of the community - how others value the information, how it is categorised and contextualised by other community members. The added layer of “meaning” that a web community provides is always at hand. In particular, discussions on the content at hand are possible from within this view (see Figure 15). By having relevant community interaction tools in view at all times, the service aims at reducing the “cognitive load” that is associated with engaging with relevant features that in the case of other solutions would be located in a physically separate location.
5.1.4 Data editing and revisions

Within the “Browsing bar” view, a number of additional functionalities are available. Metadata related to a resource can be viewed (in a “fold-out” section from the original top bar), and can directly be modified by users from within this view (Figure 16).

Past modifications of this metadata are stored and can be viewed, individual revisions can be discussed, and specific changes can be reverted (Figure 17). The “timeline” of any such modifications is therefore publicly viewable, and can help a user in following the process that led to the current state of the information being displayed.
5.2 Design Preparation

Prior to developing a system design, I assembled a list of requirements from which to work. I further developed a number of use-cases that would illustrate how the system was supposed to be used by different kinds of users, each with differing goals.

5.2.1 Definition of Needs and Requirements

As a starting point of this design I worked from a number of requirements. These were derived from my earlier observations of the intended target audience, and my discussions with the community expert (see “Case Study: the Community "living with TN!"”). Most importantly, I conducted a dedicated Skype interview for the purpose of obtaining additional insights into the issues users are facing (See Appendix E: Skype interview with community expert).

As the aim of all design and implementation efforts was a system that would be suitable for being employed in a “real-world” scenario, it was important to work on the basis of actual user needs. The following is a short summary of issues and needs I had identified:

**Issues mentioned in the discussion with the Community Expert**

- Users frequently suffer from cognitive issues related to attention span and stamina
- Users may have issues with verifying trustworthiness and value of resources. “Users are not ‘critical thinkers’”
- Existing listings of resources were not well frequented
- There are various types of users, those that lived with condition for a long time, as well as newly diagnosed people, and their needs may differ significantly
- There is little involvement by medical professionals
- Users taking ownership can lead to unproductive processes when collaboration is concerned, as they get defensive when their opinions are challenged
- Sifting through large amounts of resources, “Arbitrating”, is a major challenge.
- Moderators usually assist with keeping conversations civil and coherent
- Information typically should be very easy to read and comprehend, easy to access as well as **actionable**
Topics I noted during my own community analysis

- Obtaining opinions and recommendations from peers very clearly seems to be the main motivating factor for using the existing community.
- Users are interested in the options that are available to them, and how these are received by their peers.
- Much exchange seems to be driven by altruistic motives or a need for social interaction, as users have no immediate tangible benefit from joining discussions.

From these issues and needs, I derived the following requirements:

**Navigation should impose low Cognitive Load**
Users should be able to navigate through the system, identify and access an information resource, without encountering any unnecessary hurdles in the interaction flow. The system should provide an interface that specifically emphasises ease of use and low “cognitive load”. Few hurdles and straight-forward interaction are necessary in order to accommodate users that might suffer from reduced attention span or similar impairments. (As well as such design being best practice for usability)

**Information presented should be of an Appropriate Level**
Information needs to be of a reading level/complexity that is appropriate to the type of user accessing it - complex medical information without further explanation and context would be of little use to many users. A user being exposed to information that suits their reading level/comprehension will allow them to make the most of the system. “Appropriate” is therefore defined as information the user can be expected to comprehend and discuss.

**Resources should be accompanied by peer Opinions / Community perceptions**
For many users it is essential to be able to obtain information on how their peers perceive a certain information resource. This is their main motivation for interacting with existing systems, and the added value provided by this community-generated information should be of great value to the user.

**System should offer means of easily sifting through information resources**
As there are likely very large amounts of resources available, it is important to allow users to identify and pick the kind most relevant to their needs. Users struggle to identify information that is most suitable to their needs, and existing means of conveying or collating information are not ideal for the purpose.

**System should offer means of easy contribution**
As efforts regarding assembling advice are commonly community-driven, with medical professionals and similar sources typically not being able to provide comprehensive overviews of existing information sources, a community-driven effort should be supported.

5.2.2 Designing for Different User Types

“[While] interactivity can significantly increase comprehension of online health content, the literature has also revealed that greater interactivity may in fact create more difficulties for information seekers who are less competent in navigating online environments, who may be less familiar with the content of the Web site, or who may be less motivated to navigate the site in the first place. […] The challenge, therefore, is
how to strike a balance between providing an engaging and visually appealing Web site, and providing a site that the least competent information seeker could easily navigate without too much guesswork.” - Lustria, 2007

In the case of rare diseases, interested users can be roughly split into three categories:

- Patients suffering from the disease in question
- People not living with the condition, but otherwise engaged: Friends and family, caretakers and similar persons
- Medical professionals

These user types have different requirements in regard to the types of information they are looking for, as for example a paper in a medical journal might be very interesting for medical professionals, but of little value to many patients, due to the complex nature of its content.

**Novice users**

It is standard procedure in the interest of “usability” to design systems in a manner that imposes as little complexity and requires as little “getting used to” as possible (Krug, 2006). Considering the special circumstances of TN-sufferers, this becomes a particularly major concern when it comes to implementing a prototype solution for this group. It can be expected that the vast majority of users falls in the above mentioned “Patient” category, and that a significant amount of these patients suffers from the effects described earlier.

**5.2.3 Development of Sample Use-Cases**

The below use cases illustrate how different types of users with different intents may interact with the system, illustrating in which ways the system design supports these processes.

**5.2.3.1 First Time User Looking for Advice**

This use-case describes the scenario for the most “basic” type of user - a “novice user” seeking out immediately usable information.

- A user, recently diagnosed with TN, is searching for relevant information on treatment options.
- Upon first visiting the web service, they are greeted by the “landing page”. Here, an overview of the types of information that are available at the website is provided.
- The user clicks on the most relevant category (“Treatment options”), and is immediately provided with a list of resources related to the topic in question, and which are the most popular among other visitors.
- After selecting an interesting web resource, the user is now presented with the “browsing view” - consisting of the resource in question, and a small navigation bar at the top of the screen, signifying that the user hasn’t left the system.
- By means of the bar, the user can now see the comments that other community members have left in regards to this particular web resource, how the community in general values the content’s helpfulness, along with other relevant (meta-)information.
- After browsing the available information, the user may then return to the previous page, and browse the other available resources.
5.2.3.2 User Wishing to Share Experiences
The second use-case describes a user that after previous interaction with the system seeks out to become more involved, to start contributing their own opinions and experiences. This use case is important, as a goal of the design is to support all users in the process of becoming active participants and members of the community.

• A user that has been using the service for a while for the purpose of browsing the available information resources has come across a resource she wishes to voice her opinion on.
• She goes to the resource’s browsing view
• Using the commenting function, she is able to leave her own take on the information in question, as well as being able to see and engage with other users that have commented.

Note: For this workflow the user should not be required to create an account, as anonymous comments are possible - one can immediately engage with the community.

5.2.3.3 Experienced User Wishing to Share a Resource
This use-case describes the process of adding a resource - the “claiming” step of Territory Building.

