

# **Analysis of Web 2.0 Technologies for Medical applications: Turning I-CAN into a collaborative tool**

## **D i p l o m a r b e i t**

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## **1.0 Introduction**

### ***1.1 Motivation***

I-CAN do it! That is the motto of the Centre for Disability Studies (CDS) and their instrument for the classification and assessment of support needs I-CAN. Since 2001, the CDS and partners are developing a tool to help support services to determine the current and future support needs of persons with disabilities.

The current version 4.2 is the first web based tool and was introduced recently in 2008. However, the CDS is already looking ahead and is thinking about improvements for the following versions of their tool. With the huge success of Web 2.0 applications for the general use, also the health informatics sector got conscious of this technology and developed their own Web 2.0 tools. These applications, called Medicine 2.0 applications, are buzzwords in the health informatics community that appear in the press more and more often. In September 2008, the first Medicine 2.0 congress took place in Toronto, Canada and introduced the interesting concepts of Medicine 2.0 applications.

The CDS is also interested in this development and is interested in exploring how I-CAN can benefit from these new concepts. Their main concern is to empower persons with disabilities to get actively involved in their health care, according to the motto: I-CAN do it!

### ***1.2 Aims of Thesis***

The goal of this thesis is to look at Medicine 2.0 and to demonstrate the possibilities this new approach has to offer. The next version of the I-CAN, version 5.0, should have Web 2.0 features according to the statements of the developers. Medicine 2.0 is a new term that basically describes web based services and tools for health care consumers, caregivers, patients, etc. that use Web 2.0 technologies. The CDS should get a clear picture about what Medicine 2.0 is, and how they can benefit from

these technologies after reading this thesis. Furthermore, after defining Web 2.0 and Medicine 2.0 this thesis shows a proposal of a Web 2.0 enabled version of I-CAN that can be the foundation for further developments.

### **1.3 Abbreviations**

AAIDD	American Association on Intellectual and Developmental Disability
ALS	Amyotrophic Lateral Sclerosis
AMMC	Ann Myers Medical Centre
API	Application Programming Interface
CDS	Centre for Disability Studies
I-CAN	Instrument for Classification and Assessment of Support Needs
PCHR	Personally Controlled Health Records
PHA	Personal Health Application
PHR	Personal Health Records

### **1.4 Structure of Thesis**

Chapter 2 will introduce the current version of I-CAN, the development history, the underlying assessment framework, and the functionality. It also defines the current limitations of the system, regarding participation of persons with disabilities.

Chapter 3 looks at Web 2.0 and its development, as well as introduces some of the most popular Web 2.0 applications such as photo/video communities, social networking, instant messaging, etc.

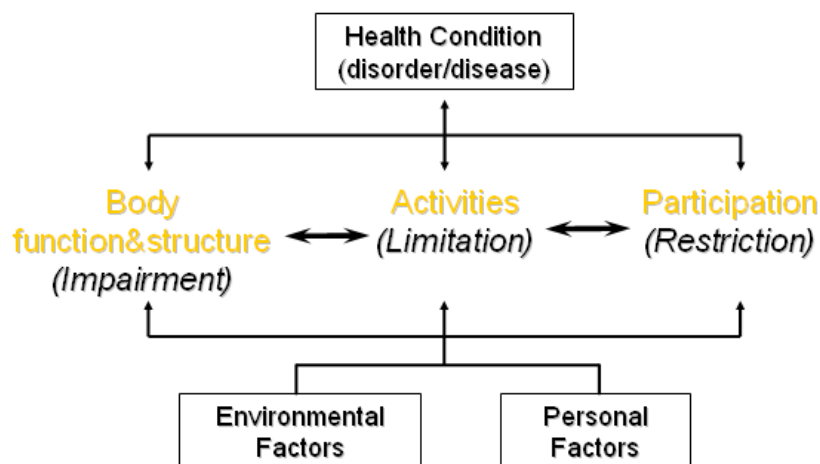
Medicine 2.0 is defined in Chapter 4 with all its elements, but also its tensions like information inaccuracy, ownership and privacy issues, etc. Chapter 5 is dedicated to current Medicine 2.0 applications and shows examples of already available and successful websites with Web 2.0 features.

The PatientsLikeMe community is discussed in chapter 6. This case study reveals how the most successful social networking platform for patients with ALS, HIV, MS, etc. works, and which lessons I-CAN can learn from it.

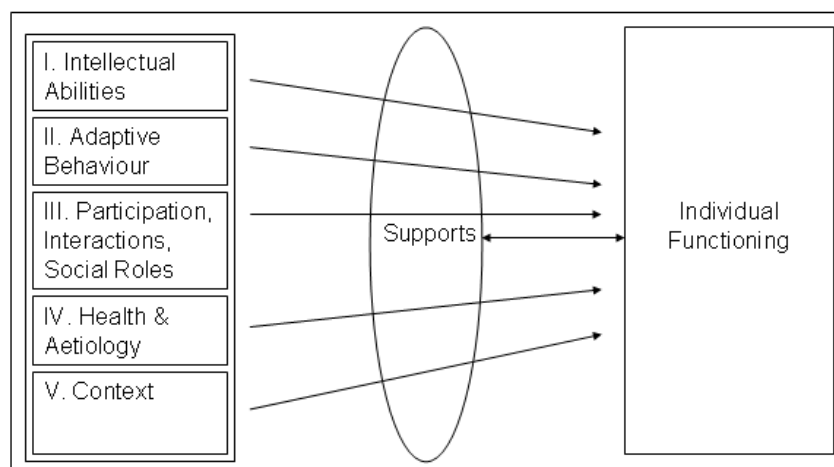
Finally, chapter 7 shows a prototype design for a Web 2.0 enabled I-CAN and discusses the disadvantages of such a tool as well. Chapter 8 concludes this thesis.

## 2.0 I-CAN

In 2001, the University of Sydney (and Industry Partners), the Royal Rehabilitation Centre, Sydney and the Centre for Disability Studies (CDS) formed a project to develop a needs assessment instrument. Goal was to develop an innovative, rigorous and robust system of identifying and classifying support needs based on the conceptual framework introduced by the World Health Organization in 2001 and the American Association on Intellectual and Developmental Disability (AAIDD) supports concept (Arnolds et al. 2008).



**Figure 2.1:** The International Classification of Functioning (ICF) framework (WHO 2001)



**Figure 2.2:** The AAIDD Theoretical Model of Intellectual Disability (Luckasson et al. 1992)

This instrument shall identify individuals' development capacities and/or functional skills and deficits. The I-CAN (Instrument for the Classification and Assessment of Support Needs) focuses on: "The individual's need for support to undertake desired activities and to participate in community life recognizing that support may be required in a range of areas including health and well being to achieve this goal (Llewellyn et al. 2005)"

In summary, the I-CAN is a tool to identify the frequency and intensity of support needed for each individual with a disability irrespective of type or level of disability, place of residence, age, or health condition, to be an active and participating member of our society (Llewellyn et al. 2005).

For more information about the methods, procedures, participants, and results of the study to determine the needs for people with disabilities, please refer to the report "I-CAN: Instrument to Classify Support Needs for People with Disability" from Llewellyn and colleagues (2005).

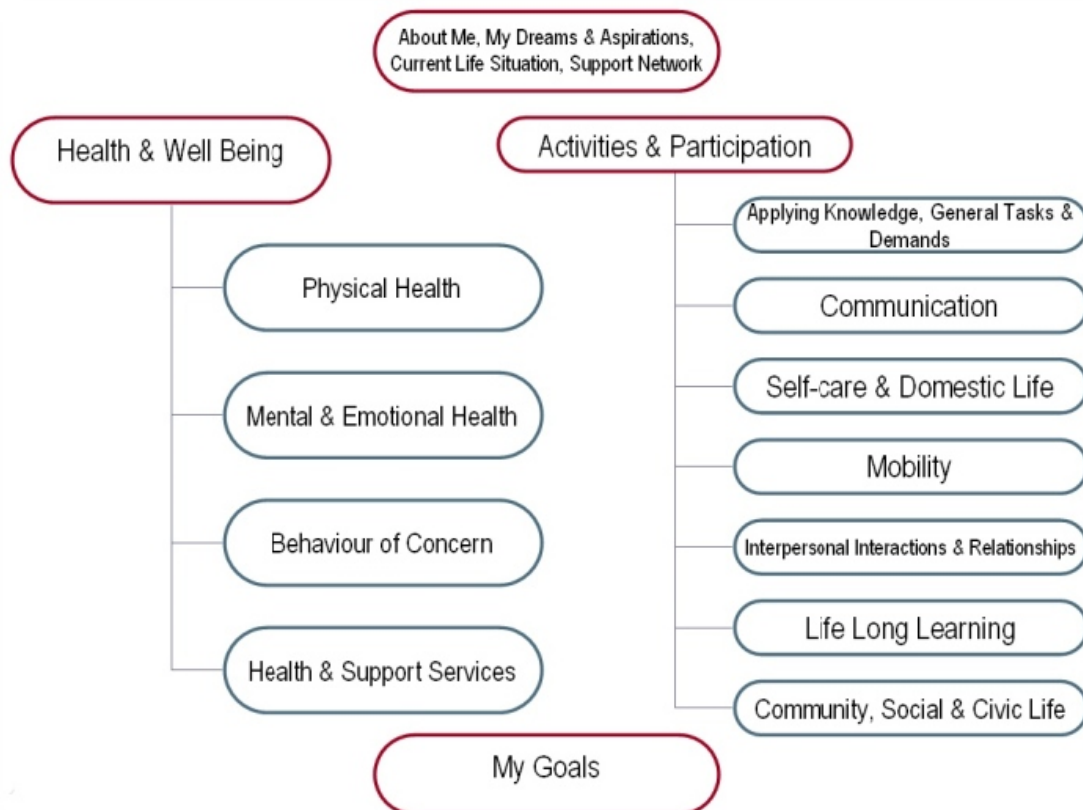
### ***2.1 Introduction to I-CAN 4.2***

The current I-CAN version 4.2 was released at the end of 2008 and is a completely web based software, developed with HTML, PHP, and MySQL. It is available online at <http://www.i-can.org.au/>. The target group for this software are support services that want to assess the needs of people with disabilities. These services can purchase access to the system and do the assessment online. Furthermore, the CDS offers manuals, face to face training sessions, data entry service, telephone, and email support for their customers.

I-CAN identifies the areas in which support is needed in the current and/or future environment. The areas comprise health and well-being and activities and participation in daily life. The items within each domain are rated according to the frequency and level of support required. Support needs are balanced on important to and important for a person with a focus on the person's long term dreams and goals.



The resulting support for the person with disability must be seen as an engagement, empowerment, and inclusion for a life of quality.



**Figure 2.3:** Domain structure of the current version 4.2  
(I-CAN 2008)

I-CAN is designed to be used across disability types and levels of impairment. It focuses more on the support needed than on deficits or skills of people with disabilities. The trained facilitator, together with the person with a disability and key people involved in that person's life complete the assessment and decide on future support activities. The immediate access to the system, the ability to record individual assessments over time, and the graphical preparation of support intensity within each domain are real benefits for support services.

## **2.2 The functions of I-CAN 4.2**

I-CAN offers a variety of functions that are described in the following paragraphs.

The support services can enter personal data of the person with disability into the system either directly during the interview process or afterwards with the help of the pen and paper form that can be used if there is no Internet access available. CDS also offers to enter the data into the system. The data are stored on the I-CAN server where every support service has limited access to their section of the database and can only read or write in its own organization group.

The screenshot shows the 'I-CAN Health and Well Being - Mental and Emotional Health' data entry form. At the top, there is a blue header with the title. Below the header, a question asks 'Is this section applicable?' with radio buttons for 'Yes' (selected) and 'No - N/A'. To the right, a note reads 'N.B. Have you cc questions below cigarettes, sleep'. The main form area is divided into sections. The 'Mood' section includes checkboxes for 'varying mood', 'depression- crying, upset' (checked), 'bipolar disorder', 'agitation / irritability', and 'withdrawn'. There are also dropdown menus for 'F: 4.Daily' and 'L: 3.Moderate'. Below this, a text box contains the text 'Bob needs emotional support praise and someone to talk by minor things and want to'. To the right of this text box is a 'Frequency of Support' table.

Frequency of Support	
Never	no support required
Occasionally	support required less then once a month
Monthly	support required 1-3 times a month

**Figure 2.4:** Screenshot of I-CAN data entry form  
(I-CAN 2008)

After the support services enter the personal data they can generate discharge reports for any person in different document formats (pdf, doc, etc.). The report is automatically generated by the website, and there are also additional options to download only summarized reports and task lists. (cf. Appendix A). The report shows beside the needs summary, the current life situation, etc. also statistical graphs that show exactly where support is needed. These graphs can be used for classification, comparison, monitoring change over time and measuring outcomes. The photo upload function allows the support services to upload pictures of their persons and generate a more personal report with picture.

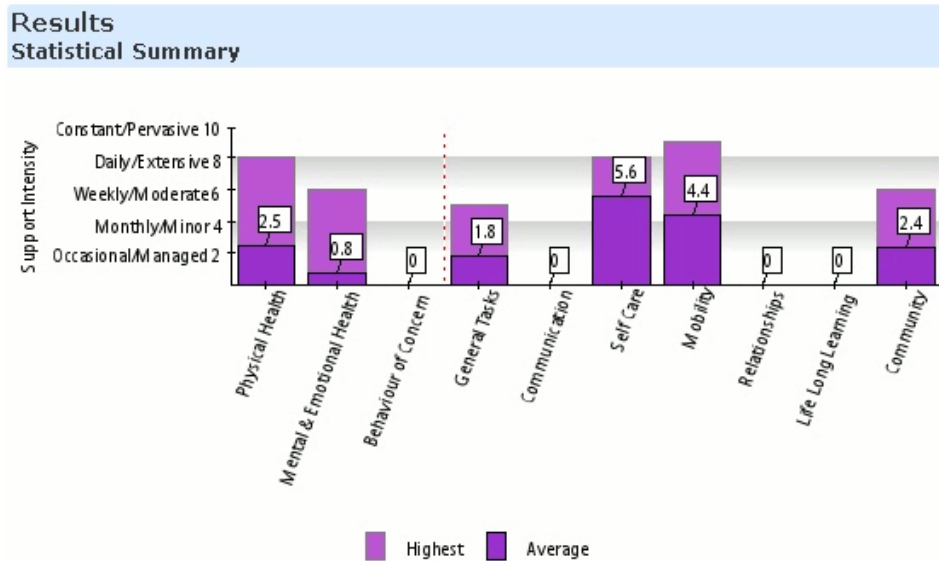


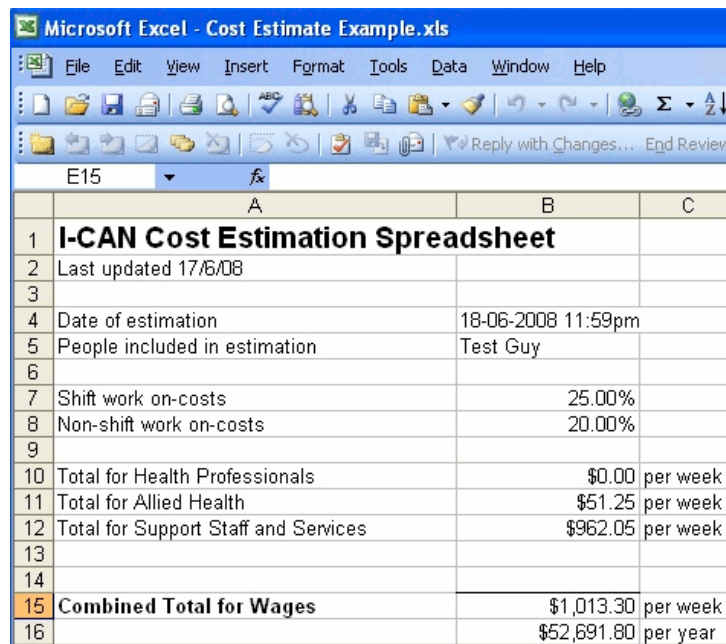
Figure 1: Highest and Average Support Intensity

**Figure 2.5:** Statistical Summary of Support Intensity in the domains.

(I-CAN 2008)

The personal data can be edited as there are always changes in the life situation of the disabled person. These changes are tracked from the system, so it is possible to monitor the development of every single person over time and to predict possible support needs in the future.

The cost estimation function calculates the estimated costs of providing services based upon the actual support needs (from the discharge reports). The outcome is a Microsoft Excel worksheet that allows adjustment of on-costs and organisational costs as well to predict the costs more accurately within the particular setting.



	A	B	C
1	<b>I-CAN Cost Estimation Spreadsheet</b>		
2	Last updated 17/6/08		
3			
4	Date of estimation	18-06-2008 11:59pm	
5	People included in estimation	Test Guy	
6			
7	Shift work on-costs	25.00%	
8	Non-shift work on-costs	20.00%	
9			
10	Total for Health Professionals	\$0.00	per week
11	Total for Allied Health	\$51.25	per week
12	Total for Support Staff and Services	\$962.05	per week
13			
14			
15	<b>Combined Total for Wages</b>	\$1,013.30	per week
16		\$52,691.80	per year

**Figure 2.6:** Outcome of an I-CAN cost estimation.

(I-CAN 2008)

### **2.3 Current limitations of I-CAN**

In the current version 4.2 only support services have access to the system. This is a major limitation for all groups involved with I-CAN and the person with disabilities. The purpose of I-CAN is, among others, to encourage, and empower people to be active members of society. This also includes to actively taking care of their health care and their support needs. The participation of persons with disabilities and their family members/friends in I-CAN however is limited to the process of answering questions at the beginning of the assessment. However, it would be desirable for both, the support services and the disabled person, to have access to the system and contribute actively. (Not all persons with disabilities are able to use a computer, therefore their family members and/or friends should be able to contribute too.)

Currently the persons with disabilities benefit only passively and indirectly from the system, by receiving better support service because the health professionals have more detailed information about the persons' needs and can therefore provide better support. The question is, how can disabled persons and/or family members/friends be more involved in I-CAN and benefit actively from the tool?