• A user has come upon a website that contains a web resource which she believes has not yet been captured within the system.
• By going to the “Add a resource” page within the system, she encounters two options: Adding relevant information manually, or using a “bookmarklet”.
• She decides for the latter option, dragging the bookmarklet to the browser’s bookmarks bar.
• Now, on the resource’s website, she clicks the bookmarklet, and is immediately redirected to a page where she can add the resource, with the page’s title and URL (the base necessary information) already filled in.
• If the resource had already been captured within the system, the user would instead be redirected to the appropriate “browsing view”.
• The “add a resource” page allows filling in additional metadata such as a description, selecting a target group, or adding custom tags. Once this data has been entered, a click on “save” will add the resource to the system, and redirect to the browsing view of the newly added resource.

5.3 System Design
This section details the motivations and design considerations that led to the state of the implemented system as described in “Implementation of the Design”. The design goal was to create a website, using standard web technologies, accessible through any regular web browser.
This section describes features that were considered and explored in relation to the Territory Building approach. Some features were not included in the implementation, and for the sake of completeness are listed in Appendix H: Features not included in the implementation.
5.3.1 High Level Entities of the Design
From a user’s perspective, two main components make up the main functionality of the system: The portal, which acts as the initial point of entry and main interface of interacting with the system, as well as the “Browsing Bar”, which acts as an extension of the portal whenever a particular web resource is being visited.

The **portal** lists resources, allows browsing available resources, the addition of content, profile management, and provides moderating features (the latter aren’t implemented in the prototype).

The **browsing bar** is a web interface which is superimposed on an existing web page, so as to offer a means of accessing any specific information offered by the system. Such a web-page, in combination with the information accessible through the browsing bar, is referred to as **Resource**.

5.3.2 Resource-Specific Discussions
As much of the value created within a community is based in discussions between its members, a key feature of this approach is to offer means for such discussions. As the approach is structured around individual web resources, it makes sense to link these discussions to these individual resources. Site-wide discussions would mirror the interaction methods already found in existing communities, and likely add little value over them.

Discussion functionality can be divided in synchronous (such as live chat), as well as asynchronous discussions (such as forum threads or comments). Much of the interaction I observed in existing communities was of the asynchronous kind - as the information is typically available for longer, and the effort of facilitating such discussions is significantly lower. These are the ones present in the implementation, though synchronous discussion options are discussed in the Appendix H: Features not included in the implementation.

5.3.3 User-Defined Metadata
Meta-data in this case describes all the additional data which helps composing the *Body of Knowledge*, or “added value”, as discussed earlier. Much of the “added value” created by users comes from explicitly specified data, such as

- **Descriptions** - Short summaries of a resource’s content, making it easier to obtain a picture of what it is about.
- **Tags and classifications** - Further allowing to identify relevant content, and to classify resources that relate to a specific topic.
- **Comments** - *Resource*-specific discussions allow users to discuss content, add to it, and put it in context.
- **“Helpfulness” votes and favourites** - A means of easily describing whether users found a resource worthwhile, allowing browsing users to define content that has been well-received in the past, and allowing larger collections to be sorted in a way that prioritises helpful content.

5.3.4 Means of Modifying Meta-Data, Keeping Revisions
Users drive the system, and users specify what information is presented, and in which ways. It’s not up to the system to decide who gets to provide data, or even who gets to overwrite it. Much like in the example of Wikipedia, it’s up to the community and the norms established within it to decide on the data being presented.
Discussions related to meta-data and revisions
The system provides a platform for this process by firstly enabling discussions (and by these I do not refer to the previously mentioned content-related discussions, but rather such that are concerned with other meta-data), and secondly revisions - allowing changes to be recorded, retraced, as well as reverted, if needed. Allowing users to follow the process by which information had been revised, the path it had taken, helps with the aim of illustrating the process by which any sense-making happened.

5.3.5 Navigation
In order to efficiently “browse” the Territory, and to find specifically relevant information, appropriate navigation functionality must be available.

This includes
- Free-text search in titles and descriptions
- Filtering by user-defined tags
- Filtering by user-defined target groups

By some means of persistence it should also be possible to retrace steps - to return from “browsing” a resource to the view of searching other ones, for example. A mock-up of the navigation view can be found in Appendix C: Mockups.

5.3.6 In-Context Browsing and Interaction
As previously mentioned, the process of accessing, and being able to change user-defined information, should happen in context - at the same time as a web resource is being viewed.
These web resources are therefore presented simultaneously with an overlay/addition offering additional, system-related functionality, namely

- Viewing user comments, and adding own ones
- Seeing “helpfulness” ratings, and leaving own ones
- Viewing and modifying tags
- Viewing and modifying other metadata like titles and descriptions
- Means of returning to the navigation functionality for the purpose of exploring additional content

A mock-up of the in-context browsing bar can be found in Appendix B.1: Mockups.

5.4 Evaluations of the design
I used a number of steps along the way for the purpose of evaluating the design, examining its usability and suitability for the intended target audience prior to the “public” launch.

5.4.1 Community Expert Feedback
At several steps during the development process I contacted the community expert, explaining my design decisions and the motivations behind them. He then provided feedback as to how he viewed these decisions in face of his experience with the livingwithtn.org community, regarding aspects that might require adjustments for example. Much of his feedback was centred on the challenges imposed by determining the value of resources, in particular in regards to the medical validity of information.
On the subject of introducing a moderator role that is restricted to dealing with disruptive behaviour, otherwise letting users decide how the make use of the system:

“Overall, your expressed descriptions of moderator roles strike me as constructive. In evaluating the trustworthiness of sources from a patient perspective, a moderator oversight role can be crucial for weeding out SPAM and extreme viewpoints not well supported by science or the experience of multiple contributors.” Richard Lawhern, Personal Communication, 10.06.2014

On the means by which the proposed design would organise data, and allow browsing it:

“[...] the format seems succinct without being terse. It's at least a fair way of organizing a large body of information. Be prepared to index over 1,000 data objects to cover this field adequately.” - Richard Lawhern, Personal Communication, 06.10.2014

5.4.2 Usability Tests
At the point at which the prototype reached “feature completeness”, I performed a number of usability tests, in order to evaluate whether the design progress was in line with the earlier expressed ideals of an easy-to-use, streamlined interaction process.

5.4.2.1 5-second test
As a simple but valuable means of judging whether the page design would generally be appealing to users, I conducted a “five-second test”24. The point of this test was to evaluate the initial appeal of the front-page, the first impression that typically is vital in the users decision to further engage with the website, or to leave immediately without further interaction ("bouncing", which typically happens within 5-10 seconds of opening a page). Eleven users viewed a screenshot (Figure 18) of the portal's navigation page - which at that point was the landing page - for five seconds. The test indicated that the state of the front page was still somewhat confusing for a first-time visitor, the purpose of the service not immediately clear. While sample size and non-specific demographics of the target group limit the impact of these results, this information, along with further user feedback, informed the later decision to develop a separate Landing Page, in place of greeting the user with this Navigation Page.

The full results of this test can be found in Appendix D: 5-second test results.

24 http://fivesecondtest.com
5.4.2.2 Informal User Tests

Another means of low-cost usability testing was a number of “informal” user tests. This means I invited users to interact with the system, performing a specified task, while asking them to loudly narrate their decisions and motivations as they progressed through it. This could for example be in a manner of “I’m interested in seeing what other users have to say about this, so I’m clicking on the speech bubble icon. That should get me to the comments, I think”.

This was based on the “thinking aloud” method commonly used in usability testing (Nielsen, 1994). The observer does not actively guide the participant, except for encouraging them to keep vocalising, or in a situation where the user cannot progress at all. The tests were conducted through a Skype screen-sharing session for two participants, and in person for another one. None of the participants were native English speakers, and they were not part of the intended target audience. It is due to the limitations in scope and structure that I refer to these tests as informal.