The answer to this can be found in Web 2.0 technologies and the possibilities for users to create content. Medicine 2.0 is another buzzword that describes Web 2.0 technologies in combination with e-health applications. According to Pagliari and colleagues (2007) there is a mounting demand for flexible access to personal health information, encouraged by technological trends and policies promoting patients' rights.

The following chapters will look into Web 2.0 and Medicine 2.0 closer and introduce new concepts of how patients get involved in their health care and how they can benefit from that.

### **3.0 An introduction to Web 2.0**

The Internet is in the focus of new business models since the mid 1990s. At the beginning of the new century, the WWW became more and more popular for private users around the world. The development to a mass media was originally initiated in the USA first, and then spread around the globe gradually. Especially the new possibilities that the Internet had to offer inspired the people.

The term “New Economy” arose in 2001 and many companies were founded, whose business models were based exclusively on the World Wide Web (WWW). The founders had no problem getting funding for their ventures and investors were infected by the “New Economy Hype”. In 2001, however, the Internet bubble burst and many investors and companies backed out of the Internet business. That was for now the end of the dot com era, which was at the same time a turning point for the World Wide Web (O’Reilly 2005). This turning point describes a new generation of interactive Internet and web applications, which allows the users to produce content together in a simple way and publish it in the WWW.

#### ***3.1 Emergence of the Term***

The term 2.0 is originated from the software development and describes a revised version of a certain program. Smaller steps in the development are labelled in tenth steps, while the jump to a next higher number before the point describes a radically changed version. The term Web 2.0 should therefore suggest that the Web 2.0 is a completely new version of the web, which is a mistake. Although, the Web 2.0 introduced new technologies, like for example RSS-Feeds that allow users to subscribe to contents of websites or to integrate this content to other websites, it is not a fundamentally new approach to the WWW. Tags, to categorize information such as digital images or internet bookmarks became popularized through Web 2.0 sites like Flickr or Delicious as well.

The actual term Web 2.0 was coined in a brainstorming session between the O'Reilly publishing house and Live Media International, in Person of Internet pioneer Tim O'Reilly and his vice president Dale Dougherty in October 2004. Dougherty was convinced that the web was "more important than ever before" (O'Reilly 2005) and that in particular the possibilities for applications and web sites that survived the Internet collapse could exhibit important conceptual and content similarities. These similarities that achieved acceptance during the Internet Bubble are the foundation of today's Web 2.0 applications. Weblogs (online diaries) are an example of this statement. In the times before Web 2.0 more and more weblogs appeared in periodical intervals.

Google (2008) finds currently 383 M search results for the term Web 2.0, and according to Google AdWords (2008) it is searched for 74,000 times monthly. Therefore, four years after the introduction of the term, Web 2.0 continues to be a popular area of research and interest. However, it is still not clear what the term includes. In the following chapters, the basic attributes of Web 2.0 will be clarified and explained.

## ***3.2 From Web 0.5 to Web 2.0***

### **3.2.1 Web 0.5**

The inventor and developer of the WWW was the British computer scientist Tim Berners-Lee, who developed at CERN (European Organization for Nuclear Research) in Geneva, Switzerland, a hypertext system in 1989 as a project. Initially it was just a cross-linked document management system, which was available for only a few users. It was mainly used for E-Mail and data communication. The first browser, called "WorldWideWeb" (also known as "Nexus") could only display plain text. The focus of the web at this time was clearly to develop the technology and infrastructure (Schmitz 2007). In the first years of the 1990s, the WWW, was almost exclusively used for Business to Business purposes.

### 3.2.2 Web 1.0

Web 1.0 existed predominantly of static HTML web sites, with a pure one way communication and classical homepages (Kellner 2005). These web sites were published from companies or private persons with a certain expertise and were altered and renewed with the help of Content Management Systems (CMS). The content was therefore offered and organized from the owner of the web site.

### 3.2.3 Web 1.5

With the technological development, the static HTML pages evolved into dynamic websites from 1996 on. The time of Web 1.5 started.

Basically, Web 1.5 was about page impressions and visual aesthetics. With the creation of interactive pages like eBay (1995), and Amazon (created 1994, online since 1995), the E-Commerce developed as well. The focus for companies changed from a communication tool for specialists into a mass media for mass communication. The production of information and the consumption of information were, however, still separated. The interaction of users was limited to reading the web sites, ordering of goods online, and the click on advertisement banners.

Table 1 shows the most important attributes of the stages of development to Web 2.0

Web	0.5	1.0	2.0
<b>Title</b>	The technical Web	The promotional Web	The social Web
<b>User</b>	Experts	Commerce and Customer	People
<b>Focus</b>	Know-how and organisation	Click-rates and products	Opinion making and community
<b>Relationships</b>	B2B	B2C	C2C



<b>Effect</b>	Rationalisation	Infotainment	Socialisation
<b>Methods</b>	Rationalisation	Quantification	Qualification

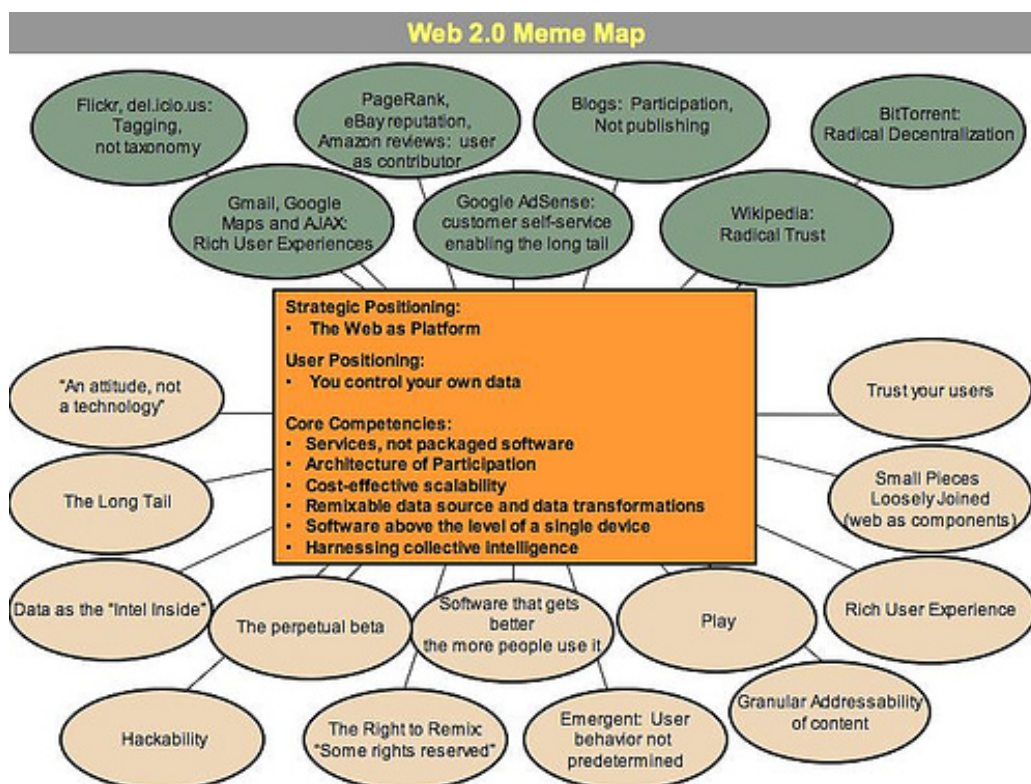
**Table 3.1:** Web Generations  
(Smoke & Mirrors 2008)

### 3.2.4 Web 2.0

There is no unique definition for Web 2.0. All previous changes and developments were factors for today's Web 2.0. Tim O'Reilly (2006) who introduced the term defines Web 2.0 as:

*“Web 2.0 is the business revolution in computer industry caused by the move to the Internet as a platform, and an attempt to understand the rules for success on that new platform. Chief among those rules is this: Build applications that harness network effects to get better the more people use them. (O'Reilly 2006)”*

O'Reilly (2005) describes Web 2.0 as a concept that does not have hard boundaries, but rather, a gravitational core. Furthermore, he states that the best way of visualizing Web 2.0 is to see it as a set of principles and practices tied together as a veritable solar system of web sites that demonstrate some or all of those principles, at a varying distance from that core.



**Figure 3.1:** Meme Map of Web 2.0, Shows the many ideas that radiate out from Web 2.0 core (O'Reilly 2005)

Experts are still arguing today what Web 2.0 really is, and if it actually exists. Is Web 2.0 just a buzzword or is it a real revolution? It is well accepted that the Web changed as a result of the New Economy (as described earlier). The User and the user's expectations changed as well with the new developments and technologies. Broadband speed and availability, cheaper Internet plans, easier and more user friendly web sites are all factors that contribute to the emergence and popularity of Web 2.0. It is much easier to say what Web 2.0 is not. Web 2.0 is not a new web design, and also not a fundamentally new technology. The users do not need special programs to use Web 2.0. To clarify what is behind Web 2.0, the following table shows the meaning of the concept formulated by Tim O'Reilly (2005) and Dale Dougherty with the help of examples.

<i>Basic service</i>	<i>Web 1.0</i>		<i>Web 2.0</i>	<i>New characteristics</i>
<b>Online advertisement</b>	DoubleClick	→	Google AdSense	Dynamic advertisement based on the page content
<b>Photo sharing</b>	Ofoto	→	Flickr	Personalized templates, tagging, annotating & comment
<b>Website</b>	personal websites	→	blogging	
<b>File sharing</b>	Akamai	→	BitTorrent	Peer to peer source & each downloading machine becomes server
<b>Music sharing</b>	mp3.com	→	Napster	
<b>Online encyclopaedia</b>	Britannica Online	→	Wikipedia	Open content & collaboratively written
<b>Online event organizing</b>	Evite	→	upcoming.org & EVDB	Event request & comments from collective users
<b>Identity</b>	domain name speculation	→	search engine optimisation	Marketability
<b>Visitors volume</b>	page views	→	cost per click	Navigation behaviour
<b>interfacing 2 programs</b>	screen scraping	→	web services	Merging into 1 platform: The Web.
<b>Centralized authorship</b>	Publishing	→	participation	Democratisation of authorship
<b>Centralized managed content</b>	content management systems	→	wikis	Open content
<b>Pre-defined</b>	directories (taxonomy)	→	tagging ("folksonomy")	User-defined
<b>Single provider</b>	stickiness	→	syndication	Federated provider

**Table 3.2:** Web 2.0 with Examples modified with Basic services and Basic characteristics (O'Reilly 2005)

Table 3.2 was modified from the original table from O'Reilly with two new columns "Basic services" and "Basic characteristics" to clarify and describe the services mentioned. It shows clearly the distinction between the new characteristics with the former Web 1.0 services. The new services, labelled as "Web 2.0", have a more social-centric approach in delivering, while their older counterparts have a more content centric approach (Kuswara, Cram et al. 2008).

Another approach to describe the difference between Web 1.0 and Web 2.0 was made by Drumgoole (2006).

Web 1.0 was about...	Web 2.0 is about...
Reading	Writing
Companies	Communities
Client-server	Peer to peer
HTML	XML
Home pages	Blogs
Portals	RSS
Taxonomy	Tags
Wires	Wireless
Owning	Sharing
IPOs	Trade sales
Netscape	Google
Web forms	Web applications
Screen scraping	APIs
Dialup	Broadband
Hardware costs	Bandwidth costs
Top down	Bottom up

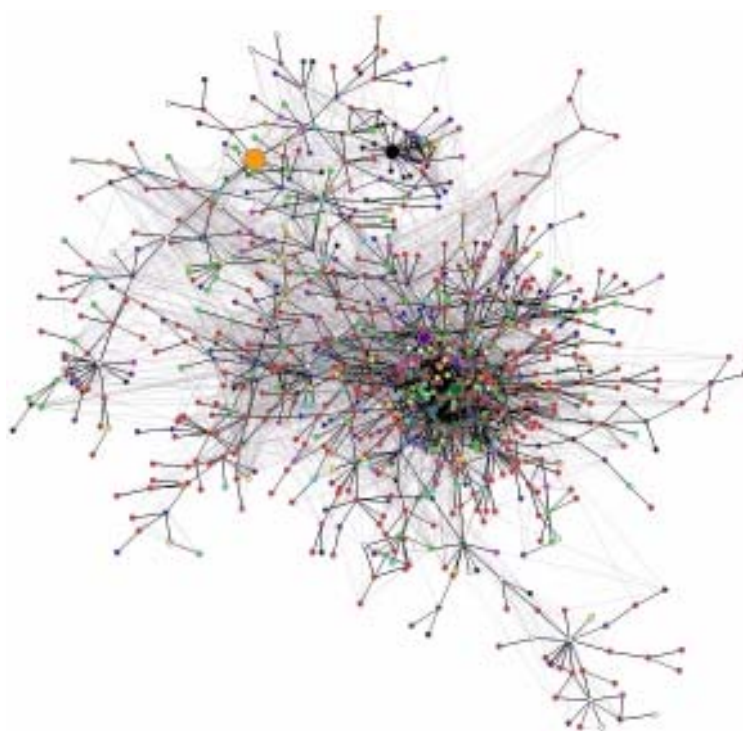
**Table 3.3:** Web 1.0 vs. Web 2.0  
(Drumgoole 2006)

### 3.2.4.1 Collective Intelligence

An important development of Web 2.0 was the evolution of collective intelligence. Collective intelligence is also called group intelligence which emerges from the collaboration and competition of many individuals. It does not only appear in computer networks, but also in bacteria, animals, and humans. Opinions, ideas, knowledge and positions are collected and published in the Web. People can communicate with each other, publish content, and generate therefore collective intelligence as a group.

Wikipedia, the popular online-encyclopaedia, is using exactly this phenomenon. Wikipedia allows every user to publish their own articles to all different kinds of

topics, but also to edit or to read other articles. The phenomenon of collective intelligence is also articulated in the so called blogosphere. Blogosphere is defined as all blogs and their interconnections under the perception that these blogs exists together as a connected community or as a social network. The users link blogs on their pages that creates an impressive network.



**Figure 3.2:** Blogosphere  
(Blogosphere 2008)

Even before the Web 2.0 era, collective intelligence existed. The companies that survived the dot-com bubble used that phenomenon to their advantage.

Hyperlinks are one example. They are basically the foundation of the WWW. When users put new contents and new pages online, they are automatically included in the structure of the web through the hyperlinks of other users. Google is another example. The search engine became successful with their PageRank method. This method concentrates on the appearances of a certain search term in the content of web pages. According to Google, PageRank estimates objectively the importance of a website with criteria like relative appearance of a search term (keyword density), the places of appearance within the web site, as well as the exposure of the search

term weighted in the document (Google Technology 2008). Google used this link structure to deliver better search results.

More and more companies are using this knowledge in the Web 2.0 era. Therefore, almost all social software systems are using collective intelligence.

#### **3.2.4.2 User Generated Content**

Because of the many changes within the Web, technological progresses and especially the changes of the user from a passive reader to an active co-designer, the buzzword user generated content appeared. It is referred to as publicly available media content that was produced by end-users. These contents can even have professional or journalistically relevant tendencies. Even the smallest changes of a web site through a user is called user generated content. These changes can be articles or comments in discussion boards, weblogs, pictures, or videos. Tagging, the indexing of contents, is also a form of user generated content.

The involvement of users became only popular through the Web 2.0 applications and feedback channels. With the help of comments and notes it is now possible to give direct feedback and thereby become involved in communication, discussion, and knowledge sharing with other users. This new interactivity, made possible through Web 2.0 technology and user generated content, makes the direct and indirect creation of social networks possible.

#### **3.2.4.3 Social Software**

The technical term *social software* appeared in 1987 for the first time. It had, however, a different meaning at that time. At the end of the 1990s the first social networks as we know them today appeared (e.g. Wikipedia). Social software systems of today are defined as systems that allow users to interact, communicate, and collaborate on the basis of social networks. According to this definition, E-Mails would also be included in social software. However, E-Mails are only good for

communication between individuals, but do not cover the aspect of visibility to team or group communication (except group e-mails and mailing lists), which is a standard for modern social software applications. This “older” systems are differentiated through the visibility. Visibility of persons, relationships, and contents is a central instrument of social software (Razavi & Iverson 2008).

According to Tom Alby (2007, p. 87), two more criteria are necessary to call a system a social software:

- The software has to support and encourage the creation and the self management of a community.
- The software has to regulate itself.

Therefore, the focus of social software is less on the information of the individual, but more on the structure that grows from the linkage of the information (Hippner & Wilde 2005).

The users are responsible for the rapid development of social software applications, whereas the wide spread of fast broadband connections is another crucial factor for success. The main basis for social software is still the blogging movement that became popular in 2002.

Social Software Applications are:

- Video communities
- Photo communities
- Blogs
- Wikis
- Instant Messaging
- Social Bookmarking
- Social Networks

All these applications will be explained in detail in the following sections.

There are two categories of social software according to Alby (2007, p. 88):

- Social Software where the communication is at the fore (the communication is usually not recorded) and
- Social Software where the content of the users is at the fore. The community idea is at the fore.

The first category of social software web application is for example instant messaging (e.g. MSN, Skype). The second category are pages like Wikipedia, discussion boards, photo communities like Flickr or networking platforms such as Facebook.

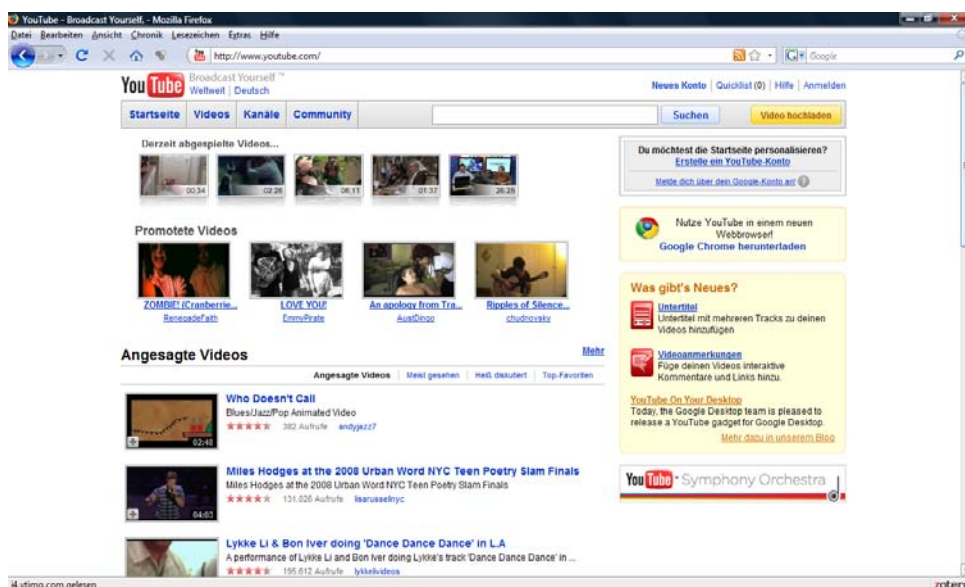
### ***3.3 Web 2.0 applications***

In the following chapters, some common Web 2.0 applications will be explained with the help of one example. Thereby the single applications are only shortly described, and the relevant Medicine 2.0 applications will be covered in more detail during the course of this work.

#### **3.3.1 Video communities**

On video platforms, that can be used as video communities as well, videos can be uploaded, watched, reviewed and commented. These short videos, most of the time, are either filmed by the user themselves with their own cameras, cuttings from TV shows or movies, music videos, or funny TV advertisements. However, the self made videos by the user are the most common. The slogan of YouTube, the biggest video community, is “Broadcast Yourself <sup>TM</sup>”. Daily, around 65,000 videos are uploaded to YouTube (Arrington 2006). The aesthetic of the self made videos is not relevant; the focus is on the user that creates the video (Alby 2007, p. 107).



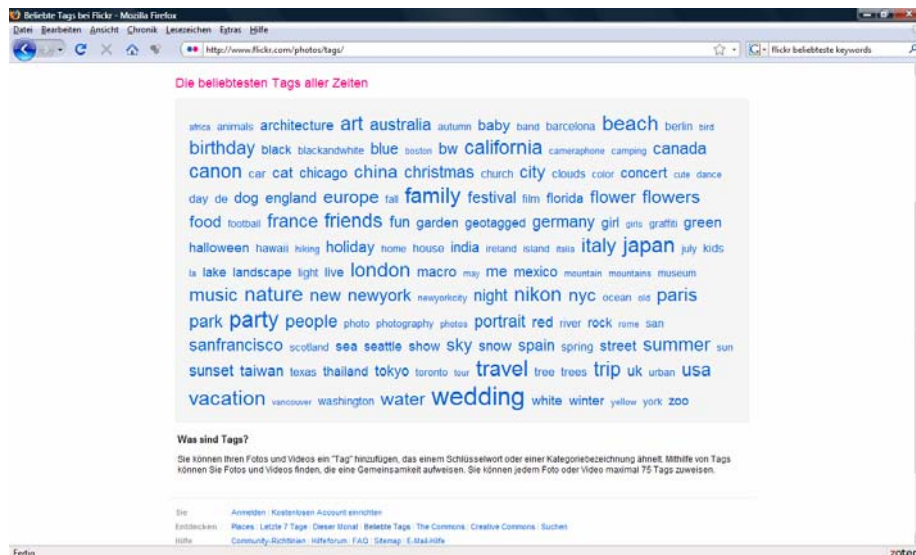


**Figure 3.3:** YouTube Homepage  
(YouTube 2008)

YouTube offers a variety of functions. Users can add their favourite videos to their personal favourite list, create playlists, and can create and operate their own “Channel” with their uploaded videos. It is also possible to subscribe to channels of other users and automatically get messages when there is an update of the channel. Additionally users can send each other messages which create a kind of community as well. With a special tool, the API (Application Programming Interface), it is possible to embed YouTube videos in other web sites, for example, personal blogs, homepages, etc. The advantage is that the video is still stored and viewed on the YouTube servers, so the owner does not need to store it on his server and has no additional costs therefore. Daily, around 100 million videos are watched on YouTube worldwide. Hence, YouTube is one of the most popular and fastest growing web pages (Alexa 2008).

### 3.3.2 Photo communities

Similar to the video community YouTube, Flickr is the equivalent photo community. The user can, in addition to uploading pictures, tag them. Here, every picture gets enriched with keywords. If any user is searching for a specific keyword, he will find all pictures that possess a tag with that keyword.



**Figure 3.4:** Most favourite tags in Flickr  
(Flickr 2008)

The uploaded pictures can get edited on the Flickr Homepage, and the user can add notes to his pictures and create photo albums as well. Like in YouTube, users can comment and rate other users' pictures and can write blogs about the pictures. There are also additional features available that have nothing to do with the pictures, but respond more with the community idea. The user can align to thematic groups, send messages, and make new friends online.

### 3.3.3 Blogs

A Blog is an abbreviation for Weblog and is made up of the words “web” (short form of World Wide Web) and “log” (diary, log book). It can be seen as similar to an online diary, whereas the further definitions widely differ.

The following definition is based on Wibbels (2006, p. 3) and describes the core idea of the concept of blogs:

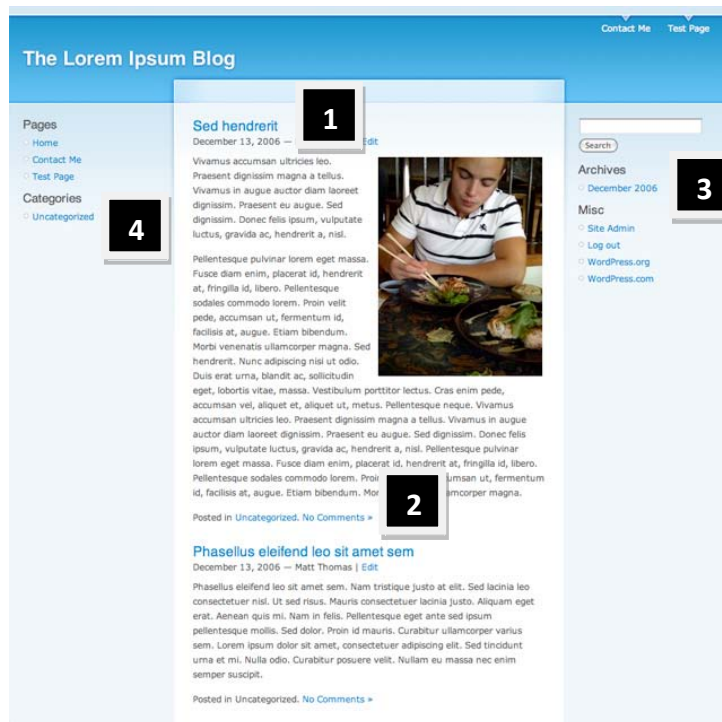
*Blogs show the contents in short, so called “posts” or articles that are displayed in a timely contrary order and contain mainly personal opinions, but also facts. Blogs are often updated, sometimes daily and sometimes even more often a day. (Holtz 2006) “The archive [of entries] can get categorized according to contents*

*(Wibbels 2006).” Contents are usually linked with other websites and the reader can comment on them as well. These comments can generate a real surplus because the user can highlight eventual errors or weak points of the article and correct them. Real discussions can develop from comments.*

A blog does not just contain text, but it can contain pictures, videos, and audio files as well and can deal with different topics:

- Watchblogs (monitor critical media and companies)
- Litblogs (are blogs about literature)
- Corporate Blogs (from companies)
- Blawgs (blogs with judicial topics)
- Photoblogs (publishing of photos)
- Audioblogs (audio articles)
- Linkblog (collection of links)
- Moblogs (mobile weblogs through the mobile phone)
- etc.

The linking between the single blogs unites into a large network, called blogosphere. The bloggers personality decides the style of the blog, so that every blog can be designed individually and is unique. The structure of a blog however, is always the same.



**Figure 3.5:** Blog example  
(WordPress 2008)

The headline of an article (Nr. 1, Figure 3.5) is at the same time a link that always leads back to this article, regardless of where the reader is scrolling at the moment. These so called permalinks are also used with comments (Nr. 2, Figure 3.5), that are always located under the article. In the archive (Nr. 3, Figure 3.5), it is possible to find older entries, that can be categorized at the same time (Nr. 4, Figure 3.5). (Alby 2007, p. 24)

### 3.3.4 Wikis

Wikis are, similar to Blogs, a new form of Content-Management-System. Even laymen can publish their own content in the WWW with these systems. Wikis are a public collection of websites that can be edited, usually from all users, with the help of a simple online form (Picot 2005, p. 19). These single sites are usually automatically linked. The online encyclopaedia Wikipedia is generated from these kind of Wikis. Every visitor of the page can edit and add content to the encyclopaedia. When a user discovers an error or wrong information in an article, they can change it immediately. Thus, it creates a self regulated mechanism and the

collective intelligence is used to improve the quality of the website. Wikipedia is the biggest encyclopaedia in the world and one of the most visited websites (Alby 2007, pp. 88-89).

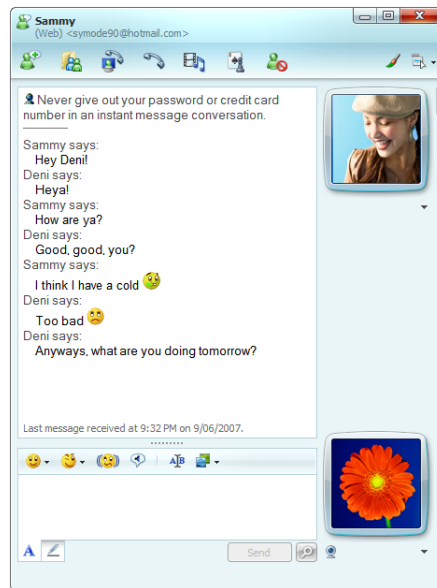
However, there are different areas in which Wikis are used:

- Travel guide wikis (WikiTravel)
- Dictionary wikis (Wictionary)
- City wikis (city wiki of Karlsruhe, Germany)
- Wikis about pop culture topics (Memory Alpha, Wookieepedia)
- Wikis about subject-specific topics (PlanetMath, LinuxWiki)
- etc.

In schools and universities, Wikis are used for different educational purposes as well.

#### **3.3.5 Instant Messaging**

With Instant Messaging software, the user can communicate in real time with other participants. In contrast to chat rooms, a software application has to be installed on the computer. Short text messages are delivered with the help of the push technology through the network, and the receiver of the message can answer immediately. Figure 3.6 shows a chat window in which the users enter their messages and send them to the receiver by pushing the button “Send”. Additionally, it is possible to transfer and exchange files with the partner.

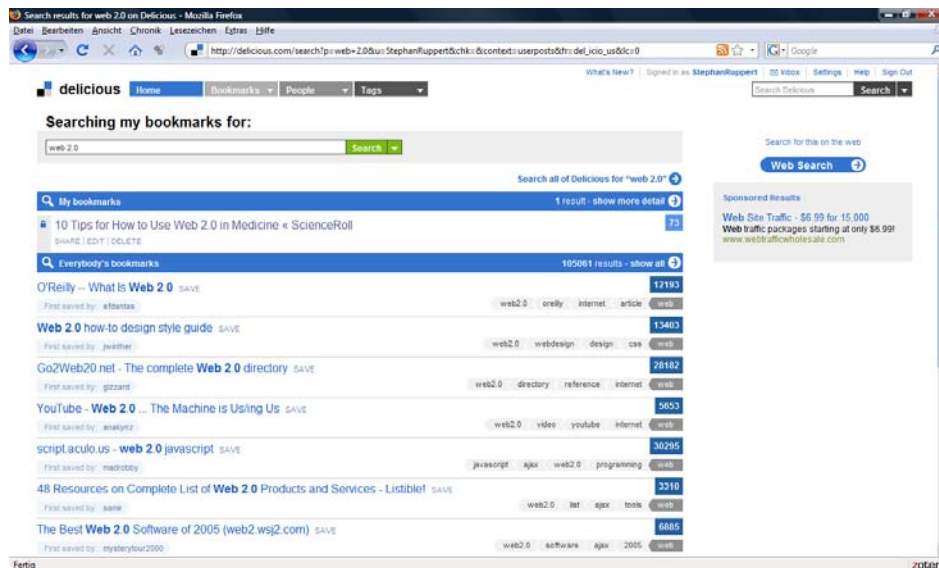


**Figure 3.6:** Chat Window of Windows Live Messenger  
(Windows Live 2008)

Skype is a very popular instant messaging tool, because in addition to text chatting, and file sharing, it offers VoIP functions. With Skype it is possible to telephone with people around the world through the Internet. Furthermore, with the help of a webcam, users can also see each other while talking.

### 3.3.6 Social Bookmarking

Social Bookmarking is a description of a collection of bookmarks that are saved on a webpage and are furnished with tags. These systems also offer a browser based collection and categorizing of bookmarks. The user can store their favourite websites online, add a title and put tags on it to make it accessible for other users. By tagging, the bookmark collection gets categorized and grouped. The indexing of the single links develops into a big unit that can be searched for with keywords afterwards. The access to the bookmarks is through the web browser, therefore independent of local computers or browsers. An example of a social bookmarking page is [del.icio.us](http://del.icio.us)



**Figure 3.7:** Screenshot of del.icio.us  
(Delicious 2008)

In del.icio.us there is the opportunity to enter a keyword. The system is looking for all websites that are furnished and stored with this keyword. On del.icio.us there are not only the latest bookmarks shown, but also the most popular ones. It is especially interesting that the user can see in the search results how many other users added this URL to their bookmarks. (Alby 2007, p.92)

### 3.3.7 Social Networks

According to Raabe (2007, p.43), social networks are focussed to alleviate, create, and cultivate social relationships and social networks. These community platforms enable the user to create profile pages and to design these individually with personal information, text, pictures, videos, etc. Furthermore, it is possible to become friends with other users. Some platforms even offer the possibility to see which friends they have in common with another person. Groups can be formed with different topics, similar to discussion forums. User can join these groups and create topics to share information about relevant topics. It is also possible to send private messages to users in most platforms.



**Figure 3.8.:** Screenshot of a sample Facebook profile  
(Facebook Profile 2008)

Facebook, along with MySpace, is one of the most popular social networking sites. It was originally founded by Harvard Student Mark Zuckerberg as a hobby project to connect with his fellow students, but soon turned into an international phenomenon. Currently, Facebook has more than 140 million active users, whereby an average user has 100 friends on the site. Especially the photo upload is very popular with 700 million uploaded photos monthly. There are more than 19 million user groups on the site and users collectively spend on average 2.6 billion minutes on Facebook each day. The marketing and commercial potential of Facebook is enormous as well, with more than 660,000 developers and entrepreneurs from 180 countries developing applications for the platform to promote their products and services. (Facebook 2008)

### 3.4 Chapter Summary

In this chapter we considered the origin of Web 2.0, its development from Web 0.5 in 1989 for only a few selected users to Web 1.0 with only static web sites and one way communication to the pre version of today's interactive web, Web 1.5.

We discussed the concepts behind Web 2.0, called collective intelligence, user generated content, and social software. The last part of the chapter described some



of the most popular and wide spread applications of Web 2.0: Video communities, photo communities, Blogs, Wikis, Instant Messaging, Social Bookmarking, and Social Networks.

In the following chapter we look specifically at the use of Web 2.0 in the medical domain and define the term Medicine 2.0 and its components.

### 4.0 Definition of Medicine 2.0

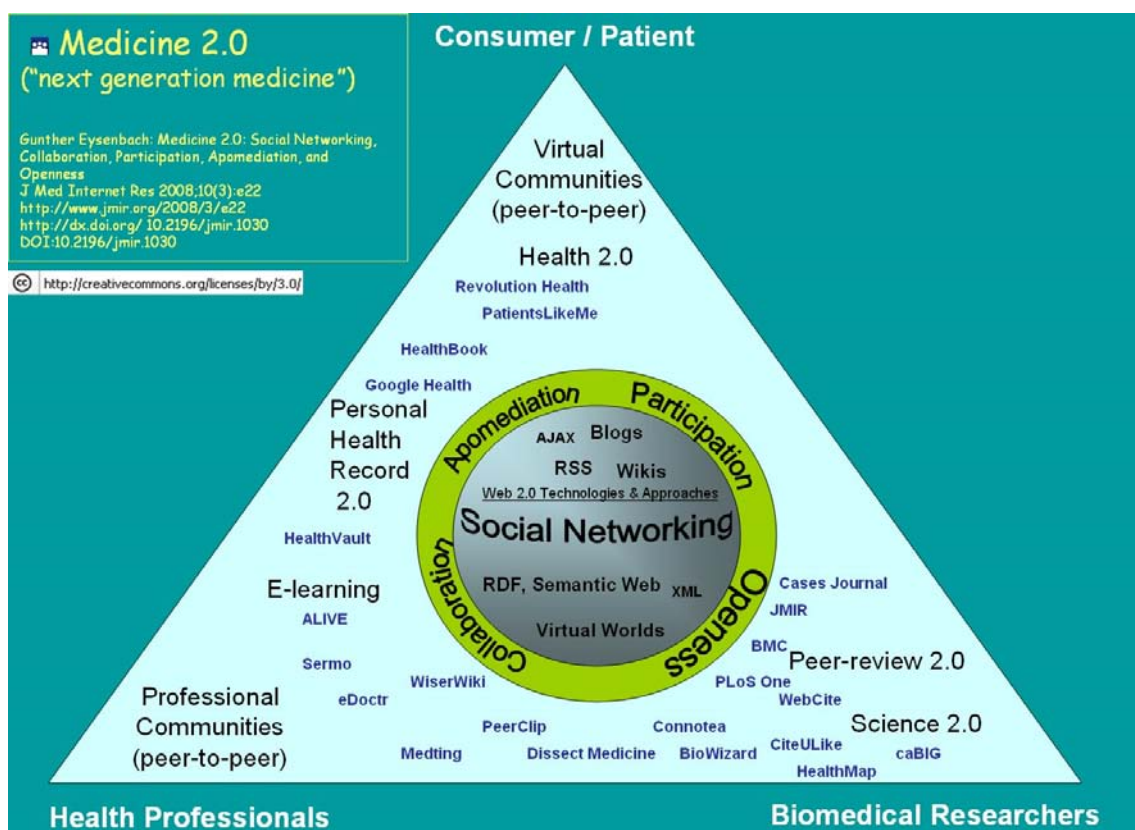
The broad adoption of Web 2.0 technologies/approaches and the more recent emergence of Personal Health Application (PHA) Platforms and Personally Controlled Health Records (PCHR) introduced compelling steps in the development of eHealth (Eysenbach 2008a). Mandl and Kohane (2008) argue in the *New England Journal of Medicine* that these developments even represent “tectonic shifts in the health information economy” with far-reaching consequences for patient involvement, as the gravity shifts away from health care providers as the sole custodian of medical data. The current approach to medical records is changed fundamentally with PHA or PCHR platforms, as here patients can create and store their records and grant permission to institutions, clinicians, researchers, or public health agencies themselves.