Based on these informal usability tests I gathered further insights as to how well the intended workflows for novice users behave in practice, and whether the offered functionality is intuitive enough for the purpose of allowing a novice user to accomplish the tasks that were described in the design. Changes based on issues noted in these tests were mainly small-scale aspects such as the styling of certain buttons, to make them more distinct, or the wording of some descriptions.
6 Findings and Discussion
In this section I will present the findings of my work, discuss them in the frame of what this research set out to do, and will present some concluding remarks and suggest some possibilities for future work.

6.1 Findings
This section describes the results of the empirical process of my work (explained in “Feedback and Observations”), taking place after I deployed a working prototype of my design. They are interpreted and discussed in the section following afterwards.

6.1.1 User Interaction in Numbers
The following data is based on examining the database records of the prototype, and is presented here with the purpose of illustrating the ways registered users were interacting with the system. This information can help gauging how well different aspects of the system were received in general.

- In total, 80 people created an account on incommunitynavigator.com.
  - Of these, 66 registered during a one-week period in mid-December - after the service was mentioned on a mailing list.
- Only two users left comments, and
- 10 engaged in providing feedback: Voting helpful/not helpful, marking resources as “favourite”.
- Four did modify an existing resource, and
- Three added their own ones using the on-page functionality.
- In total, 31 resources were added based on user suggestions since December 2014 - the majority was added to the system manually, after user-suggestions coming in by email.

6.1.2 Google Analytics Data
The data included here was collected using Google Analytics, and refers to the period from 1. December 2014 to 1. April 2015, unless otherwise mentioned. All traffic data was filtered for known bots and “referral spammers” that could have skewed the results.

In total, 312 users where recorded by Google Analytics during that period of time.

6.1.2.1 User Activity and Bounce Rates
Initially, after the test launched and the page was publicly announced, there was little user activity, and bounce rates (users that left within a short time of accessing the page) were high. Two events though had significant effects: The introduction of a new type of landing page, as well as the mention of the website in a popular mailing list.

25 https://megalytic.com/blog/how-to-filter-out-fake-referrals-and-other-google-analytics-spam
Figure 19: Development of “bounce rate” and number of sessions over the course of a two-week period in December 2014.

Revised Landing Page
The announcement of the revised landing page (see Portal / Landing Page) attracted a number of additional users and, more importantly - significantly reduced the previously very high bounce rates (see Figure 19), referring to users that left within a very short time. After this change, the bounce rate remained significantly reduced, fluctuating around the 50% mark (a value commonly seen as standard in many web sites). Apart from a comparatively short period in December 2014 there was little overall activity though, making data from afterwards fairly unreliable.

Mention on Mailing List
The single most significant influence on visiting rates was due to very “old-fashioned” means: The page was mentioned on a mailing list specific to Trigeminal Neuralgia, the author of the email prompted his readers to explore the website and provide feedback on the state of the implementation. Several users became proactive in sharing their own resources at this point - as intended in the approach. These suggestions arrived by email though, even though the implementation provides online functionality for exactly this purpose. The increased activity and interest did not sustain however, and eventually the service saw fewer visitors in later weeks.

6.1.2.2 Level of Interaction
When looking at the data of users that did not “bounce”, a significant number of sessions did reach a certain “depth”, meaning they spanned multiple individual navigation operations, as shown in Figure 20. Figure 21 details the duration of these sessions - 60% lasted more than a minute.

In regards to gauging how well the concept of “zero degrees of separation” fared in practice, the data of visits to the “browsing view” in particular is interesting. Users on average spent 02:25 minutes viewing an individual Resource, with 38% exiting the system afterwards. This indicates that those users that started exploring resources were moved towards some additional engagement with the system.
Figure 20: Non-bounced sessions between 1. December 2014 and 1. April 2015 and their respective “depth”.

Figure 21: The amount of time users interacted with the system in case of “non-bounce” sessions.

6.1.2.3 Traffic sources
In order to gauge the effectiveness of the “awareness strategy” (see “Awareness Strategy”), where I engaged users using social media as well as online ads, the data on “traffic sources” - meaning the places from where visits to the website originated - is
As shown in Table 2, during the tested period 73% of all traffic came from direct sources, 11% from social sources, and 10% from referrals. Paid ads only accounted for one percent of all visits.

<table>
<thead>
<tr>
<th>Default Channel Grouping</th>
<th>Sessions</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct</td>
<td>537</td>
<td>73%</td>
</tr>
<tr>
<td>Social</td>
<td>84</td>
<td>11%</td>
</tr>
<tr>
<td>Referral</td>
<td>72</td>
<td>10%</td>
</tr>
<tr>
<td>Organic Search</td>
<td>26</td>
<td>4%</td>
</tr>
<tr>
<td>Paid Search</td>
<td>7</td>
<td>1%</td>
</tr>
<tr>
<td>(Other)</td>
<td>5</td>
<td>1%</td>
</tr>
</tbody>
</table>

Table 2: Distribution of traffic sources

6.1.3 Feedback After the Public Launch

Several users provided feedback and suggestions by email after visiting the prototype implementation. A common theme were suggestions of resources to be included on the page, along with other advice on how to prepare and present content. Out of six users providing feedback, four suggested additional resources to be added to the website. The wording of these submissions suggested that the users were not aware of the possibility of adding these resources with the tools provided on the site.

Several users provided rather general positive feedback, and indicated a general need for services of this type:

“It looks like it could become an extremely beneficial website for people with the condition.”

“I wanted to let you know that I think that you have done a great job with the website format and content. I sure wish that I had that type of info readily available to me when I was first diagnosed with TN.”

“I'm sure it will be a very helpful resource for TN patients around the world.”

“I am always looking for more information on TN. I have suffered with it for over 20 years and it just gets worse with no real relief in sight. Please keep up the great work”

“It's always wonderful when I meet new pages of informations, always with the purpose of sharing awareness and informations about TN.”

An administrator of an existing self-help group explained their previous means of assembling knowledge:
“One of our first files we wrote was about coping with the pain. We asked our group members for any tips they used themselves so that when people are struggling with their pain, they may be able to find something to help from that file. The file grows because every so often, someone will find something new which helps them. This always brings hope to people.”

Users confirmed the particular challenges that people living with TN face:

“My only suggestion is to add some videos if possible. Many people with TN find it difficult to sit at the computer for extended periods of time to read. When reading from the computer one often has their head leaning forward slightly for extended periods of time and this can be a trigger or stressor.”

Regarding expert input, a medical professional stated:

“It would be of much help to the TN site if physicians and oral surgeons and dentists had input. Lay persons are not knowledgeable, and may give each other improper information. Dental schools need to be involved, and should Mayo Clinic, etc.”

6.2 Discussion

Based on the lessons learned throughout this work – from the design process with close involvement of users, the implementation, to the testing of this implementation – I will now address and discuss the themes I set out to explore through my previously defined research questions.

6.2.1 Territory Building for Small Online Communities

My first research question is “In what ways can the approach of Territory Building guide and support the process of assembling and deriving meaning from web content for a small special interest online community?” The following points address the ways that I explored.

6.2.1.1 Providing Guidance Through the Geographical Metaphor

The Territory Building approach makes heavy use of a geographical metaphor. This is not intended as a guide for users navigating the service and its content (The implementation does not explicitly mention this metaphor), but it helps structuring the underlying concept: A set of web resources that are of relevance to an online community, and the additional information they create regarding these resources, make up their Territory.