The expectations of users have changed as well since the emergence of Web 2.0 applications. The recent advances in web technologies and user interfaces transformed the way users interact with these applications. The changes in the architecture, appearance, usability, and spread of Web applications play their part in changing expectations. According to Eysenbach (2008a) users expect the applications to be open and interoperable. Open Web standards improve the collaboration and communication across applications. Collaboration between users is especially popular in social networking approaches. Users can communicate with each other, connect to other users in the network, and can find helpful information. Finally, Web 2.0 technologies like AJAX improve the Web interfaces and transform web applications into desktop like applications with real-time responsiveness. (Eysenbach 2008a)

In September 2008, the first Medicine 2.0 Congress took place in Toronto, Canada. One of the goals of this congress was to introduce the idea behind the term, and also to encourage the participants to do more research in this new area of health informatics. The following definition of Medicine 2.0 was proposed at the congress:

*Medicine 2.0 applications, services and tools are Web-based services for health care consumers, caregivers, patients, health professionals, and biomedical researchers, that use Web 2.0 technologies and/or semantic web and virtual-reality tools, to enable and facilitate specifically social networking, participation, apomediation, collaboration, and openness within and between these user groups. (Eysenbach 2008a)*

Figure 4.1 describes a graphical framework to Medicine 2.0:



**Figure 4.1:** Medicine 2.0 Map with Examples  
(Eysenbach 2008a)

As can be seen from the figure above, there are five major aspects that become apparent from Web 2.0 in combination with eHealth:

1. Social Networking,
2. Participation,
3. Apomediation,
4. Collaboration, and

### 5. Openness

These core aspects will be explained in detail in the following chapters. Furthermore, at the apex of the triangle, the framework also discloses the three main user groups of Medicine 2.0, who are:

1. Consumer/patients,
2. Health professionals, and
3. Biomedical researchers.

The “formal” training of these users is different. However, the consumer/patients (end users) are recognized as experts as well, because according to the philosophy of Web 2.0, their collective wisdom can and should be harnessed (Eysenbach 2008a): “The health professional is an expert in identifying disease, while the patient is an expert in experiencing it” (Davidson & Pennebaker 1997).

The current Medicine 2.0 applications are situated somewhere in the triangle at the moment, depending which user group is targeted. The goal of an ideal Medicine 2.0 application would be to connect different user groups and foster the communication between them. This could be done by engaging the public in the biomedical process, for example. The result would be that the applications would move more towards the centre of the triangle. (Eysenbach 2008a)

Hughes et al. (2008) carried out an extensive literature review of Medicine 2.0. They concluded that there is a broader idea behind Medicine 2.0 as well. In their opinion healthcare systems need to move away from hospital-based medicine, and should focus on promoting health, provide healthcare in people’s own homes, and empower consumers to take responsibility for their own health instead. That is why Medicine 2.0 is also an additive for a new and better health system, which focuses on collaboration, participation, apomediation, and openness, contrary to the traditional, hierarchical, closed structure within health care and medicine. (Hughes et al. 2008)

### **4.1 The Elements of Medicine 2.0**

As mentioned in chapter 4.0, Medicine 2.0 focuses on five major aspects: Social Networking, participation, apomediation, collaboration, and openness. The basis for most of these concepts (explained in detail in the following chapters) is the article “*Medicine 2.0: Social Networking, Collaboration, Participation, Apomediation, and Openness*” from Gunther Eysenbach from the University of Toronto and publisher of the Journal of Medical Internet Research.

#### **4.1.1 Social Networking**

In Medicine 2.0 and Web 2.0, social networking is central to many applications. Essentially it involves the explicit modelling of connections between people, forming complex networks of relations that in turn enables and facilitates collaboration and collaborative filtering processes. One example is to see the activities of the people the user has a relationship with (e.g. “friend”, “colleague”, “fellow patient”) and to get up to date with new developments. According to Eysenbach (2008a) the social networking approach enables furthermore:

- Automated selection of relevant information.
- Reputation and trust management.
- Accountability and quality control.
- Fosters viral dissemination of information and application.

Social networking is also a perfect tool to encourage users to participate in a virtual community. It provides “social” incentives to enter, update and manage personal information. (Eysenbach 2008a) As mentioned in chapter 3.3.7 Facebook users spend a lot of time online to update their status, and to keep their profile up to date with the newest applications.

The question however is, if social networking applications will be the “killer applications” that sustain the interest of users (the patients) constantly over time, or if the user will lose interest and stop use of this tool. Because the social networking

concept is relatively new in the Health Informatics field, it cannot yet be answered. The time will show if it stays successful. One success factor will certainly be to constantly implement new useful features to the applications. This will ensure the spread of information and applications.

### **4.1.2 Participation**

Another core value in Medicine 2.0 is Participation. This is especially important for consumers and patients, but is also important for researchers and health specialists. The concept of participation involves opening up electronic health records for patients, so that they can access their data. Personal Health Records (PHR) is the term for this kind of application. Before the Internet, the concept of public health records accessible for patients seemed to be an unrealistic goal, but Internet technologies have changed the attitude and culture in health care, and empowered the user to get actively involved. Especially Web 2.0 tools can bring the user to participate better than any other technology. (Eysenbach 2008a) A good example of participation are Wikis. All kind of user groups, like scientists or health professionals, can use these tools to communicate with other users.

Eysenbach (2008b) states that there is another aspect why Web 2.0 and PHR excites consumers and researchers alike: Patients can decide themselves if their data can be used for the secondary purpose of research studies. This can eliminate the problem that patients feel during a consultation which is that health professionals tend to focus more on the research than on the health of the patient. Mandl and colleagues argue that: "Patients should be able to grant or deny study access to selected personal medical data. [...] All these functions should be accessible from any web browser in the world. (Mandl 2001)"

In conclusion, the emergence of Web 2.0 and social networking platforms, in combination with PHR application create new levels of user participation and good opportunities to engage users actively in their health, health care, and health research. However, this also leads to privacy issues. For example users may not be

always aware, that their information can be stored permanently and can be accessed in the long term (e.g. by future employers). (Eysenbach 2008a)

### 4.1.3 Apomediation

Apomediation is a term that characterizes the “third way” for users to identify information that are trustworthy and relevant information and services. According to Eysenbach (2008b), the term was introduced to avoid the term “Web 2.0” in a scholarly debate.

The first way to retrieve information is to use intermediaries (middlemen). This can be health professionals that are providing information to patients. An example for this can be trusted web portals that only contain information that are checked by experts. Bypassing the middlemen would be the second possible way. This approach is referred to as disintermediation. Travellers’ booking their tickets directly from the airline without the help of a travel agency is an example of this approach.

The third way is the Web 2.0 way, which is a special form of disintermediation. Users get guidance from apomediarities, for example by networked collaborative filtering processes. (Eysenbach 2008)

As mentioned above, apomediarities guide consumers to relevant information. They are agents (people, tools) in “stand by” mode that are not prerequisite to get the information, while intermediaries are necessary to get the information. In the intermediary case, the quality of the information is also very dependent on the quality and the credibility of the intermediary. However, these differences are not absolute, as people may move back and forth between apomediation and intermediation models. (Eysenbach 2008a)

In the apomediation theory, the apomediarities are users who can help other users finding the right information from the extensive amount of information available in the Web. An example of this is the customer rating system from amazon.com. User can share their opinion about products by writing a review and rate them from 1 star for a product they did not like, to 5 stars for products with extraordinary quality. When a

potential buyer sees the ratings of a certain product, he can see how other users liked it and then decide if he wants to purchase it too, or look for a similar product with better ratings.

Health professionals and scientists are also switching from intermediaries to apomediaries. A few years ago an information broker had to supply researchers with the information from Medline (medical database), while today researchers can search in PubMed (public medical database with search engine) directly or use social bookmarking tools where they can find relevant articles based on the opinion of the users who saved and tagged the bookmarks. (Eysenbach 2008a)

However, there are also drawbacks in the apomediation approach. Eysenbach (2008a) states, that it “requires a cultural shift as well as strong incentives” to make it interesting for researchers to contribute actively. For applications with this approach, the people have to see an immediate benefit for them as well as trustworthy and secure, in order for them to participate.

### **4.1.4 Collaboration**

Connecting people together, who have not yet or have insufficiently worked together in the past is the concept of collaboration. It is also useful to connect different user groups together, for example engaging the public in research issues. This collaboration for example is also useful to get better communication between both sides and to translate the knowledge to turn the research findings into practice(Eysenbach 2008a).

### **4.1.5 Openness**

The Web 2.0 basically stands for openness. Transparency, interoperability, open source and open interfaces are all philosophies that are mentioned and practiced in the Web 2.0 context. So for example the Personal Health Applications HealthVault and Google Health both have open Application Programming Interfaces (APIs) for



other applications to connect to. Furthermore, the openness concept also enables access to research data (e.g. open data, open access journals) and even engages the public in the research process itself (open peer review). (Eysenbach 2008a)

### ***4.2 Tensions of Medicine 2.0***

Beside all the advantages that Web 2.0 has to offer for patients and health professionals, there are also drawbacks. The lack of a clear Medicine 2.0 definition is one as well as the loss of control over information. Ownership and privacy issues are also disadvantages that come with Medicine 2.0. The following sections will discuss these problems in detail.

#### **4.2.1 Lack of clear Medicine 2.0 definition**

There is a lack of a clear Medicine 2.0 definition which basically results from the disagreement of researchers about what Web 2.0 is, and if it really exists. This is certainly an issue that mostly concerns researchers but has also consequences for other parties. (Hughes 2008) Versel (2008) claims that terms like Medicine 2.0 and Health 2.0 may be a fake “gold rush” because some studies have claimed justification only based on the number of participants and the number of people who recognized it as a concept. Giustini (2007) argues that Web 3.0 applications will make some Web 2.0 applications such as social bookmarking redundant and irrelevant. However, Medicine 2.0 tools will still be used by people, and the term Medicine 2.0 will be used in the future in an academic or international focus, while Health 2.0 is used for business and commercial audience (Hughes 2008).

#### **4.2.2 Loss of control over information**

The second main issue with Medicine 2.0 concerns the collaboration between doctors and patients. Some doctors fear that their patients will be misled by the information they get through the Internet. Separate to the information inaccuracy problem, doctors predict that patients will change their behaviour through the use of

Medicine 2.0, for example choosing not to consult a physician or consulting too late, or coming to wrong conclusions about their conditions even if the available information is correct. This results in the resistance of some doctors in their patients' use of Medicine 2.0 and therefore a resistance of doctors to use these tools. Doctors do not have enough training and can therefore not advise their patients on the use of these tools. It is necessary that doctors become aware of the emergence of Medicine 2.0 and that the current (lack of) training is no longer adequate. (Hughes 2008)

### **4.2.3 Information inaccuracy**

Inaccurate information online and the potential risks associated are the third major tension in Medicine 2.0. Misinformation has always been seen as the biggest problem in eHealth. (Hughes 2008) However, the study of Croggo (2008) and colleagues argues that there is no big support for this concern. A more recent study from Esquivel (2006) and colleagues found out, that most information in an Internet-based cancer support group was accurate and that incorrect information were corrected immediately. The concept of apomediation, described in chapter 4.1.3, also contributes its part towards making increasingly better quality information available. Apomediarities or gatekeepers act as filters and guide the consumer to the relevant information.

However, despite the results of these studies, there is still a resistance of practitioners and researchers toward information inaccuracy in the Internet. The responses of Medicine 2.0 articles still suggest that "consequences could be disastrous for any inexperienced trainee following the advice", or people request clarification when authors suggest that Google could be used as a diagnostic tool. (Hughes 2008)

### **4.2.4 Ownership and privacy issues**

In addition to information accuracy, ethical, privacy, legal, and ownership issues arise as well due to the nature of health information. Doctors that are using social networking sites for medical education and debates are concerned with these issues

too. Identity management and authorization schemes should therefore be researched as well (Hughes 2008). Ferguson (2007) even states that the patient groups that run specific sites claim ownership of these data and increasingly use this information to influence research agendas.

### ***4.3 Chapter summary***

This chapter defined the term Medicine 2.0 which describes applications, services, and tools that are web based and use Web 2.0 technologies to enable consumer/patients, health professionals, and biomedical researchers to connect with each other. Medicine 2.0 = Web 2.0 + Medicine. Furthermore, the chapter looks at the different aspects of Medicine 2.0 like Social Networking, Participation, Apomediation, Collaboration, and Openness. The problems related to Medicine 2.0 are discussed in the last part of the chapter. These problems are the lack of a clear definition, the loss of control over information, information inaccuracy, and ownership and privacy issues. The next chapter will look in more detail to currently available Medicine 2.0 applications.

## **5.0 Medicine 2.0 Applications**

The following chapter will introduce some Medicine 2.0 applications that are currently available. This list is not a complete list of applications as it is not the goal of the paper. It is much more an introduction and perspective for the next version(s) of I-CAN and a discussion of possible problems with these tools.

### **5.1 *Second Life***

In 1999, Linden Lab in San Francisco started developing Second Life with the goal to create a parallel world that can be controlled by the users, where humans can interact, play, trade, and can communicate with each other. In 2003, this world went online and has attracted 16.5 million members since then (SecondLife 2008).

Second Life is an enduring virtual world in a 3D environment. This environment was developed and maintained completely from its inhabitants. It is possible to create almost anything and to become whatever the player want. The player is symbolized through an “Avatar”, a digital figure within the game that can be controlled to take action. The integrated tools in Second Life enable the player to customize its Avatar so that the personality of the player can be seen in his digital reflection.

Technically, the Second Life physical environment is calculated and executed on a backbone computer which is connected to hundreds of other computers, so that the simulation looks as real as possible. Currently, the interactive world of Second Life spans several ten thousand hectares of virtual cities, streets, buildings, islands, etc.

Part of the game is to create and sell 3D contents, and to buy land to build houses on it for sale. It is possible to earn virtual money with transactions like these and to change it into real money. Therefore, Second Life is not just a game; it is also an opportunity to create a company in it and to earn real money. (SecondLife 2008)

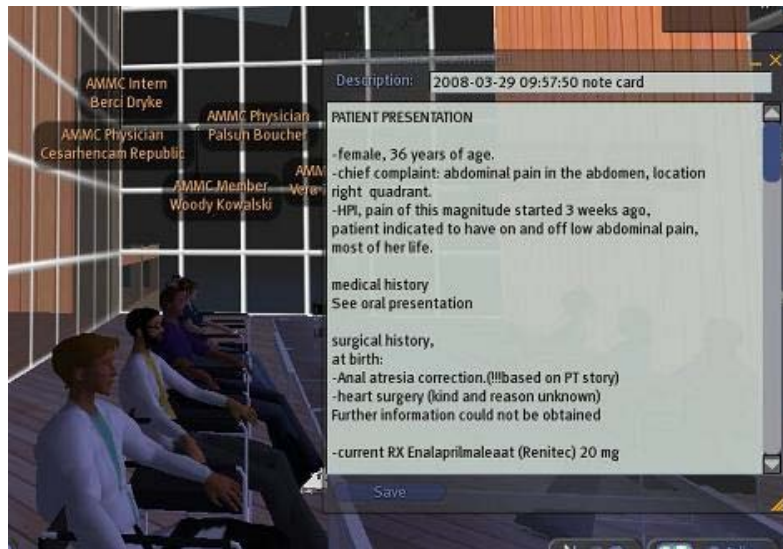
### 5.1.1 Examples

One interesting example for the use of Medicine 2.0 in Second Life is the *Ann Myers Medical Center (AMMC)*. The centre was founded by Doctor Ann Buchanon, to test the possibilities of virtual training for First Life medical and nursing students.



**Figure 5.1:** Ann Myers Medical Center  
(AMMC 2008)

The AMMC supports the medicine students to listen to their patients closer, because in the current medical education this is not covered appropriately. Patients oftentimes reveal important aspects of their disorders through their words. However, physicians do not always listen closely and miss important indicators. Another aspect of the AMMC is to train students to care more for their patients, as it is the philosophy of the founder that it is often much more effective to really listen and care for a patient than to prescribe him any medication. Furthermore, AMMC links telemetric builds (ECG, oxygen saturation machines, etc.) to real time outputs via URL. The student can click the URL and then practice to accurately diagnose the medical issue of the patient with the help of the telemetric outputs. (AMMC 2008)



**Figure 5.2.:** Case Presentation at the AMMC  
(AMMC 2008)

AMMC currently has several voluntary staff. This staff consists of Psychologists, Haematologists, Oncologists, Radiologists, etc. The vision is to create an “open” medical arena for all to collaborate and learn. (AMMC 2008)

Another interesting example of Second Life using Medicine 2.0 is *Gene Pool*. Gene Pool is a site, created by Professor Max Chatnoir from the Texas Wesleyan Institute. He teaches classes in genetics there with the help of simulated experiments that students can use to enhance their online class work. The use of a physical lab is therefore no longer necessary. Within the Gene Pool students can learn more about the law of inheritance, discovered by Johann Gregor Mendel. It contains notecards with much of the information of Mendel’s writings and links to websites with further information as well. The Gene Pool has furthermore a greenhouse where students can follow virtual experiments of, for example, cross breeding between various types of peas and flowers. Students can observe these experiments and predict the outcomes with the help of particular rules. Students can write their answers into a notebook for Chatnoir to examine.