Staying with the geographic metaphor, a user navigating to a resource that has been captured within the community’s Territory does not face the challenge of exploring “new land” - they profit from it having already been charted. By not starting from zero whenever encountering a new piece of information, the user can focus on adding to it, using it.

The Territory Building approach aims at making the concept of a community’s Body of Knowledge (Zettsu & Kiyoki, 2006) more tangible, allowing users a better understanding of what is contained within it, and how to extend on it. The “collective value” that users build both through explicit processes (like commenting, amending information), or even as an “automatic by-product” of their self-motivated interaction with a system (such as the number of clicks or views a page gets), is captured within the
concept, and made more easily accessible to users. By explicitly providing an “architecture of participation”, the community can be supported in aggregating information, and deriving meaning from it.

The task the user is facing becomes less daunting, less broad - as content being encountered has been worked on by other users, its relevance has been established, and the process of making sense has already begun. When it comes to encountering new resources, users also are supported in the way they interact with it. Adding it to the service (“claiming” it), acts as a prompt to others to share their opinions on this new resource, and the user becomes aware of the role of expanding, and contributing towards, the shared Body of Knowledge.

The activities of Territory Building can support a process that brings both individuals and the community as a whole closer to the ultimate goal of sense-making in regards to online information. As this existing information moves through the steps, its value increases.

In the “claiming” step, discovery is supported. The sub-set of “claimed resources” is a lot easier to search through than the World Wide Web as a whole.

In the “charting” step, relevance is established. Based on classifications, descriptions, and similar meta-data, it becomes clearer why and how any specific piece of content can be of relevance to users.

Finally, in the “colonising” step, a constructive and collaborative process guides various user opinions, value judgements, and discussions into place. The community “works” the information, and an individual can profit from this context when it comes to fitting this information into their own process of making sense of it.

6.2.1.2 Collaborative and Individual Sense-making

Many members of online communities are interested in the opinions of their peers regarding various topics. The task of filtering though large amounts of information, of identifying what’s truly valuable, can be daunting. Knowing other people’s take on a subject can help with this process.

Territory Building includes functionality which in an explicit and immediate fashion provides means for activities such as those discussed by Paul & Reddy (2010) in their work on sense-making processes: “one way of disambiguating information, especially by taking advantage of the expertise of others, is to provide the ability for group members to comment on and annotate information found by others.”

Through immediate access to what her peers have generated, an individual can profit from the collaborative wisdom of the community, in particular the contributions of such members that have gained significant expertise on the subject domain due to their continuous engagement (As described in “Expert patients”). Simultaneously, she may support her peer’s sense-making processes, by adding her own contributions and interpretations to the ongoing process.

A second main design principle identified in Paul & Reddy’s work is to “support persistence of the process and products of sensemaking by visualizing sensemaking trajectories”, through features such as timelines. These “timelines” are means for an individual to follow the process by which the collective has arrived at a certain point, at an agreed understanding or interpretation of information.

The revision system found as part of the Territory Building concept, along with comments and revision-specific discussions, allows visualising this timeline. It is an
immediate means of observing the way information has been changed, and the motivations for doing so. The thought-processes behind this collaborative sense-making process become easier to comprehend. Individual and collaborative sense-making process are therefore tightly interwoven.

6.2.1.3 User Engagement
The topic of user engagement, while not an explicit goal of this work, is quite relevant for the purpose of observing the use of the Territory Building approach in action. Only through users that are sufficiently motivated and driven to invest their own time and knowledge can such a collaborative effort succeed. If a majority of users is driven by a motivation to find and consume relevant information, but none are willing to share information they have come across, the “ecosystem” on which this community approach relies, may fail.

Challenges of “starting up” a community
The most critical time is the starting phase of a service, as there exists a problem of providing an engaging starting point which may attract contributors, prompting them to expand on it. With no tangible rewards, and users driven through aspects such as altruism or seeking recognition, the prospect must be compelling enough to invest time and effort in the first place, and a “blank slate” is not necessarily the most compelling starting point. After all, the service/approach may fail, and the efforts of these early contributors might be in vain.

Effect of the service design on user engagement
The focus of the Territory Building concept in regards to connecting functionality to individual web resources may have influenced user perception of the service, and could be seen as a potential challenge for the approach as a whole. A potential extension of the concept which pays closer attention to “social networking”-like functionality, an interaction layer on top of the Territory Building process that more explicitly supports relationships between users, could be more effective in regards to encouraging an active participatory culture.

Presentation of content
First impressions count a lot when it comes to web services, with many users ready to leave within seconds (“bounce”), if the offering does not look immediately useful and attractive. Changing from a presentation that favoured “navigation” and “finding” capabilities towards one that “showcased” content resulted in a significant user interest spike (See User Activity and Bounce Rates), along with a reduction of users that immediately left. Without changing available content, this change of interface emphasised a clearer “call to action”, and categorising content recommendations in an easily accessible manner. User comments claiming a “confusing” interface no longer occurred after this change.

This simple change in the ways information is presented could also have been performed in different ways, and may be used for very different intents. An interesting option, for example, would be to prioritise user submissions and sharing immediately on the landing page, even further lowering the barrier to contribution. Another option could for example be the presentation and highlighting of some random resource, and an immediate “call to action” prompting users to leave their feedback on this particular resource - this way lesser visited resources could be highlighted, and a larger amount of user feedback data could be assembled.
6.2.2 The Idea of “Zero Degrees of Separation“
My third Research Question is “How can the idea of “zero degrees of separation” influence the way users interact with the system?”
In the implementation of this approach, the Browsing View component (see Browsing View) of the design was the main means of exploring this idea, presenting external web content, user-generated data and interaction functionalities in the same view. This idea results from the specific focus of Territory Building – to take a specific piece of web content through several stages that position it within the community’s Territory.

Reducing “Cognitive Load”
In existing systems that offer means of interacting with external information resources, it can be expected that the separation of content and meta-data, and the need for users to switch between these contexts, imposes a significant additional cognitive load, as for example aspects of a resource they wish to comment on have to be kept in “working memory” when switching towards the context where they can place such a comment.

Based on my understanding of commonly agreed best practices in the field of usability (Krug, 2006), as well as research on the effect that switching between “events” can have on memory (Radvansky, 2012), I hypothesised that by “bridging” the gap between a context for viewing web content, and the context in which related activities (such as voting or commenting) happen, users would be able to commit more of their focus and their mental resources to their actual objective, reducing such cognitive load. This allows freeing up “mental resources” for the ultimate goal of user interaction: sense-making.

Collected usage data (described in the section “Level of Interaction”) regarding the length of time users spent browsing, as well as the session “depth” (number of pages viewed per session), indicates that users which starting exploring the system made considerable use of it. While this does not allow the immediate conclusion that the “browsing bar” feature is advantageous over other approaches, it indicates that the concept did indeed invite users to explore several resources “in-depth”.

Level of separation - the “Separation Scale”
Potentially, separation between content and additional functionality could be further reduced - when user-generated data and the content of existing web resources are presented as one, when what exists and what others may have modified is merged into one view. Such an approach could allow a user to access even more contextualized information – but it brings additional challenges, when a source of information and interpretation of it run danger of being indistinguishable.

When seen on a “separation scale”, the end opposite of “zero degrees” would be close to the way most approaches that reference external web resources - such as social bookmarking - operate nowadays. The service in question is typically in its own window/tab, while the resource in question sits in another. Typically, any discussions or other interaction in regards to a web resource happen separately from the actual resource.

6.2.3 The Approach in Context
My third research question is “How can the Territory Building approach fit into the existing landscape of social media solutions?”
Users’ reactions and feedback regarding the implemented prototype indicated that this approach could be a welcome addition to existing online services in use today (see “Feedback After the Public Launch”), as identifying relevant online information, and making use of it, is one of the major challenges faced by rare disease sufferers.

My design and implementation of the approach examined it in one particular context – defined by the topic of Trigeminal Neuralgia. The unique condition of TN sufferers has affected the design of this approach, and what I learned indicates that the effect of this condition can significantly affect user’s potential engagement with any online system (see “Special Considerations”). Territory Building employed in the context of a different rare disease, therefore, might look different in practice. It would be interesting to explore such additional contexts, though any deployment ought to be accompanied by a similar close collaboration with users from the intended target audience.

**Networking and social interaction**
Social networking-like functionality was not the main emphasis of this concept. As discussed in “The honeycomb of social media” – establishing relationships is not one of the potential social media functionalities that is explicitly emphasized in this idea. In the face of existing networks and communities, it is supposed to act as a complimentary solution, a means to index and contextualize the knowledge that is distributed across numerous sources and solutions. The role of related resource-sharing web-services such as social bookmarking approaches could be partially taken over by this approach, as far as they fall within the same topic domain as the Territory Building implementation. An interesting direction to further make use of what is already being created could be to more closely integrate the Territory Building approach with existing social networks and communities, to provide more immediate means of “sending or submitting” something like a comment or opinion on a certain web resource, even if it is created on Twitter, for example.

**Scope of the Territory**
In the context in which I implemented this concept, the Territory was defined as being made up from any web resources, along with related community-generated content, that relate to the topic of Trigeminal Neuralgia. The extent to which a resource counts as related is up the individuals contributing, and such individuals may be any that do have an interest in the defining topic. This definition of the scope of such a Territory, however, could hypothetically be defined by different aspects, tightened, or loosened further. If, for example, the Territory would be defined by a certain, clearly specified group of people - such as members of an existing online network - it could have a somewhat different shape. Existing customs, norms, or even rules of such a community could be expected to be “brought along”, applying even to this Territory. This could address issues of establishing such norms and rules of interaction at an early point (as explained in Crowd sourcing & norms) - but likely would also severely limit the potential directions any further developments might take.

**Organising through sub-communities**
In small-scale communities, it can reasonably be assumed that resources that prove popular are likely relevant for large amounts of the user population, and by some simple categorisation of user types can be tailored even more precisely. In the context of a larger-scale community without a precisely-defined unifying topic, additional problems would likely emerge when it comes to organising the amount of
web resources along with the means of navigating them. Additional strategies might be necessary to handle such a scenario.

In such a case it might be interesting to explore a split into separate sub-communities - for example in the way that Reddit handles it: In the case of Reddit, interested users can create specific “sub-reddits” that cater to smaller sub-communities. Users may follow any amount of such sub-communities simultaneously, a user may for example be “subscribed” to a community concerned with soccer, one on amateur woodworking, and one for professional web developers, and view relevant content of these communities simultaneously.

Such a case would cross the boundaries of the geographical metaphor of the Territory. Content could belong to more than one sub-community, but be treated differently within the context of each, as different communities may have different viewpoints, or interpretations of it - and the web can be viewed from their different viewpoints. No absolute limitations requires a single “land-owner”, or single perspective - each such approach may exist in its own “layer”.

6.3 Conclusion

While Territory Building is not the first approach that allows building a Body of Knowledge or that supports sense-making, it supports these concepts explicitly, and in a very immediate manner. It explicitly guides users along a process that aims to help with establishing a scope – a virtual territory – of relevant web resources, and provides a place for accessing, as well as adding, relevant user-generated information.

By providing tools that allow users to explicitly mark information as being of interest (“claiming”), it allows a clearly defined, narrowed-down scope compared to the web at large. Within this scope, structure can be established (“charting”), and the process of incorporating the contained information in a shared understanding, making sense of it through discussion, interaction, providing supplemental information - the “colonising” of these resources, provides a more tangible means of interacting with a community’s Body of Knowledge.

Users acting within this structure, aiming to personally make better sense of this information, do not start “from zero”, do not need to “chart the land”, but can profit from what the community has already done.

In conclusion I believe that the potential of Territory Building in regards to making distributed and unstructured online information more accessible, is an interesting one. As a structuring tool for the process of engaging with and extending the body of web knowledge available in regards to a particular domain, the approach has the potential to provide a more immediate and controllable means for engaging with abstracted information.

For newcomers to a particular topic it might offer easier access to what is available, while at the same time providing a more structured means for users to capture their opinions and ideas with the interest of sharing these with their peers.

The concept of Territory Building, in the state of a more complex implementation based on the conceptual approach and feature-set described in this work, can have the potential to make the lives of rare disease sufferers easier, and to support them in regards to their struggles with assembling and “making sense” of online information. The potential that communities demonstrate when it comes to assembling knowledge as a collective is one that can be further harnessed, it’s benefits can be brought further into the immediate reach of the individual user.
Services that emphasise social engagement and sharing in regards to web resources – such as social bookmarking and social news aggregation – enjoy great popularity, and motivate their members to participate by offering a means of “curating” a breadth of information that might otherwise seem unmanageable. I believe that harnessing this potential, applying it to the purpose of empowering patients, is a worthwhile pursuit within the domain of social media, and Territory Building is one potential means for pursuing this purpose.

**Social Layering**
The Social Layering approach served as the basic structuring principle of adding social functionality to web resources already found on the web. In its core, the influence of Social Layering is the process of taking existing web resources, and building “something social on top” of them - functionality that is not defined or limited by the social interaction functionality offered by any of these individual resources. While Social Layering does not dictate that any approach based on this principle must be community-driven, the separation of responsibilities in this idea provide an interesting starting point for an approach that is explicitly community-focused.

The geographical metaphor, describing the creating of a collection from this information, a Territory, for the purpose of appropriating this information, making sense of it, and the choice to construct an approach based on community contributions, are not immediate conclusions of the Social Layering approach, but were choices made specifically for this work.

**Benefits for Rare Disease Communities in particular**
Potentially, rare disease communities can benefit from a clearer understanding of the domain of their diseases, the information available to them, and the way it can fit into the context of their own personal situation. Users can gain a better understanding of treatment paths that would be interesting to pursue further, learn about coping strategies that helped others in similar situations. The available means for a patient to take charge, to become a proactive part of their own health care, are increased.

**Critical factors for the success of this approach**
Based on my exploration of this approach, I conclude that the most essential factors for any implementation of it is a sound strategy for continuing community engagement - from the starting phase, to questions of sustainability. The concept relies on engaged users carrying it, and on a continuous approach to “make it their own”. It is furthermore essential to take great care as to how any user-facing functionality is designed, how the intended interaction means are conveyed, and how processes are guided.

6.4 Future Work

**Observations over longer durations**
Building something from a collaborative effort of a small number of volunteers takes time - and an approach newly introduced into an existing “ecosystem” may simply need time to be incorporated, adopted, and used. The limited time-span available for observing interaction with the suggested prototype therefore limits what can be learned about emerging patterns of interaction: Community-generated norms and procedures, the peculiarities of how exactly a community makes the approach “their own”. In future
work, observing this concept over a longer duration might provide interesting insights in regards to emerging community culture and models of behaviour.