On the ground floor of the six story high rise building a complete Watson-Crick DNA model is replicated showing the double helical structure of the DNA. The second floor contains some experiments showing the relationship between DNA to Proteins. At the third floor, students can see fruit flies and examine them under a microscope.

For the examination, there is a large CO<sub>2</sub> cylinder available to paralyze the flies. The fourth floor has models of the 24 human chromosomes where users can click to find more information about the particular chromosome. Information on bioinformatics and cross-species protein is available on the fifth floor of the building.

However, the creator Chatnoir commented that “the experiments in the Gene Pool do not take the place of what students might experience in a lab class. The main value would be practice in Data Analysis. A real lab is never this cut and dried.” (Qi 2007)



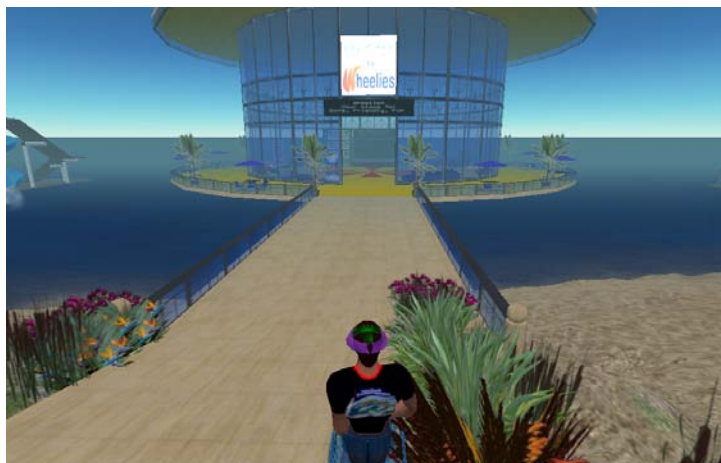
**Figure 5.3:** The Gene Pool  
(Qi 2007)

The target group of the last two examples - the Ann Myers Medical Centre, and the Gene Pool - was both students of medicine. The next examples will focus more on the patient and on how Second Life can be used to empower patients coping with their disease/disability.

Simon Stevens, a British disability consultant and trainer, created a virtual nightclub in Second Life which is known as *Wheelies*. *Wheelies* is the first disability themed nightclub within Second Life and was first launched in September 2006. Disabled and non disabled users can meet in this friendly environment and dance without fear of prejudice. Located right next to the nightclub is the Stevens Center for disability training.

The nightclub presents DJs from America and Europe, so that users from both continents can enjoy the music in for them convenient times. Of course, the club is easily accessible for wheelchair users. There are no stairs in the whole club, but lots of ramps and elevators. In the future, the club will be accessible for blind persons as well. Users can even rent one-room apartments in the nightclub for about 50 – 100 Linden Dollar per week to finance the nightclub. Wheelies also rents out commercial space to retail shops that are specialized in wheelchairs.

The whole philosophy of Wheelies is to demonstrate that the visitors are not disabled, but are differently abled. The user can do anything anyone else can do, just differently. As a result, there are volunteer escorts in Wheelies to assist and help every user through the premises. (Stevens 2008)



**Figure 5.4.:** The Wheelies nightclub  
(Stevens 2008)

The *Medical Library 2.0* at Health Info Island is another example for a Medicine 2.0 application in Second Life. This virtual library is open for anyone. It was created by Namro Orman from the Central Medical Library of the University Medical Center Groningen, the Netherlands. The goal of the whole project was to make librarians and interested people work together to provide Library Services in Second Life. Specifically, the library offers displays, programs, and methods of access most libraries do not offer in real life spaces, but that patrons like and want or need, focused more on visual and audio exchange than on text. Experiments with innovative delivery of service can be done, while also exploring interactive



possibilities between library & library staff and visitors. Future projects of the creator include a Second Life health directory which will have the form of a wiki. (Brekel 2006)

Since opening the Medical Library 2.0, the founders could accomplish the following additional points as well:

- Collecting and presenting quality consumer health resources about illness, drugs, allied/alternative and complementary medicine by using US, European and other resources. This includes also presenting information about freely available medical research, e-books, E-journals, Databases and Repositories as well as Podcasts modules for listening to themed podcast sessions via MP3.
- An in-world PubMed search available in the Library.
- An artificial intelligence (AI) experiment with a Chat bot, where the bot, named “Healthy” answers question about medicine.
- Virtual workshops on the evaluation of health information on the internet.
- Trial access to EBSCO’s Consumer Health Database and to Reuters Consumer Health News accompanied with Workshops on the Consumer Health Database.

Furthermore, the Medical Library also has cooperation with institutions like the Specialized Information Services/ National Library of Medicine (SIS/NLM), the National Institutes of Health (NIH), the Center of Diseases Control and Prevention (CDC), the University of Pittsburgh Medical Center (UPMC), and the Karolinska Institute University Library (Brekel 2006).

### **5.1.2 Analysis**

Second Life offers a new access point for people to find (health information). The ability to connect with people and exchange knowledge and information are arguably the greatest benefit of the virtual environment.

Second Life helps to transcend barriers and may well continue to develop into a Web3D browser extended and integrated with Internet and Web 2.0 possibilities, including content, tools and resources, but is currently in a early stage of maturity.

Technical issues around the use of the SL client, the numerous updates, the down-times and the mastering of the interface are serious thresholds for many people to maintain their avatar. The avatar to avatar communication is not that different from real life reference services, and it certainly enhances the more impersonal web chat or IM library services. It can also offer a trusted, secure and personal environment for consumer health issues on a one-to-one level (Brekel 2006).

With open-minded people who are willing to invest time to try to improve health services in general and really learn what users want and need, growth is inevitable. However, the costs and the complexity of creating and maintaining such facilities are not appropriate to integrate into I-CAN. Furthermore, I-CAN users are not typical Second Life users. It would take too much time to teach them the functions and possibilities of Second Life. The technical issues with the software are also a big problem. It is reported that many registered Second Life users can not login into the system. Numerous blog entries and discussion topics are available of users complaining about technical problems.

In summary, Second Life is not a real option for I-CAN at the moment even though the concepts of collaboration, openness, apomediation, and participation can be met. The development of SL has to be followed in the future. If the maturity of the software grows, and the amount of users continues to increase, it could be an opportunity for I-CAN to get involved in SL as well.

### ***5.2 User-based sites***

User-based sites are basically web pages that are community driven. A lively community creates changes and other people can follow these changes. Social

Networks like MySpace or Facebook are popular user-based sites. But also Flickr, YouTube, or del.icio.us are examples of the exponentially increasing number of user-based web sites.

### 5.2.1 Examples

*SugarStats.com* is a good example for a user-based site that is aimed for diabetic patients. The system is a web-based blood sugar tracker and diabetes management system that was developed by diabetics for diabetics. The interface is completely web-based and can track, monitor and access users' glucose levels and diabetic statistics in order to spot dangerous trends and to better manage the diabetic health.

The input and access to the system is possible via various methods, for example, web browser, mobile phone, email, twitter.com, etc. It is possible to stay connected wherever the user is to be located.

It is possible to track the blood sugar glucose level along with the elements that affect those levels such as medication, food intake and physical activity. The information can then easily be shared with health care professionals, family and friends to get further information and support. (SugarStats 2008)



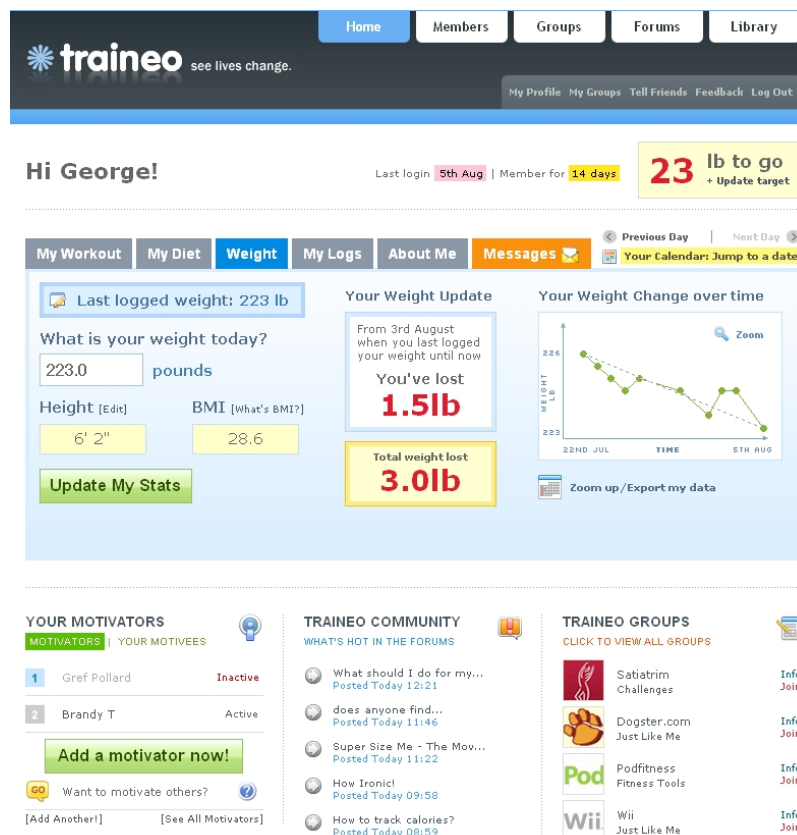
**Figure 5.5:** SugarStats Dashboard with an overview of the activities in the last 5 days (SugarStats 2008)

The feedback of all users is throughout positive. Registered users are using it every day. Goal of the developers was “to create something that was not only easy to use and effective, but something that people would WANT to use.” (SugarStats 2008).

Another community driven tool for patients is *Traineo*. Traineo is a weight loss community which combines a selection of weight loss tools and trackers with public profile pages, messaging and commenting. It is not a Facebook-style social network in the sense that the user can not add copious amounts of friends. However, users can send a message and ask other users to add them to their contacts. The type of friendship can also be set up slightly different: Members can identify themselves as “motivators” and help others to achieve their goals. New motivators can be found by messaging users on the site or inviting friends via email.

The site contains weight loss tools too. These track the workouts, log the number of calories the member consumes (Traineo redirects to the USDA Food Database to get the calorie information) and plot the statistics on a graph. A meter in the top right page monitors how near the user is to his weight loss targets, while Traineo also

awards a “Daily Diet Score” for the users performance and recommends the number of calories that should be aimed for to consume per day. Other features include for example, professionally written weight-loss articles and forums. On the profile pages there are commenting possibilities, RSS feeds and a progress meter that displays the weight loss.



**Figure 5.6:** Traineo Profile Page  
(Traineo 2008)

*PimpNotes* is an open-source project for medical students and doctors in training. The site hosts free notes, guides, books, or any other materials created by and for medical students and residents. The site contains flash cards which are basically summaries of large texts that medical students have to read. The flash cards are created and edited from the medical students themselves to help them to put the large information that they are expected to learn into an easy-accessible format. It is possible to reduce a 30-page printed article into one flash card while communicating the same content and not losing important details. This format allows students to

quickly trace every token of a disease, identify points to use intervention, and see clearer connections between the different aspects of medicine (Pimprnotes 2008).

### 5.2.2 Analysis

In summary, user-based sites offer a wide variety of possibilities to actively support patients, as well as health care professionals and students. These sites thrive from the participation of its members. Without them, the sites would soon be out of business. Especially Social Networking sites like Facebook and MySpace are very popular and can be used as an example of the success of user-based sites.

However, there are also issues with this kind of open, community driven structure. As John Stephens (2007) reports in his article “Will Technology Be New Media’s Legal Savior?” companies try to sue the operator of Social Networking sites. Universal Music Group (UMG), the world’s largest music company, taken on MySpace for copyright infringement of thousands of songs and videos as well as video sharing sites Grouper and Bolt. Similarly there are open legal suits against YouTube for the same reasons. The problem is that at the moment it is not certain who has the obligation to enforce the protection of copyrighted materials – copyright holders or web site owners? It is also not clear if it is possible for a copyright owner to force sites to take down offending materials, or if the site owner has the responsibility to monitor and remove materials when he thinks they are offending.

The problems with copyright issues could be a major drawback for I-CAN and could lead to legal problems. I-CAN should make sure to take precautions either by not allowing users to upload any material that could be under a copyright, or by constantly monitoring the uploads and letting the users know that I-CAN does not take any responsibility for the contents of the site. This could be done for example with a checkbox that users have to confirm before they upload videos or music.

Social network data is extremely sensitive. When people are being asked to disclose personal and sometimes intimate relationships it is natural for them to wonder what happens to these data and who has access to them. The privacy of every user must

be ensured at any time. Without users trusting the organization - to have strong ethical principles - behind the web site (I-CAN), it is more likely that a user-based site is going to fail.

The accuracy of data has to be precise as well. Missing data can lead to wrong results. For example, it is crucial for a website like SugarStats to know all information about the patient. If only one fact is incorrect or missing, the site would probably come to the wrong conclusion which can be fatal for the user. An example would be that the user enters the wrong height or weight and the system gives therefore wrong recommendation about the amount of medicine the user has to take. This can be fatal! For I-CAN this means to make sure that all data are accurate. This could be done for example, that only health care professionals can enter certain information, and the user can see only the results.

Nevertheless, the success of these user-based sites shows, that this could be a real opportunity for I-CAN to expand their user base and to give extra value to its customers and their patients.

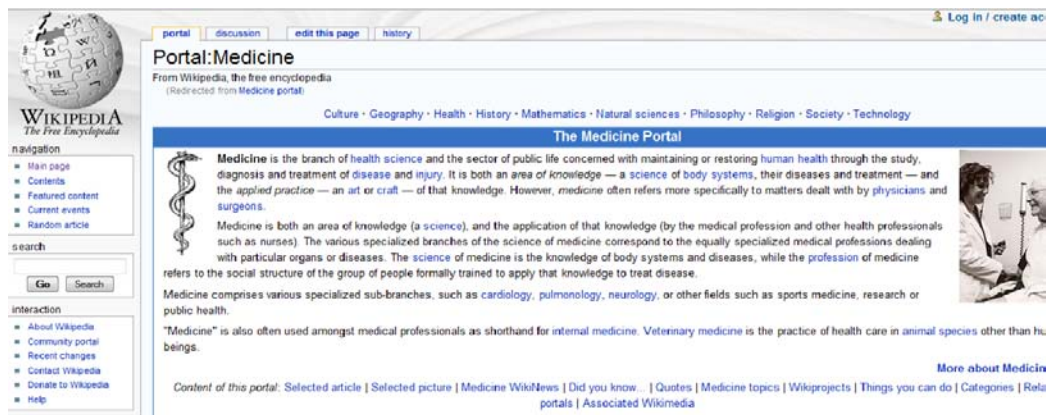
### **5.3 Medical wikis**

Wikis were already described in chapter 3.3.4. As a reminder, wikis are a public collection of websites that can be edited, usually from all users, with the help of a simple online form. Medical wikis are, as the name implies, wikis with solely medical content.

#### **5.3.1 Examples**

Wikipedia created a portal called *The Medicine Portal*. In this portal user can get information to topics like anatomy, medical treatments, pharmacology, the different diseases and disorders, and first aid tips. A section for physicians is available as well where there is information available about the medical education and the different disciplines that students can study. A section for medical equipment shows which

equipment are currently on the market for which kind of disease and shows how to use them.

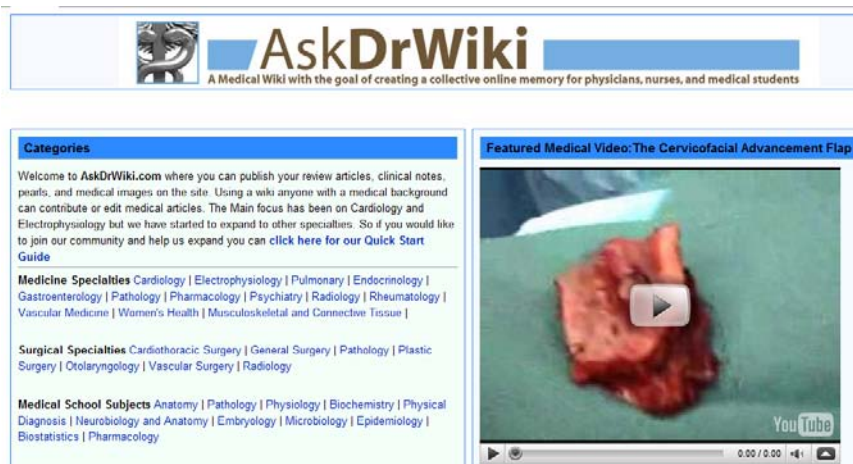


**Figure 5.7:** Screenshot of The Medicine Portal  
(Medicine Portal 2008)

In the portal, there are also wiki projects available. Wiki projects encourage people to contribute articles to selected topics for example health and fitness, alternative medicine, or genetics. The medicine projects have more than a hundred participants, and they maintain a collaboration that is refreshed every week with the aim to fill gaps in Wikipedia, to give users a focus and to improve an article even to featured level. It is also possible to rate medicine – related articles, which directly determines the main fields of work in the projects. Articles or fields with bad ratings get a higher priority to work on than articles with good ratings. (Meskò 2007a)

A similar concept to The Medicine Portal is a wiki called *AskDrWiki*. AskDrWiki allows publishing articles, clinical notes, pearls, and medical images. The wiki is open, so anyone with a medical background can contribute or edit medical articles. Initially, the main focus has been on Cardiology and Electrophysiology, but until now they have started to expand to other specialities. AskDrWiki is a complete nonprofit educational website which is operated as a public service by the Open Access Medical Informatics Group (AskDrWiki 2008).





**Figure 5.9:** Screenshot of AskDrWiki  
(AskDrWiki 2008)

The difference between these two wikis is that Wikipedia is made for laypeople. They must not include too deep medical train of thoughts even if it is important regarding the content of an article. AskDrWiki fills this gap with real medical pieces of information. For example, a video of an angiography is not essential in a Wikipedia article, but AskDrWiki can collect many of them without causing any problem and also helping physicians and medicine students more.

### 5.3.2 Analysis

Medical Wikis are especially useful for the medical education. Students can write and review articles and learn more intense than just by reading their text books. The general public on the other hand can gain good information about their problems and can use it when consulting with a doctor. The problem with wikis is the reliability of the information it contains. Because a wiki is an open structure, everyone can edit articles, which can lead to reliability issues. Registered users see changes in articles and can review them to improve the quality. In fact, wrong entries are very often corrected immediately, but still there is always the possibility that articles contain wrong information.

A medical wiki is not the best option for I-CAN. The already available wikis have a very broad topic range so that it is not necessary to create another wiki with the same contents. Furthermore, administrating and maintaining a wiki requires a lot of effort which is most probably not worth the results and goals for I-CAN.

### **5.4 Communities**

Online communities are groups that are interacting via the Internet. It does not necessarily have to be a group where there is a strong bond among the members. An email distribution list, for example may have hundreds of members and the communication taking place may be informational (questions and answers are posted), but members may remain relative strangers and the membership turnover rate could be high. These virtual communities depend upon social interaction and exchange between users online. Communities can be organizational, regional or topical. Different communities have different levels of interaction and participation among their members. It can range from adding comments or tags to a blog or message board to competing against other people in online video games.

#### **5.4.1 Examples**

*MDJunction* is an example for an online community. It is basically a meeting place for people with health challenges. People can help others, and get help from others. MDJunction was initially founded in 2006 with only one support group and limited community features. In 2008, 630 Online Support Groups are within the site and each of these is dedicated to one health challenge. Likeminded people can discuss their feelings, ask questions and share their hopes in order to get the needed information, comfort, support and friendship with people who have the same problems and therefore understand them best. “People Helping People (MDJunction 2008).”

Categories include, amongst others, children’s health and parenting issues, men’s and women’s health, allergies, cancer, addiction, and infectious diseases. It was

mainly created to fill a need for an online community of patients. However, MDJunction cannot be seen as a replacement for traditional medical treatment.

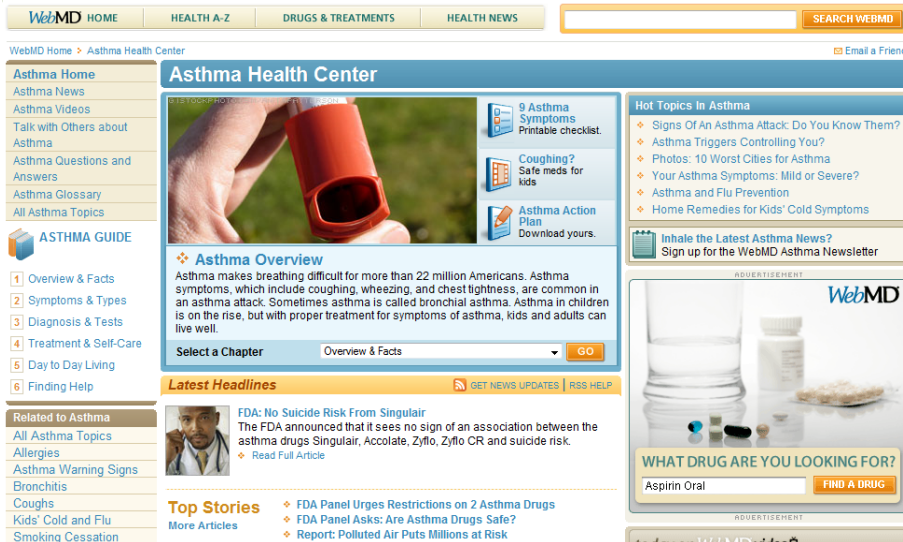


**Figure 5.10:** Screenshot of MDJunction.com  
(MDJunction 2008)

The main focus is people helping people. Therefore, MDJunction created a community which is managed by the community, and strives to empower the members to lead, make a change and have a positive effect on their friends and fellow warriors. Core belief is that achievement is a crucial part on the way to recovery and a better life. (MDJunction Interview 2008)

Similar to MDJunction is the online community *HealthBoards*. Beside the support community with over 150 message boards and structured like MDJunction, HealthBoards offers a comprehensive Health Guide with valuable health information and tools for managing members health. In this Health Guide users can choose the disease they are interested in and then get forwarded to the disease main page. At this page, the user find published articles, news, videos, question and answer section for this specific disease. A guide is available as well, where the affected patients learn more about the symptoms, diagnosis, treatment, etc. The “Related to” section shows other diseases that have similar symptoms and links them directly to the main pages of these diseases.

## 5.0 Medicine 2.0 Applications



The screenshot shows the 'Asthma Health Center' on WebMD. The top navigation bar includes 'WebMD HOME', 'HEALTH A-Z', 'DRUGS & TREATMENTS', and 'HEALTH NEWS'. The left sidebar contains a navigation menu with 'Asthma Home', 'Asthma News', 'Asthma Videos', 'Talk with Others about Asthma', 'Asthma Questions and Answers', 'Asthma Glossary', and 'All Asthma Topics'. Below this is the 'ASTHMA GUIDE' with numbered links for 'Overview & Facts', 'Symptoms & Types', 'Diagnosis & Tests', 'Treatment & Self-Care', 'Day to Day Living', and 'Finding Help'. The main content area features a large image of a hand using an inhaler, followed by an 'Asthma Overview' section. To the right of the overview are links for '9 Asthma Symptoms Printable checklist', 'Coughing? Safe meds for kids', and 'Asthma Action Plan Download yours.'. Below the overview is a 'Select a Chapter' dropdown menu set to 'Overview & Facts' with a 'GO' button. The 'Latest Headlines' section includes a news item: 'FDA: No Suicide Risk From Singulair' with a sub-headline 'The FDA announced that it sees no sign of an association between the asthma drugs Singulair, Accolate, Zflo, Zflo CR and suicide risk.' and a 'Read Full Article' link. The 'Top Stories' section lists 'FDA Panel Urges Restrictions on 2 Asthma Drugs', 'FDA Panel Asks: Are Asthma Drugs Safe?', and 'Report: Polluted Air Puts Millions at Risk'. On the right side, there are 'Hot Topics In Asthma' with links like 'Signs Of An Asthma Attack: Do You Know Them?' and 'Asthma Triggers Controlling You?'. Below this is an advertisement for WebMD with the text 'WHAT DRUG ARE YOU LOOKING FOR?' and a search bar containing 'Aspirin Oral' and a 'FIND A DRUG' button.

Figure 5.11: The Health Guide for Asthma at HealthBoards.com  
(HealthBoards 2008)

For physicians and health care professionals *Tiromed* is the first choice to connect with others. Tiromed is a free social networking, resource portal for physicians and students of medicine. Networking with colleagues, classmates, students, etc. is possible, as well as finding and sharing information. This information can be study guides, powerpoints, articles, or websites. The mission is to provide unique features and functionalities that allow members to research and learn, and connect with others in the same field (Tiromed 2008).



The screenshot shows the homepage of Tiromed.com. The top navigation bar includes 'Home', 'Ask a Mentor', 'Forums', 'Members', 'Groups', 'Associations', 'Classifieds', 'Promote', 'Store', and 'Help'. The main content area features a 'WELCOME!' section with the text 'Tiromed. Your portal to the medisphere. Join Your Peers. Ask a Mentor. Be a Mentor.' and a list of user types: 'Physicians In Practice', 'Fellows', 'Residents', 'Medical Students', and 'Premedical Students'. There is a 'JOIN NOW' button and a 'WHAT IS TIROMED?' link. To the right is a 'LOGIN' section with fields for 'Email Address:' and 'Password:', a 'Remember me' checkbox, and 'LOGIN' and 'JOIN' buttons. Below the welcome section is a 'TIROMED JOURNAL' section with a news item 'Tiromed Welcomes NMSS to the Tiromed Network' and a logo for 'NEPAL MEDICAL STUDENTS SOCIETY'. On the left side, there is an 'ASK A MENTOR!' section with a profile picture of a woman and the text 'IrvineMD' and 'Primary Care Medicine, Women in medicine, 31 Visa,'. Below this is a 'MEMBERS' section with a profile picture of a young girl.

Figure 5.12: Homepage of Tiromed.com  
(Tiromed 2008)

### **5.4.2 Analysis**

Online Communities are very similar to user-based sites. The community thought is more in the foreground than in user-based sites. The idea to help each other and to build a community where people with the same problems can connect has the highest priority in the concept of online communities. User-based sites do not necessarily aim to connect people with the same problems/interests, even though most sites have features to form groups where people with same interests can connect.

I-CAN could benefit from a community feature. It would be possible to connect the health care providers with each other so that they can share information and benefit from the shared knowledge. However, such a system would mean extra work for the professionals. The benefits are possibly not visible for every user and therefore it would be a challenge to encourage the providers to participate in it. Eventually, this can only be done with the help of incentives in form of prizes, money, etc.

### **5.5 Medical Blogs**

Blogs are described in chapter 3.3.3. Medical Blogs are simply blogs that provide content and express opinion on healthcare that is unlikely to be found in a medical paper. Patients as well as physicians have the chance to write in their own words about certain topics on healthcare.

#### **5.5.1 Examples**

*Diabetes Mine* is a popular blog for people with diabetes. The author, Amy Tenderich, was diagnosed with Type 1 diabetes in May 2003 and had started to write a blog about her life with diabetes since then. In her blog there are information of her own experience on every imaginable aspect of living with diabetes. From food scales

to pharma news and book reviews, to the exasperating things that other people say about the disease. The blog covers all possible topics about diabetes. The author wants to talk straight in her blog, which means she wants to call a spade a spade, and furthermore encourage people with diabetes to take control of their disease (Diabetes Mine 2008).



**Figure 5.13:** Screenshot of Diabetes Mine  
(Diabetes Mine 2008)

Similar to Diabetes Mine, there are a lot of other personal blogs available from patients for patients:

- **Chronicbabe:** A blog for younger women with chronic health issues
- **TheFurryMonkey:** A blog about living with Non Hodgkin's Lymphoma
- **FightPompe:** A blog of a young boy suffering the Pompe Disease
- etc.

An interesting blog for physicians could be for example *Docinthemachine* by MD Steven F Palter. Palter is an internationally known pioneer in the translation of cutting edge high technology developments into surgical procedures and tools. In his blog he provides a unique perspective on new technology developments in medicine with a special focus on minimally invasive surgery, imaging, fertility, women's health, and high tech innovations. (Palter 2008)

Other physician blogs well worth seeing are:

- **Emergiblog:** The Life & Times of an ER Nurse
- **Eye on DNA:** How will DNA change your life?
- **GruntDog:** Ramblings of an Emergency Physician in Texas
- etc.

### 5.5.2 Analysis

Medical blogs are a good tool for people to share their stories with other people. It is definitely empowering for the reader to know that there are others out there with the same diseases and problems. The language is in most cases direct and personal which generates a sense of connection between the reader and the author.

However, a Medical Blog is not an option for I-CAN. Blogs are only instruments for private persons to share their thoughts about certain topics or for companies to post about new products and services.

### 5.6 *Blog Carnivals*

A blog carnival can be seen as a blog event. There are similarities to magazines because blog carnivals are dedicated to a particular topic and are published regularly, weekly or monthly. A carnival is a form of a blog article that contains the links to other blogs with the same topic. Mainly, blog carnivals are a way for blogger to recognize each other's efforts, to organize blog posts around important topics, and, most importantly, to improve the overall level of conversation in the blogosphere.

The big advantage of blog carnivals is that it saves time for interested users. They do not need to look through all blogs and other sites; they can just look at a carnival and see the best posts on a subject from time to time.

### 5.6.1 Examples

Some examples of blog carnivals for medical topics are:

- **Grand Rounds:** A weekly rotating carnival of the best of the medical blogosphere.
- **Mendels Garden:** A carnival devoted to genetics.
- **Gene Genie:** Genes and genetic conditions are the topics of this carnival.

**BlogCarnival.com** is a directory of carnivals, and lists many more sites all with medicine, health & fitness topics.

### 5.6.2 Analysis

As mentioned before, Blog Carnivals save time. The authors of the carnivals spend time researching the best articles and publish them in their carnivals, so that the reader finds an overview of all important articles with links. Just like Medical Blogs, carnivals are not an alternative for I-CAN as blogs are more suitable for private persons or companies that introduce new products or services.

## 5.7 *Medical Search Engines*

The difference between a search engine like Google, or Yahoo and a medical search engine is, that the normal search engines do not select among sources, which makes many of the medical search results irrelevant. The medical search engines however, use peer-reviewed sources and sites that are selected by experts and that provide the most relevant and reliable medical information of the best quality. (Meskò 2007b)



### 5.7.1 Examples

The following five medical search engines are, according to Boswell (2008), the most useful to find medical information at the moment:

- **OmniMedicalSearch.com:** Search results are from 30 different sources, and it is possible to search up to 12 different medical search engines at one time. It is possible to set options to search only for news or images which then search only specific domains among the major search engines.
- **WebMD.com:** Beside the search engine, WebMD has a lot of interesting interactive calculators, quizzes, and other fun stuff to simplify understanding medical information.
- **PubMed:** PubMed is probably the site with the most extensive medical search engine/database which is a service of the National Library of Medicine (USA). Currently there are over 15 million Medline articles and journal citations available, some are free to view, some are for purchase.
- **Healthline:** Healthline is very similar to WebMD and offers beside interactive tools also unique features like physician-filtered results and clustered “healthmaps”.
- **HealthFinder:** This site was put together by the US Department of Health and Human Services. The user can search through over 1500 health-related organizations at the moment.

The screenshot shows the Healthline homepage with a navigation menu at the top. The main content area is divided into several sections: 'Top Health Topics' with a dropdown menu for 'Anxiety / Panic Disorders', 'Health News' for January 14, 2009, and 'Health Tools' including a 'Weight-Management Tools' section with calculators for BMI and burn rate. There is also an advertisement for Imodium.

Figure 5.14: Screenshot of the Healthline homepage.  
(Healthline 2008)

### 5.7.2 Analysis

Medical search engines offer better and more reliable search results than conventional search engines. The fact, that these search engines only look in peer-reviewed articles and websites makes them trustworthy and offer a good instrument for people to find more information about their disease.

Again, a medical search engine is not the best option for I-CAN. It is not the goal to create a pure (medical) search engine as there is no collaboration between patients and their physicians.

### 5.8 Medical Podcasts and Videocasts

Podcasts are downloadable audio files (videocasts are video files) that users can subscribe to and get regular updates from when a new episode is released (usually weekly). The term podcasting combines “broadcasting” and “iPod” and was coined from Apple’s big success with their portable mp3 player iPod. Almost all pod- or

videocasts are free and with the help of Apple's iTunes program it is easy to subscribe to one of them.

The audio or video files are all in formats that portable mp3 player can play back. For video files the user need mp3 players that are able to play videos, or the user has to watch it on his computer.

### 5.8.1 Examples

Some examples of medical podcasts are:

- **ACC Conservations with Experts:** A podcast with the mission to advocate for quality cardiovascular care – through education, research promotion, development and application of standards and guidelines – and to influence health care policy.
- **Journal of the American Medical Association:** The editor in chief Catherine D. DeAngelis, MD, MPH, summarizes and comments on the issues of the current medical developments on a weekly basis.
- **New England Journal of Medicine:** The New England Journal of Medicine offers a podcast version of its journal with interviews and article summaries of the current issue.
- **Lancet:** The Lancet is a weekly medical journal which is renowned for the publication of high quality peer-reviewed research and reviews from around the world. In the weekly podcasts, the editors discuss highlights of the current issue, including interviews with authors of key articles.
- **John Hopkins Medicine Podcast:** The current top medical stories of the week are discussed in this podcast. Goal is to get people become informed participants in their own health care.

Examples for videocasts with medical topics are:

- **National Institute of Health VideoCasting:** This webpage gets funded from the U.S. Department of Health & Human Services and broadcasts seminars, conferences or meetings as a real-time streaming video. The videos can also be recorded so that viewers can watch at their convenience on-demand or as a downloadable podcast.
- **Cleveland Clinic Videocast:** It is possible to watch the doctors, scientists and healthcare professional advancing medicine.

### 5.8.2 Analysis

Podcasts and videocasts are handy tools for busy people. They can download the files on their mp3 player and listen to it while exercising, working, or driving the car. It can be used for educational purposes, as many Universities today already do, as well. Even high ranked politicians use podcasts to communicate to their nation. The subscription function makes it easy to be up to date with new podcasts because the computer downloads new content automatically.

It is not the purpose of I-CAN to broadcast news and information to users that is why the podcasting and videocasting is not an option for now. It could be an idea for the future to include podcasts or videos with interviews of patients or health professionals, but this has at the moment not a priority.

## 5.9 Chapter Summary

Chapter 5 introduced different, currently available, Medicine 2.0 applications. These applications are Second Life, User Based Sites, Medical Wikis, Communities, Medical Blogs, Blog Carnivals, Medical Search Engines, and Medical Podcasts and Videocasts. After a short definition of the terms, we looked at examples of existing applications and discussed the relevance to I-CAN.

The next chapter will introduce the PatientsLikeMe community and the experience with the website in detail.

## **6.0 Medicine 2.0 Case Study: PatientsLikeMe**

The online community PatientsLikeMe was built to support information exchange between patients. Its goal is to help patients understand and share information about their condition. The website provides customized disease-specific outcome and visualization tools that make it easy to get information. In March 2006 the site officially opened to the public and has attracted around 1600 verified patients ever since, whereby 1140 members are living in the United States. The patients join the site mainly because of recommendation of their health providers, other patients, or patient blogs or after finding the site through online searches and Google ad words.