User perceptions
Limited levels of engagement also limited the amount of data to be gathered on user’s perception of the services concept as a whole, as well as it’s defining aspects - in particular the concept of “Zero degrees of separation”, and whether users view it as being advantageous over the means by which other services handle such aspects. In future work, it would therefore be interesting to establish further relationships with users, to entice them to share their views regarding the system they are encountering. As the Territory Building concept governs underlying structure, and is not openly presented to users, it would be interesting to see how their perceptions of the concept align with the actual design intentions expressed in the approach.

Identifying key topics
Much of the work described here focused on the “hows” of user interaction, of exploring means that support assembling information and making sense, and how these are used in practice. Another interesting aspect to observe - from the perspective of social sciences or medicine, possibly - would be what is being shared and discussed. Within the domain of rare diseases, for example, insights in the factors that are most essential to patients - the addressing of which could be expected to positively affect their well-being - could be very valuable.

Increased degrees of interactivity
Within Östlund’s (2015) work on Social Layering, reference is made to approaches such as real-time collaboration and interaction with web content, functionality such as commenting that happens directly on a web page. Exploring features that allow more “intimate” engagement with external web content - annotating specific paragraphs, live discussions, attaching contextual references - could increase the appeal of, and usefulness for a user community.
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Appendices

Appendix A: One-week sample of livingwithtn.org discussions

The below table lists all the discussion threads that were analysed.
The most popular topic, by far, was the discussion of various treatment options, such as medication or surgical procedures. People share experiences with different approaches, solicit advice in regards to which options they might pursue or which specialists to contact. As much of the medication and (Neuro-)Surgery that is discussed in relation to TN may be associated with significant effects and side-effects, personal experiences of others that explored or experienced these options are much sought after. Information and advice shared is largely anecdotal, though studies and other information assemblies are also frequently referred to.

An additional area frequently discussed is living and coping with the condition. Once more, users seek practical advice and experience from their peers in regards to means and techniques related to coping with the effect of the disease as well as related aspects such as medication side-effects.

Topics that explored “alternatives” - treatment options that are not commonly conducted/recommended by medical professionals, due to not having been tested, or due to not having been shown to be efficacious, are discussed, and users are seeking for anecdotal advice. This seems to reflect the common theme of users seeking options and alternatives regarding treating their condition or mitigating its effects.

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### Appendix B: Initial starting set of resources

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<td>1</td>
<td><a href="http://www.thedoctorsTv.com/videos/lib/init/658">http://www.thedoctorsTv.com/videos/lib/init/658</a></td>
<td>Link to TV show about TN</td>
<td>Very often discussed link to a TV special on TN (20 mentions in total)</td>
<td>tv show, report, the doctors</td>
</tr>
<tr>
<td>2</td>
<td><a href="http://www.multigson.com">http://www.multigson.com</a></td>
<td>Manufacturer of cranial ultrasound machines</td>
<td>This was the most linked (24 times) website in the past year.</td>
<td>ultrasound, technology, company</td>
</tr>
<tr>
<td>3</td>
<td><a href="http://doctor.webmd.com/doctor/brian-willis-md-1da43bac-57a9-4a8c-90f-65f70a2fe11e-overview">http://doctor.webmd.com/doctor/brian-willis-md-1da43bac-57a9-4a8c-90f-65f70a2fe11e-overview</a></td>
<td>A neurosurgeon’s page in a physician directory</td>
<td>Page of a certain doctor at webMD, has been recommended 15 times in the past year.</td>
<td>doctor, doctor recommendation, surgeon</td>
</tr>
<tr>
<td>4</td>
<td><a href="http://www.msworld.org/Forum/showthread.php?t=116871">http://www.msworld.org/Forum/showthread.php?t=116871</a></td>
<td>Discussion of a certain diet in a Multiple Sclerosis discussion board, what is there apart from anecdotal evidence?</td>
<td>A discussion in another forum, referenced 10 times</td>
<td>diet, nutrition, discussion, evidence, scientific validity</td>
</tr>
<tr>
<td>5</td>
<td><a href="http://www.ncbi.nlm.nih.gov/books/NBK390/">http://www.ncbi.nlm.nih.gov/books/NBK390/</a></td>
<td>Book chapter on types of sensations, how they work and get examined</td>
<td>Often mentioned, represents a scientific text of direct value</td>
<td>scientific, book, sensations,</td>
</tr>
<tr>
<td>6</td>
<td><a href="http://www.healthboards.com/boards/">http://www.healthboards.com/boards/</a> #</td>
<td>Health-related discussion board, covering very broad range of topics</td>
<td>Often mentioned, presents alternative source to find information apart from very specific TN-related one</td>
<td>[discussion board, forum]</td>
</tr>
<tr>
<td>8</td>
<td><a href="http://www.buzzle.com/articles/tooth-resorption.html">http://www.buzzle.com/articles/tooth-resorption.html</a></td>
<td>Discusses a dental issue, often related to TN</td>
<td>Dental issues are related to TN because they consider the same nerves, TN may be misdiagnosed as a dental issue, or symptoms may start occurring after dental procedures.</td>
<td>dental, medical condition</td>
</tr>
<tr>
<td></td>
<td>URL</td>
<td>Description</td>
<td>Keywords</td>
<td>Link Type</td>
</tr>
<tr>
<td>---</td>
<td>-----</td>
<td>-------------</td>
<td>----------</td>
<td>-----------</td>
</tr>
<tr>
<td>9</td>
<td><a href="http://pmj.bmj.com/content/87/1028/410.full.pdf">http://pmj.bmj.com/content/87/1028/410.full.pdf</a></td>
<td>An overview paper: “Trigeminal neuralgia: the diagnosis and management of this excruciating and poorly understood facial pain”</td>
<td>Direct link to highly relevant scientific article</td>
<td>article, [scientific, research, paper]</td>
</tr>
<tr>
<td>10</td>
<td><a href="http://www.webmd.com/hw-popup/diabetic-neuropathy">http://www.webmd.com/hw-popup/diabetic-neuropathy</a></td>
<td>Short definition of diabetic neuropathy, nerve damage caused by diabetes</td>
<td>Very little content, but nonetheless this definition was mentioned several times.</td>
<td>nerve damage, diabetes, definition</td>
</tr>
<tr>
<td>11</td>
<td><a href="http://umanitoba.ca/cranial_nerves/trigeminal_neuralgia/tutorial/">http://umanitoba.ca/cranial_nerves/trigeminal_neuralgia/tutorial/</a></td>
<td>A flash tool explaining what TN is, including animations etc.</td>
<td>Gives people a short and clear overview of TN</td>
<td>tutorial, overview</td>
</tr>
<tr>
<td>13</td>
<td><a href="http://www.skepticnorth.com/2011/10/evaluating-cefaly/">http://www.skepticnorth.com/2011/10/evaluating-cefaly/</a></td>
<td>Skeptical evaluation of a product claiming to prevent/treat migraine headaches</td>
<td>The importance of skeptical evaluation of “alternative treatments” has been mentioned by Richard, people suffering from particularly debilitating diseases might tend to try non-evidence based approaches.</td>
<td>skeptical, headaches, treatment, science, cefaly</td>
</tr>
<tr>
<td>14</td>
<td><a href="http://www.dailymail.co.uk/health/article-2582114/Scientists-use-venom-cone-snails-create-painkillers-powerful-morphine.html#ixzz2w90R2ogP">http://www.dailymail.co.uk/health/article-2582114/Scientists-use-venom-cone-snails-create-painkillers-powerful-morphine.html#ixzz2w90R2ogP</a></td>
<td>Newspaper article about new painkiller</td>
<td>Has been often shared, pertains to TN symptoms, warrants skepticism and caution</td>
<td>newspaper, article, medication, painkillers</td>
</tr>
<tr>
<td>15</td>
<td><a href="http://www.webmd.com/drugs/drug-4181-">http://www.webmd.com/drugs/drug-4181-</a></td>
<td>WebMD article about a certain treatment type</td>
<td>An example of a numbe of WebMD articles linked</td>
<td>medication, treatment</td>
</tr>
<tr>
<td>capsaicin+top.aspx</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix C: Mock-ups
These mock-ups illustrated the core functionalities of the system, and allowed further refinements before the technical implementation. The sketched components are the “Portal Page” (Figure 22), including any information presented there, as well as the permanent “Browsing Bar” (Figure 23) which will be displayed on any website which is visited from within the system.