Users of the website are mainly patients diagnosed with amyotrophic lateral sclerosis (ALS), whereby the community expanded recently and now includes other conditions such as Multiple Sclerosis, Parkinson, etc. as well. They can post data on their current treatments, symptoms, and outcomes to the system. The data are then graphically displayed within their personal health profiles and are reflected in composite community-level symptom and treatment reports. Users can review and discuss these data within the Forum, private messaging, and comments posted on each other's profiles. (Frost & Massagli 2008)

This case study looks at the construction, the features, of the system first, and then analyses how users use this system and how they communicate with each other, especially how patients react to sharing considered private information (personal health data).

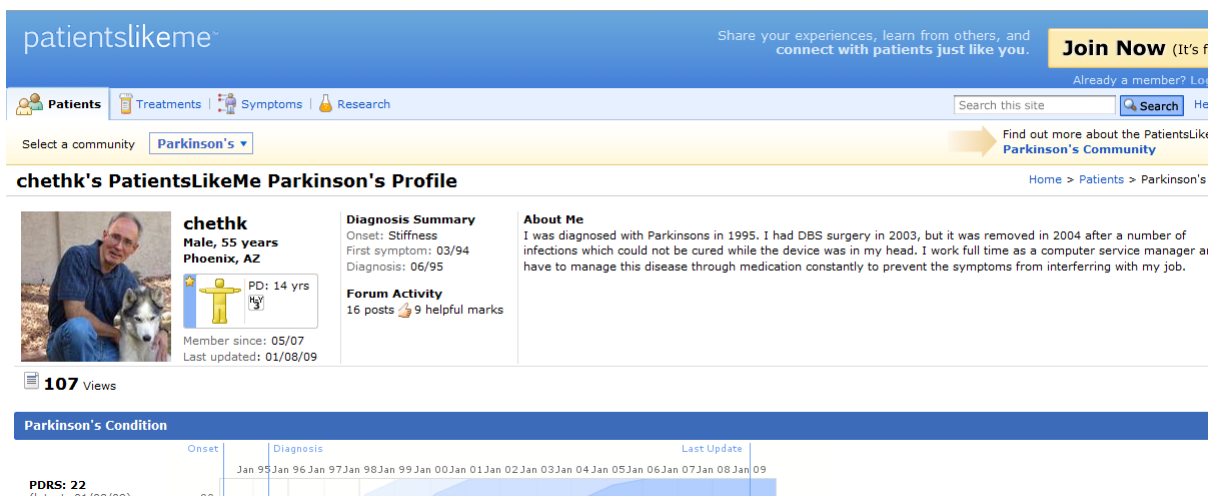
### ***6.1 The structure of the system***

Every member has a personal health profile in the system. After filling out the registration form where the patient has to enter his personal data, the system generates the profile and shares it within the site. The profiles contain a summary representation of the patient's current status. This includes a:

- profile picture,

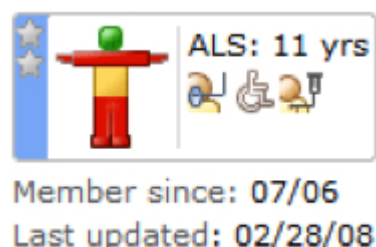
- diagnosis history,
- autobiographical statement,
- diagram of functional impairments,
- and a series of charts.

The developer can chose to display the data as graphics to consciously make them more accessible compared to static lists and tables. (Frost & Massagli 2008)



**Figure 6.1:** Profile of a patient with Parkinson disease in PatientsLikeMe  
(PatientsLikeMe 2009)

An interesting diagram is the so called “nugget” summary diagram which displays the current function score as a color code mapped onto affected areas of body, the number of years with the disease, the equipments currently used, and stars that indicate the level of participation on the site.



**Figure 6.2:** The “nugget” summary diagram  
(PatientsLikeMe 2009)

In the main area of each profile are the charts displayed that show the current condition of the patient, the treatments, and symptoms, each listed on a time scale.



**Figure 6.3:** Condition, Treatment, and Symptoms charts in PatientsLikeMe (PatientsLikeMe 2008)

The useful feature of these charts is that patients can rearrange charts within the profile manually and therefore explore relationships between data types (Frost & Massagli 2008). Each user has to answer questions about common symptoms of his/her disease, but they can define and extend the ontology as well. This structure enables patients to create valuable information for themselves and for research purposes.

The system offers social tools as well. For example, the browsing tool allows members to locate other patients with similar conditions or medical experiences to find each other. The Forum, private messaging, and posted comments on profiles are used to discuss profiles and reports as well as general health concerns. The Forum is open for every member to post questions, research findings, etc. via a

threaded dialogue. Private messages are, like the name says, private and therefore nobody else can read these messages, not even the administrator. They are used to send emails from one user to another within the site. Comments can be seen as remarks that are posted on another member's profile and are visible for anyone in the community. Users can delete comments from their own profile (not from other profiles). There are also already predefined comments available, such as "Thank you for filling out your profile!" These comments can be created easily with a single click. The "nugget" diagram tracks down every contribution of members and displays it with a graphic representation for any of these functions (Frost & Massagli 2008).

Another interesting feature of the website is that it collects and aggregates data from all individuals within one community and creates thereupon summaries of treatments and symptoms (Frost & Massagli 2008). The treatment reports also contain, in addition to the standard descriptions of the treatment, community-level data. These data are for example, time on the treatment, distribution of dosage levels, reasons why individuals started/stopped a treatment, etc. Furthermore, it contains information from forum posts on users' opinions of particular treatments. The symptoms report includes similar information. For each symptom there is the prevalence and severity within the community and which treatments people are using for each one. The reports are all hyperlinked to related items of interest, for example, to Forum posts or to people using the same treatment.

### ***6.2 Experiences with the Website***

Frost and Massagli (2008) summarized the experiences with the Website in the time frame from December 2006 to February 2008. In this time period users in the ALS community alone (PatientsLikeMe was initially designed only for ALS patients) commented 17,059 times to other user's profiles, whereby 7,852 comments were composed completely from the scratch. 63% of all members (986/1570) posted at least one original comment on the site. The authors studied the comments and identified 123 postings that met the criteria that were based on the key phrases ("I see you", "I can see you", and "notice you"). Most of these comments referred to treatments (23%), and symptoms or outcomes (7%). 45.5% of these comments had



at least one question in it, and half of these questions were explicit requests for advice. These questions can be categorized into three categories:

- **Targeted questions to others with a shared experience:** Users with a particular treatment question addressed their question to people that are already using that treatment. Questions about patient's opinion to treatments the asking user is intending to get. Etc.
- **Advice and recommendations:** User offered personally acquired knowledge to another member with a shared syndrome. Geographically appropriate suggestions like addresses of local support groups. Etc.
- **Forming and solidifying relationships based on similarities:** Patients invited other users for further contact, to share data. Patients looked for similarities that were not medical related such as location, employment history, etc.

In summary, the website helped patients to connect with each other. Patients met and formed relationships that would not have happened offline. The website is still growing with new conditions being added. Schonfeld and Morrison (2007) listed PatientsLikeMe as one of 15 companies that will change the world. They state that the website is a central repository for firsthand accounts about what living with diseases is like and helps patients to track their progress. Especially medical researchers are interested in this site, because it is a fast bypass around restrictive privacy rules. This bypass of restrictive privacy rules however, is also a concern that will be discussed in the next chapter

### **6.3 Discussion**

Frost and Massagli (2008) state that there is a growing demand by patients for access to their own health data. However, this new approach in medicine is groundbreaking and there is not enough research done in this field to show how people will use these data if they are made available to other patients with similar conditions or to any other person that could be interested in this information. The PatientsLikeMe platform was designed to help patients share their personal health

information through graphs within accessible personal profiles. The results of the websites show that patients are using the information to start detailed discussions of health-related topics with each other. The themes of these discussions were mentioned earlier and show the benefits that a system like this can offer to patients, but also to researchers. The structure and the design of the website enable patients to create valuable information – for themselves and for research. The study done by Frost and Massagli (2008) however, is limited in several factors, including the functionality studied and the sampling method employed. They focused only on posted comments and only on those that fit the predefined criteria to explicitly referencing another user's health data. As a result, it is not clear what an analysis of all the references to data on the site would reveal.

Privacy rules are another concern that follows with an open – information sharing – structure like this. Researchers can gather data from patients and use these for their purposes without bothering asking them for permission. For researchers that are doing important and urgent work it could be a shortcut to get the data they need and for example develop a cure for a disease. However, people with dishonest intentions could use these data for their purposes.

The study also showed that design innovations are needed to promote data-centered patient conversation (Frost & Massagli 2008). Currently the system does so by offering the ability to search for other users based on criteria like treatments, symptoms, and demographics. The open commenting and private messaging are also part of that conversation. However, these features have to be enhanced by offering search functions with a larger range of criteria, as well as the ability to comment on a specific portion of someone's health profile (Frost & Massagli 2008). Methods of identifying and presenting comments on someone's profile that would be useful for a wider audience are another feature that should be considered for future designs.

In conclusion, the PatientsLikeMe project debunks the assumption that people will not disclose personal health information. It adds value by asking member questions to make data more valuable and actionable, and enables patients to create valuable information as well.

## **6.4 Connection with I-CAN**

The example of PatientsLikeMe shows that a social networking platform where patients publish their private health information can be a useful tool for both sides – the patients and the health professionals. The next version of I-CAN should have similar functions.

The CDS wants to empower persons with disabilities and the support services to actively participate in the support process. Furthermore, the CDS also wants to enable the family or friends of disabled persons to participate and give feedback to the support services. They are the people who live together with the person with disabilities and can see changes in their behaviours first, before the support service notices it.

However, it must be taken into consideration that not all people with disabilities are able to use a computer, not to mention an online social networking tool. According to the developer of I-CAN, only about 10% of the disabled persons that are registered in I-CAN at this moment are able to use a computer. However, the developers are also certain that the family members or friends of the person with disabilities would be very interested in the idea of having access to I-CAN and give feedback to support services or search for people that have similar conditions.

The following chapter will show a proposal of how the I-CAN could look like with Web 2.0 features and which requirements should be added to the current system.

## **7.0 A design for Web 2.0 enabled I-CAN**

This chapter will show a suggestion of what I-CAN with Web 2.0 features could look like and hopefully provide the foundation for the next version of I-CAN. The purpose of the following screenshots is to clarify the system and its functions and give the I-CAN developer an idea of how the new application could look like. It is not the purpose to present a fully functional and designed application.

In chapter 5 we discussed the currently available Medicine 2.0 applications, and came to the conclusion, that the new features could be social networking, user-based sites, and/or communities. The following chapter will introduce a system that has all these concepts included and would be a good addition for the current I-CAN.

### ***7.1 Extending the Requirements***

Chapter 2.3 discussed the current limitations of I-CAN and came to the conclusion that only support services have access to the system, but no persons with disabilities or other user groups. For a Web 2.0 enabled I-CAN it is necessary to give these user groups access to the system.

The proposal for Version 5.0 is a combination of social networking tool, user based site, and community. It allows persons with disabilities, their friends/family, and the support services to connect and interact with each other. It is a tool to empower people to take responsibility for their own health and to connect with other people with similar medical history/conditions. Socialising with other people and finding useful information is another empowering aspect of the new feature. Family/Friends can communicate with the support service and inform them about any changes in the situation of their relative, and the support service can react immediately. On the other hand the support services can communicate with the people they support, or family/friends, and inform them about changes. The forum is to discuss general

problems with all users of the tool, and also offers closed discussion with only selected members.

The requirements/functions discussed in the following section only cover the new Web 2.0 features. Requirements for the needs assessment application are excluded from this chapter.

### 7.1.1 User Classes and Characteristics

As mentioned in section 6.4, only about 10% of all users that are looked after from support staff are able to use a computer. That is why there must be different roles for persons with disabilities available. While creating the profile, the support service has to decide in which category the person falls and create the profile correspondingly.

There are seven different types of users for the I-CAN social networking system:

<b>Role:</b>	<b>Description</b>
Manager	The user Manager is the manager of a support service and has unlimited access to all functions of the social networking feature.
Staff	Staff users have limited access to the in the social networking feature.
Family/Friend	This user is either a friend or a family member of one person.
P1	A person with disabilities that has full access
P2	A person with disabilities that has modifying access
P3	A person with disabilities that has limited access
P4	A person with disabilities that has no access

**Table 7.1:** The user classes in I-CAN 5.0

The next table shows the roles and their rights to use the systems functions (explained later):

Function	Manager	Staff	Family/ Friend	P1	P2	P3	P4
Create own Profile	OK	OK	OK	NO	NO	NO	NO
Add Friends	OK	OK	OK	OK	OK	OK	NO
Send Messages	OK	OK	OK	OK	OK	NO	NO
Forum	OK	OK	OK	OK	OK	NO	NO
Search	OK	OK	OK	OK	OK	NO	NO
Status Messages	OK	OK	OK	OK	OK	OK	NO
Give Feedback	OK	OK	OK	OK	NO	NO	NO
Upload Documents	OK	NO	NO	OK	NO	NO	NO

**Table 7.2:** User classes and their rights in the system.

## 7.1.2 The Profile

The profile is the central piece of the social networking tool. It contains all the information about the members of the site. Every profile contains a main section with a picture, the name, age, and location of the person. Furthermore, the user can set his status in two ways. Either by entering a status message or by activating an emoticon that shows the mood of the user. The user does not need to fill out all information, and can leave sections that he or she does not want to publish blank.

### 7.1.2.1 Creating and editing a Profile for persons with disabilities

A persons profile can be created with the data that is saved in the needs assessment feature. If a person (or his/her family member) decides to participate in the social networking tool, the support service can create the profile for the person after the entry of the needs assessment information. The creation of the profile will be done automatically by I-CAN and basically contains all the information that can be seen in the discharge report as well.

Only support services have the opportunity to create profiles for the persons they support. It is not possible for other people with disabilities to create a profile by themselves.

The profile for persons with disabilities contains the following sections:

<b>Section</b>	<b>Description</b>
Name	Name of the person.
Age	Age of the person.
Picture	Picture of the person.
Location	Location of the person.
Status Message	Free form status message.
Status Emoticon	Status emoticons symbolizing current mood.
<b>About Me</b>	
About Me	General brief description of person with hobbies, interests, etc.
Long Term Goals, Dreams and Aspirations	Future goals and dreams of person.
Current Life Situation	Where does the person live right now, who is living with him, relationship status, etc.
Support Network	Who is supporting the person. Support service, family, friends, etc.
Day and Night Support	How much support does the person need per day, at night, etc.
Background Information	Education, employment, financial support status, physical activities, etc.
Diagnosis	Diagnosed disabilities of person.
Medication	Medication taken currently.
Brief Medication History	Brief history of medication taken.
Results	Statistical summary of support needs in graph form.
<b>Comments</b>	
Comments	Public comments from other users.

<b>Health &amp; Well Being</b>	
Physical Health	Physical health problems of person.
Mental and Emotional Health	Mental and emotional problems of person.
Behaviour	Noticable behavioural problems of person.
Health and Support Services	Which health and support services does person see at the moment.
<b>Activities &amp; Participation</b>	
Applying Knowledge, General Tasks and Demands	Ability to do basic tasks like reading, writing, calculating, etc.
Communication	Communication skills of person.
Self Care & Domestic Life	How can person take care of himself, like take shower, prepare meals, etc
Mobility	Mobility of persons body movements, and transportation mobility (drive car, take bus, etc.).
Interpersonal Interactions and Relationships	Social skills of person.
Life Long Learning	Willingness to participate in learning new things.
Community, Social and Civic Life	Behaviour and ability to actively participate in a community, engage in recreation, religious activities, etc.
<b>Follow Up</b>	
Identified Follow Up	A “to do” list for the person, e.g. change diet plan, monitor sleeping patterns, find more activities, etc.
<b>My Friends</b>	
My Friends	Listing of all friends in the I-CAN system.
<b>Documents</b>	
Documents	Documents prepared from support services, or family/friends about the person, like older discharge reports, scanned documents, etc.

**Table 7.3:** The profile of a person with disabilities.



The support service and the person with disabilities can decide together which of the information will be visible for other users. They have the option to lock/unlock information for other users. The table below shows how this access rights to profiles should be implemented on default:

Profile Information	Visible for			
	Manager/ Staff	Family/Friends	Other users (Friends)	Other users (not in friends list)
Name	OK	OK	OK	OK
Age	OK	OK	OK	OK
Picture	OK	OK	OK	OK
Location	OK	OK	OK	NO
Status Message	OK	OK	OK	OK
Status Emoticon	OK	OK	OK	OK
About Me	OK	OK	OK	OK
Long Term Goals, Dreams and Aspirations	OK	OK	OK	NO
Current Life Situation	OK	OK	NO	NO
Support Network	OK	OK	NO	NO
Day and Night Support	OK	OK	NO	NO
Background Information	OK	OK	NO	NO
Diagnosis	OK	OK	OK	NO
Medication	OK	OK	NO	NO
Brief Medication History	OK	OK	NO	NO
Results	OK	OK	NO	NO
Comments	OK	OK	NO	NO
Physical Health	OK	OK	NO	NO
Mental and Emotional Health	OK	OK	NO	NO
Behaviour	OK	OK	NO	NO
Health and Support Services	OK	OK	NO	NO

Applying Knowledge, General Tasks and Demands	OK	OK	NO	NO
Communication	OK	OK	NO	NO
Self Care & Domestic Life	OK	OK	NO	NO
Mobility	OK	OK	NO	NO
Interpersonal Interactions and Relationships	OK	OK	NO	NO
Life Long Learning	OK	OK	NO	NO
Community, Social and Civic Life	OK	OK	NO	NO
Follow Up	OK	OK	NO	NO
My Friends	OK	OK	OK	NO
Documents	OK	OK	NO	NO

**Table 7.4:** Access rights to a profile of a person with disabilities

As mentioned above, the table shows the default access rights. However, it is possible to change access rights for any role and any section at any time.