![Portal Mockup Redesign](image)

Figure 22: Mock-up of the portal page, emphasising an “explore” and “extend” split of functionalities (browsing resources as opposed to adding additional ones)

![Cleaner Browsing Bar Mockup](image)

Figure 23: Mock-up of the “browsing bar” view, with the comment functionality extended.
Appendix D: 5-second test results

<table>
<thead>
<tr>
<th>User</th>
<th>What do you think this page was about?</th>
<th>Which element on the page did you focus on most?</th>
<th>Was the design and offered functionality easy to comprehend?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>a collection of tn resources</td>
<td>the articles or boxes on the right</td>
<td>yes, maybe consider adding a secondary color (other than blue) to help group content</td>
</tr>
<tr>
<td>2</td>
<td>Healthcare</td>
<td></td>
<td>Perhaps too much text at the same time. But also the 5sec limit makes it stressful</td>
</tr>
<tr>
<td>3</td>
<td>don't know</td>
<td>huge (i) icons</td>
<td>no</td>
</tr>
<tr>
<td>4</td>
<td>TN</td>
<td>TN</td>
<td>No</td>
</tr>
<tr>
<td>5</td>
<td>tn illness resources</td>
<td>the menu on the left</td>
<td>yes</td>
</tr>
<tr>
<td>6</td>
<td>TN, but you gave that away in the question.</td>
<td>There was a lot going on. No clear CTA. I noticed the orange button in bottom left when scrolling.</td>
<td>no. Little messy.</td>
</tr>
<tr>
<td>7</td>
<td>It was about TN and gathering info on it in one place</td>
<td>The blue sections on the side</td>
<td>There was a lot of text in a lot of varying sizes.</td>
</tr>
<tr>
<td>8</td>
<td>Trigeminal Neuralgia (TN) is a rare disease. Information is spread across the web, but identifying valuable content is difficult. This page</td>
<td>the big turquoise &quot;i&quot;s</td>
<td>lot of show, little go</td>
</tr>
<tr>
<td>9</td>
<td>TN because you said so in your description</td>
<td>the logo</td>
<td>no, it was a mess, too much going on and it had no flow</td>
</tr>
<tr>
<td>10</td>
<td>Hub for information and support</td>
<td>The header</td>
<td>More or less, it may be easier to grasp if you remove the column on the right, so it's less information at once.</td>
</tr>
<tr>
<td>11</td>
<td>Help, support and advice</td>
<td>the icons</td>
<td>no there was too much going on on one page</td>
</tr>
</tbody>
</table>
Appendix E: Skype interview with community expert

I had previously researched the livingwithTN.org community, and other ones like it. I drew up a design based on my own perceptions of the issues faced, and the users present in these communities. I fleshed out features, and created mock-ups based on this design. This call was then intended to be an important step in which a community expert evaluates this initial design, and judges how far it complies with the realities faced in the communities, and proposes changes, additions, and reflections on certain decisions.

Preparatory Documents
Prior to the call, I invited Richard and supplied him with two documents: The first described the idea of the portal/territory building etc. Illustrating it with some of the mockup pictures. The second document was a PDF which contained the full mockups I had created so far. These were navigateable by clicking on links, but otherwise not interactive.

The main topics that came up during this call were the following:

Toxic Ownership
Based on own observations in the existing community, the community expert identified “Toxic Ownership” as a major issue when it comes to the community dynamics. People strongly identify with “their” disease, and their specific perception of it. This could lead to aggressively defending a viewpoint instead of contributing it to the discussion as one opinion, and when the possibility of collaborative editing exists, some users may feel compelled to overwrite different viewpoints. (As in Wikipedia “Edit Wars”)

Role of Moderators
Like in many communities, moderators may step in when discussions are uncivil, or otherwise inappropriate. This may happen in particular when the aforementioned ownership issues come into play. Additionally, since some users may struggle with expressing their views coherently, experienced moderators may offer their interpretation of what the user means to convey, for the sake of other discussion members.

Arbitration
He strongly emphasised the need for Arbitration (“The absolutely most important step”): Means of choosing the most relevant information resource out of a pool of many resources. This is an aspect that currently poses a great challenge to many community members, novice users and experts alike. Evaluating sources based on aspects such as medical validity costs great time, and with much of the information in question is an essential task.

Type of Information
Aspects that make information valuable for users are that the information is short, readable, actionable, and ideally referring to a person (such as a medical professional to talk to).
In regards to “readable”, he stated that one ought to work on the presumption that users will have relatively low reading comprehension. (“6th grade reading level”). Furthermore, information should be easily searchable, due to simple and natural language based search queries, as more sophisticated methods once again might pose to great of a challenge to much of the target audience.

Appendix F: Technical Implementation Details

Technology and Frameworks involved
The prototype is a web application composed of commonplace web technologies: Laravel, a PHP-Framework, handles system functionality on the web server, building web sites delivered to the browser. It interfaces with a MySQL-database for data storage.
Bootstrap (HTML5-Framework) allows structuring the sites, and provides pre-defined components for use in these sites. jQuery handles standard JavaScript functionality within the browser, such as asynchronous communication.

Laravel
Laravel \(^{27}\) is a PHP framework, supporting the swift development of custom PHP applications. It is not a CMS (like Drupal, for example), and does not impose a specific structure to web content or how it is presented.
The framework does encourage the use of a Model-View-Controller (MVC) for the development of applications (see Figure 24).
Reasons for choosing this framework for the development of the prototype are:
- The MVC design supports a clean and maintainable code structure
- “Eloquent”, the Object-Relational mapper included in Laravel, allows easy interfacing with the database, and aids mapping the Models to the database.
- “Blade”, the templating engine included in Laravel, allows defining a modular structure for the templates used in building the websites provided by the service.

jQuery
jQuery \(^{28}\) is a widely used standard library for implementing JavaScript functionality related to interface functions and asynchronous communication. It is fully supported by Bootstrap, and was used for implementing interactive interface functionality.

Bootstrap
Laravel is set up to work with Bootstrap \(^{29}\) as the default Front-end Framework, making it a convenient choice. The framework is a widely used standard, allowing visual structuring of a website, but also allows completely customising its look.

\(^{27}\) http://laravel.com
\(^{28}\) https://jquery.com
\(^{29}\) http://getbootstrap.com
CRUD

Resources in the system can be modified through a number of standardised methods, typically called create, read, update, delete. Following a RESTful architectural style, standard HTTP methods like GET, POST and DELETE are used.

Note: “resource” in this context describes an entity accessible through a controller, meaning that for example a “User” is a resource as well. A capitalised and italicised Resource refers to the web-resource entity central to the Territory Building concept.

Example interaction sequence

Figure 25 illustrates an example interaction sequence describing the case of a user creation a new Resource within the system.

For creating a new Resource, the user may click an appropriate button. The create route for the resource leads to the appropriate function in the ResourcesController being called. This method returns a View from the “create” template for a resource, which is subsequently created by the server, transmitted, and rendered in the browser. The user fills out the form, and hits submit. A store request triggers the appropriate method in the ResourcesController, which subsequently creates a new instance of the Resource model. This sequence is exemplary for other system functionality. A new user account, or a comment, would be created in the same way.

Figure 25: Sequence diagram describing the creation of a new Resource

http://laravelbook.com/laravel-architecture/
**ER Diagram**

The system is structured around *Resources* - A *Resource* is an entity identified by an URL and user-defined metadata (Title, description, tags). Figure 26 explains the relationships between the different entities that make up the *Territory Building* prototype implementation.

As the heart of the system, other elements are related to the *Resource* entity. Comments always belong to a specific resource. Users that mark a resource as favourite, or vote on it being “helpful” or “not helpful”, create a relationship with it. This allows tracing individual votes to users, as well as gauging the overall popularity of a resource.

A revision system logs any changes to a resource’s metadata, along with the user that performed these changes. Individual revisions may be the topic of discussions (a separate entity from comments).

![Diagram of system's architecture](image)

Figure 26: Entity-Relationship diagram of the system’s architecture. Attributes are omitted for the sake of clarity.

**Packages and libraries used**

A number of Laravel packages are used to provide specialised functionality. These are

- Revisionable\(^{31}\) - This package allows keeping revisions of a model within Laravel. In this project it is used to keep revisions of the *Resource* entity, and these revisions are used in the “Revert Revision” functionality I implemented.
- Snappy\(^{32}\) - allows creating screenshots for specified URLs via the wkhtmltopdf library. Used by Croppa.
- Croppa\(^{33}\) - This package aids the creation of thumbnails for web resources. It takes screenshots created by Snappy and re-sizes them for the use in thumbnails.

\(^{31}\) https://github.com/VentureCraft/revisionable
\(^{32}\) https://github.com/barryvdh/laravel-snappy
Baum\textsuperscript{34} - An implementation of the “nested set” pattern for Laravel. It is used for the purpose of nesting comments related to a \textit{Resource}.

Tagging\textsuperscript{35} - Provides the data structure used for the tagging system.

Flash\textsuperscript{36} - Supports the creating of flash messages (“Toasts”) for events in Laravel.

Eloquent Sluggable\textsuperscript{37} - Used for creating slugs (URL-friendly identifiers) from \textit{Resource} titles.

FontAwesomePHP\textsuperscript{38} - For easier use of Font Awesome icons in created pages.

\footnotesize{https://github.com/BKWLD/croppa}
\footnotesize{https://github.com/etrepat/baum}
\footnotesize{https://github.com/rtconner/laravel-tagging}
\footnotesize{https://github.com/laracasts/flash}
\footnotesize{https://github.com/cviebrock/eloquent-sluggable}
\footnotesize{https://github.com/kevinkhill/FontAwesomePHP}
Appendix G: Feedback from initial user tests
These results are from the participants of the initial tests with volunteers.

Participant A:
“I will look at it more when I get the chance, I’m having a tough time getting a decent internet connection. I live on a remote 20 acre ranch, off-grid, solar-powered. I only leave the house once a week. I only get 4 gb per month, so having a central website for the latest TN info will be a boon for me. One of the biggest problems I have with some sites is that most assume everyone has high speed internet. Mine is so slow I can rarely view animations and video. I prefer to read text files. I know I am a small minority, folks who have not quite joined the 21st Century. I really like what I see so far. I like how you have the site set up. It is easy to navigate, crucial for TN patients who are often older and in a brain fog due to pain and medications.”

Participant B:
“It was ok. Was easy enough to navigate, but some of the links seemed blurry. There definitely wasn’t much on the site at all and the information was not really pertinent to our particular disorder. Finding useful information that would benefit me was not found at all on the website. It was laid out a little poorly. I have seen websites that were much easier to navigate and understand. To me, it would be one I would stay away from and find a website a little easier for me to navigate and find what I want. “

Participant C:
“First thoughts - without spending a lot of time there. It is laid out in a rather weird manner, like choosing what target audience you are.

The links to other sites need to open up in new tabs, I inadvertently closed the page trying to get back to it. I’d say that most people are used to new tabs opening - like Facebook does. Each link needs to have a small (one sentence at most) write-up of what they are. In other words, the Health Boards may help, but we need to know 1) They are general discussion boards that have a specific forum for TN 2) They require a person to sign up.

The top of the page needs to have a general description of TN and ATN. And, reword your description - for instance ‘Trigeminal Neuralgia - information and resources from around the net at your fingertips.’”
Appendix H: Features not included in the implementation

This list contains certain features that were considered in the early stages of the design, but were judged not to be of sufficient value, or out of the scope of the prototype implementation. For further explorations or extensions of the approach, these features might nonetheless be very interesting.

**Presence indication**

In relation to real-time interaction, presence indication becomes relevant: The possibility for one user to see whether another one is online, or even what they are currently doing (which resources they are browsing). This functionality however would move the system closer to a social network - something that is explicitly not the aim of this concept.

**User-specific information (reputation)**

A reputation system (such as “Karma” implemented on Reddit) could allow identifying users that others consider to be particularly valuable contributors, and potentially be used as a starting point to vouch for the value of a resource or comment that user may have submitted. The problem with this idea is that it caters towards an approach that emphasises ownership and authorship - something that the Territory Building concept explicitly tries to avoid, by emphasising content. The ongoing discussion\(^{39}\) at Wikipedia regarding the ownership of articles was the base for this decision not to emphasise individuals, as this may be counter-productive for the purpose of assembling a “Body of Knowledge”.

**System-defined metadata**

Using various techniques and algorithms a system could identify and catalogue much useful data in an automated manner. This data could encompass things such as

- Language and reading level - There are approaches that allow the automatic identification of the language a text has been written in, along with others that aim to identify the reading level of a piece of text - both useful attributes when it comes to identify relevant content. (Wang, 2006; Lins & Gonçalves, 2004)
- Relations to other resources can automatically be identified by analysing user behaviour: Resources that are often read after another, or that may have been classified in similar manners. These could automatically suggest additional interesting resources, like the common “Users that viewed this item also viewed…” feature in web recommender systems.

Data that would be automatically generated and assigned by the system is not part of the implementation scope. The motivation here is that the development and implementation of the required algorithms and techniques would not be justifiable in the face of the scope of the prototype, which focusses on the idea of user-generated data and contributions.

**Synchronous Communication**

Synchronous communication was not implemented as asynchronous one seemed more suitable for the aims of the prototype, not requiring users to be online simultaneously, and having proven more popular in existing approaches.

Adapting to user behaviour
By analysing user behaviour, and observing patterns such as
• Resources frequently visited together
• Tags/Topics frequently explored
It is possible to implement a kind of “recommender system” - similar to those found in online shops or other web services, where the system automatically suggests content based on the interests of users with a similar “taste profile” or preferences.