### 7.1.2.2 Creating and editing a profile for a family member or friend

Family member or friends of the person with disabilities have the opportunity to create and edit a profile as well. This profile does not contain the same information as a profile of a person with disabilities. It contains the following sections:

Section	Description
Name	Name of the person.
Age	Age of the person.
Picture	Picture of the person.
Location	Location of the person.
Status Message	Free form status message.
Status Emoticon	Status emoticons symbolizing current mood.
<b>About Me</b>	

Relationship Status	Is it a father, mother, brother, sister, friend, etc. to the person with disabilities.
Free form biography	Biography of the person
<b>Comments</b>	
Comments	Public comments from other users.
<b>My Friends</b>	
My Friends	Listing of all friends in the I-CAN system.

Table 7.5: The Profile of a family/friend user

The default access rights for other users are shown in the table below and can be customised at any time:

Profile Information	Visible for			
	Manager/ Staff	Person with disabilities P1 – P3	Other users (Friends)	Other users (not in friends list)
Name	OK	OK	OK	OK
Age	OK	OK	OK	OK
Picture	OK	OK	OK	OK
Location	OK	OK	OK	NO
Status Message	OK	OK	OK	OK
Status Emoticon	OK	OK	OK	OK
About Me	OK	OK	OK	OK
Relationship Status	OK	OK	OK	OK
Free form biography	OK	OK	OK	NO
Comments	OK	OK	OK	NO
My Friends	OK	OK	OK	OK

Table 7.6: Access rights to the profile of a family/friend

### 7.1.2.3 Creating and editing a profile for the manager or the staff of the support service

The staff of the support service can create and edit a profile as well. Their profile contains the following sections:

Section	Description
<b>About Me</b>	
Name	Name of the person.
Age	Age of the person.
Picture	Picture of the person.
Location	Location of the person.
Status Message	Free form status message.
Status Emoticon	Status emoticons symbolizing current mood.
<b>About Me</b>	
Employer Name	Name of the Employer.
Position	Position within company.
Free form biography	Biography of staff.
<b>Comments</b>	
Comments	Comments from other users.
<b>Professional Experience</b>	
Professional Education	History of professional education.
Experience	History of professional experience.
Special areas of interest	The special area of interest.
<b>My Friends</b>	
My Friends	Listing of all friends in the I-CAN system.

**Table 7.7:** The profile of a manager/staff user.

The default access rights for other users are shown in the table below and can be customised at any time:

Profile Information	Visible for			
	Person with disabilities P1 – P3	Family/ Friends	Other users (Friends)	Other users (not in friends list)
Name	OK	OK	OK	OK
Age	OK	OK	OK	OK
Picture	OK	OK	OK	OK

Location	OK	OK	OK	NO
Status Message	OK	OK	OK	OK
Status Emoticon	OK	OK	OK	OK
Employer Name	OK	OK	OK	NO
Position	OK	OK	OK	NO
Free form biography	OK	OK	OK	NO
Comments	OK	OK	OK	OK
Professional Education	OK	OK	OK	NO
Experience	OK	OK	OK	NO
Special areas of interest	OK	OK	OK	OK
My Friends	OK	OK	OK	OK

**Table 7.8:** Access rights to the profile of a manager/staff user.

### 7.1.3 Adding Friends

A function of the new tool is to add friends to the profile. Basically every user can become friends with any other user. So for example, support staff can add other support staffs to their friends and share their experiences. Persons with disabilities can add their fellow persons to their friends, or family members can add other family members and share information about their experiences with their relatives.

When a user adds another user to his friends, an email is sent to the others users e-mail address. The receiver can then accept the friend request or deny it.

However, for users P4 it is not possible to add friends to their friends list. In this case, an email is sent to the responsible manager and the manager decides if this person can become friend and see the profile.

### 7.1.4 Sending of Messages

Messages can be sent as public (via the Comments section) and private. Users can send any other users messages, public and private (except user P3 and P4). The

public messages can be entered and sent in the Comments section of the receiver profile. Private messages can be sent as well and can only be seen by the sender and receiver, nobody else. After the message was sent, the receiver receives an e-mail in his inbox stating that he got a new message from a user in I-CAN.

### 7.1.5 Forum

The social networking tool incorporates a forum as well. The forum can be used by any registered user except P3 and P4 users and offers a place for discussions of general interest and posting of news and helpful information. The forum is a private forum and it is not possible to read posts for unregistered users, therefore it is not visible for search engines as well.

The following table shows the categories and sub-categories of the forum:

Category	Sub-category	Description
General Discussion	News	Discussion about news of general interest, e.g. changes in law, etc.
	Activities/Events	Discussion about activities/events that are planned.
Nurses Board	General Discussion	Discussion about new regulations, news in health business, etc.
	Problems with patients	Nurses can post problems with patients, get treatment tips, etc.
Disability Board	Epilepsy	Discussion about Epilepsy.
	Depression	Discussion about Depression.
	...	More sub categories for different disabilities.
Support Group	General Discussion	Discussion Board for family members or friends.
	News/Activities/Events	News/Activities/Events that are interesting for family/friends.

Help	FAQ	Frequently asked Question about the tool.
	Technical problems	Postings of experienced technical problems.
	General Feedback	Postings about general feedback about the tool.

**Table 7.9:** Categories of the Forum.

Not every user has access to every section of the forum. The following table presents the access rights for the different categories:

Function	Manager	Staff	Family/ Friend	P1	P2	P3	P4
General Discussion	OK	OK	OK	OK	OK	OK	NO
Nurses Board	OK	OK	NO	NO	NO	NO	NO
Disability Board	OK	OK	OK	OK	OK	OK	NO
Support Group	OK	OK	OK	OK	OK	NO	NO
Help	OK	OK	OK	OK	OK	OK	NO

**Table 7.10:** Access rights to the Forum

### 7.1.6 Search function

Users have the possibility to search for other users in the basic search (except P3 and P4). The advanced search feature enables users to search for other users based on criteria like name, age, location, goals and dreams, and diagnosis.

### 7.1.7 Status Messages

Status messages can be set as well. Users can write and change their current status anytime. To set a status message, the user can write the message in a textbox and save it with the push of the return button. Furthermore, statuses can be set visually by clicking on one of six available emoticons.

- Very happy
- Happy
- Little happy
- Little unhappy
- Unhappy
- Very unhappy

### **7.1.8 Give Feedback**

The “Give Feedback” feature is located right next from every section of any user’s profile P1 – P4. Here, all other users (except P2-P4) have the opportunity to give feedback about this particular section. For example, a family member could give feedback about the current status of his/her relative. If the family member notices changes in his relatives health, behaviour, condition, etc. he could write a feedback right next to the relevant section. After sending the feedback, the responsible manager gets an e-mail with the message and the details to the person and the section the feedback was sent. The manager can then reply to this feedback and/or delegate his staff to act accordingly. Staff members and users categorized P1 can send feedback messages as well.

### **7.1.9 Upload Documents**

Managers and P1 users can upload documents to the profile page of a P1 – P4 user as well. The manager for example can upload the discharge reports (older versions of it), service summaries, etc to the profile, while a P1 user, a person with disabilities that has full access to the system, can upload scanned documents like doctor reports, or other health related documents. The advantage is that all documents are then available in one central place, easy to access for the persons with access rights to it.



## **7.2 Prototype Design**

### **7.2.1 Design/implementation constraints**

The following ideals should be considered in design/implementation to ensure a quality product:

- The interface should be user friendly and easy to understand so that computer illiterate users and people with disabilities can use it easily.
- Data entry masks should recognize and correct improperly entered data.
- Confirmation notices should appear every time the user tries to enter, delete, or revise data.
- Web design conventions should be consistent throughout the whole website.
- Online help is important and should be available for all functions, accessible from any part of the website.
- Users may not be familiar with all processes involved, that is why the design should not assume that users will use the system as expected.
- The system design should follow the manual process as closely as possible.
- Potential users should be consulted throughout the design of the system.
- The system has to ensure the integrity of patient records at all times.
- I-CAN should have AJAX functionalities to improve the speed of the website.
- The I-CAN site should be hosted on a server that can provide adequate response time.
- The storage of the personal interaction items and associated records must be tamper proof and provide evidence of integrity checks to an external auditor.
- Restricted items must be stored in such a way that their contents are only viewable by authorized users.
- I-CAN must support different user access privileges and user privacy.
- All users must be authenticated by I-CAN before they can operate.
- The users must have a set of authorizations that limit their capacity to view personal records.

- I-CAN must be available 24 hours a day / 7 days a week. If there is an urgent maintenance down time, the users must be notified at least 24 hours in advance of the intended downtime.
- I-CAN must cater for concurrent usage and unlimited amount of users. It shall also be able to scale up to support more users at a time. System performance shall not degrade if up to fifty percent (50%) more users added.

### 7.2.2 The Design

The following screenshots should provide an insight of how the social networking feature could look like and how the requirements could be translated into the website. The screenshots do not contain links for “contact us”, “help”, “about us”, etc. Also screenshots for the forum is not available. The goal of the chapter/screenshots is to explain the social networking feature as this is the central part of the tool and a completely new approach/milestone for I-CAN

Figure 7.1 shows the profile of a person with disabilities (user P1, P2, P3, P4). It can be seen that the profile is separated into three parts. On top there is a navigation bar, the centre part shows the profile picture, the name, age, location and status messages. The lower part of the profile shows a tab bar with all the available information for the person. The navigation bar, and the centre part is for any user type the same. The lower part however, is different for the different user types. The profile of a family/friend user for example consists only of the tabs About Me, Comments, My Friends.

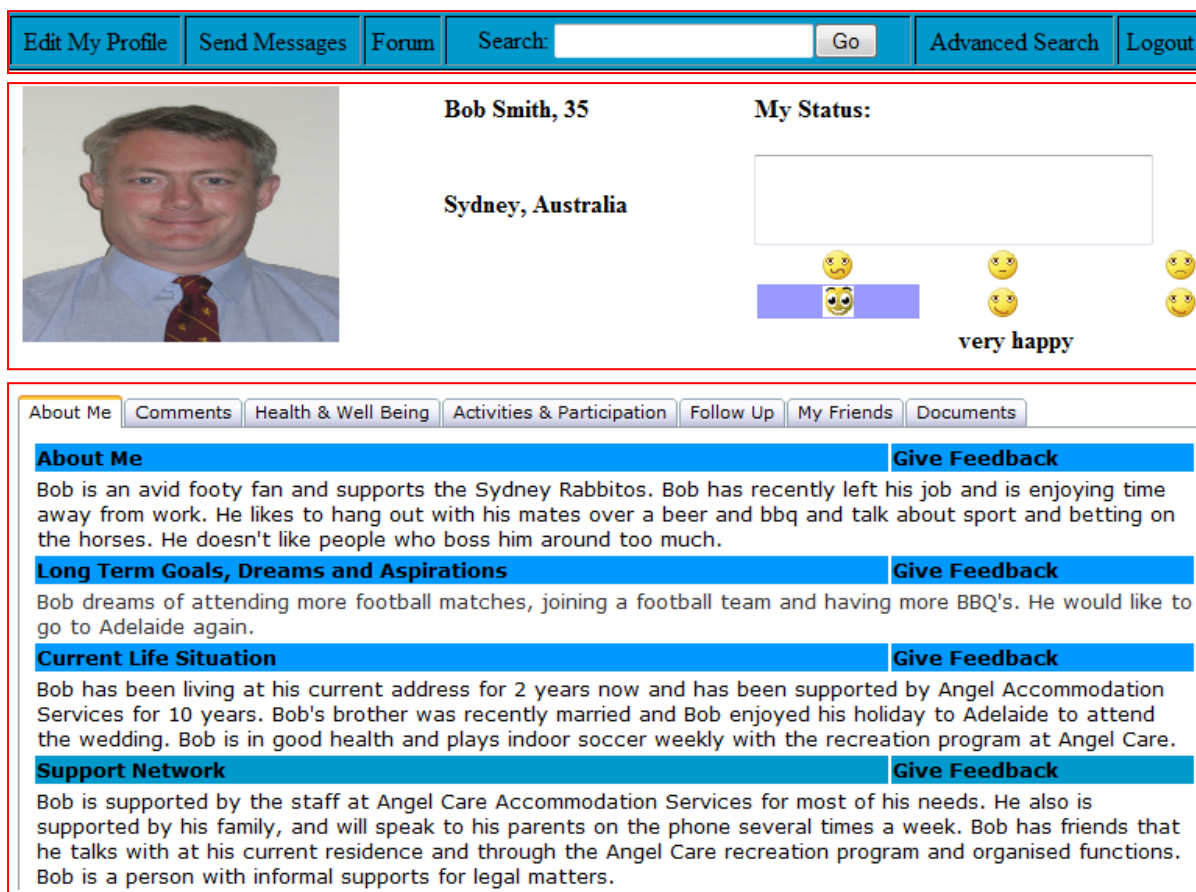


Figure 7.1: The profile of a person in I-CAN 5.0

### 7.2.2.1 The Navigation bar



Figure 7.2: The navigation bar of I-CAN 5.0

The navigation bar (Figure 7.2) is separated into the following categories:

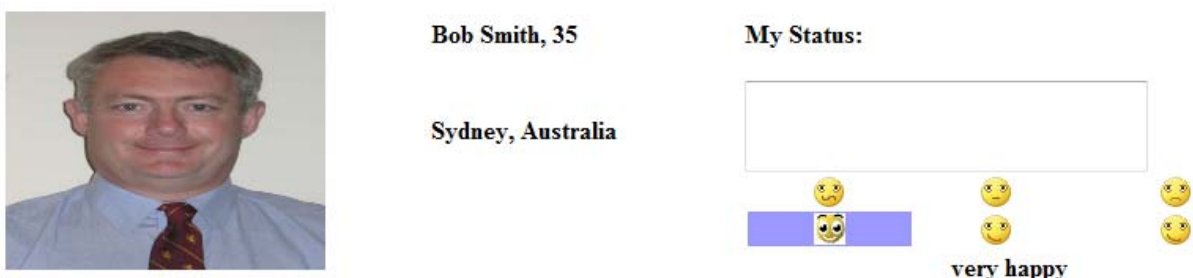
- **Edit My Profile:** Here, the user can edit his/her profile and change his information. For users P1, P2, P3, and P4 this navigation button should be deactivated as they are categorized as not (intellectually/physically) able to do this.
- **Send Messages:** The Send Messages function allows users to send private messages to any member of I-CAN. By pushing the button, a new screen appear where the user can choose the receiver, enter the topic, and type the

actual message to the receiver. For P3 and P4 users, this function should be deactivated.

- **Forum:** Leads to the discussion board of I-CAN. For P3 and P4 user this function should be disabled as well.
- **Search:** The search function consists of a textbox and a button. The user (except P3 and P4) can look for other users based on their names. As a result, the search results are listed in a new screen and the user can navigate through them.
- **Advanced Search:** The advanced search feature open a new screen where the user can look for fellow users based on the criteria name, age, location, goals and dreams, and diagnosis. P3 and P4 users are excluded from this function as well.
- **Logout:** The logout button logs out the user and leads him back to the I-CAN start page.

### 7.2.2.2 The Centre part

The centre part of the profile consists of the profile picture, the name, age, and the location of the person. Furthermore, the user can change his status either in free form with the textbox, or by clicking on one of the emoticons. Except P4 users, all other users can change their status as they wish at any time.



**Figure 7.3:** The Centre part of the profile of I-CAN 5.0

### 7.2.2.3 The Tab bar

The tabs About Me, Health & Well Being, Activities & Participation contain all the information from the discharge report. They all have the same design features. For the users P1, P2, P3, and P4 these tabs are filled out automatically when creating the profile. Other users have to fill out the tab About Me by themselves (Health & Well Being, and Activities & Participation are not available for them).

When clicking on one of the Give Feedback links, a new screen appears and the user can write feedback about the particular category. The responsible manager of the support service will get an e-mail and then eventually change the information in this category.


Category	Status
<b>Physical Health</b>	<a href="#">Give Feedback</a>
<b>epilepsy or seizures</b>	Daily Managed
Please see Bob's epilepsy management plan. Bob's epilepsy is well controlled with medication and he has not had a seizure for over 2 years. He requires 6 monthly review with a neurologist.	
<b>vision or eye problem</b>	Occasional Minor
Bob has a vision problem but can see well with his glasses on. Every year Bob has his vision checked and occasionally needs prompting to clean his glasses.	
<b>weight problem</b>	Daily Minor
is over weight and gets less exercise now that he doesn't travel to work each day. Our goal is for Bob to lose about 5-10kg. He enjoys sports and other activities if he has the opportunity. Bob requires staff to monitor his diet and ensure when he is cooking that appropriate amounts of oil and butter are used, and that he packs a sensible lunch and doesn't buy too much junk food when in the community.	
<b>nails</b>	Occasional Minor
Bob attends a podiatrist for nail care with support once every two months.	
<b>Mental and Emotional Health</b>	<a href="#">Give Feedback</a>
<b>depression</b>	Daily Moderate
Bob requires emotional support from staff, such as encouragement, praise and someone to talk to. He can become confused or upset by minor things and want to talk to staff about it. He often looks to staff for direction on what to do and should be encouraged to find positive activities he can complete at home or engage in physical activities. Our goal is to find three new interesting activities for Bob to do while at home. Bob takes anti-depressant medication that is reviewed by a psychiatrist every six months.	

Figure 7.4: The Health & Well Being tab in I-CAN 5.0


The Comments tab (Figure 7.5) is available for any user and offers a place to write comments to the profile. The textbox offers enough space to enter a message to the other user. After pushing the “Send Comment” button, the comment appear right under the textbox and the receiver gets an e-mail saying he has a new comment on his profile. The buttons “Answer” allow the user to write a comment on the sender’s profile. The “Delete this Comment” deletes the comment from the profile.

Navigation tabs: About Me, **Comments**, Health & Well Being, Activities & Participation, Follow Up, My Friends, Documents

Send Comment

 Hi Bob,  
I notice you have had a tube for about 8 months. I'm having difficulty eating, so the neurologist suggested I look into getting one. My meeting with the gastroenterologist did not leave me with desire to get one. It would help me if you would send me a message about your experience, pro and con, with your feeding tube.

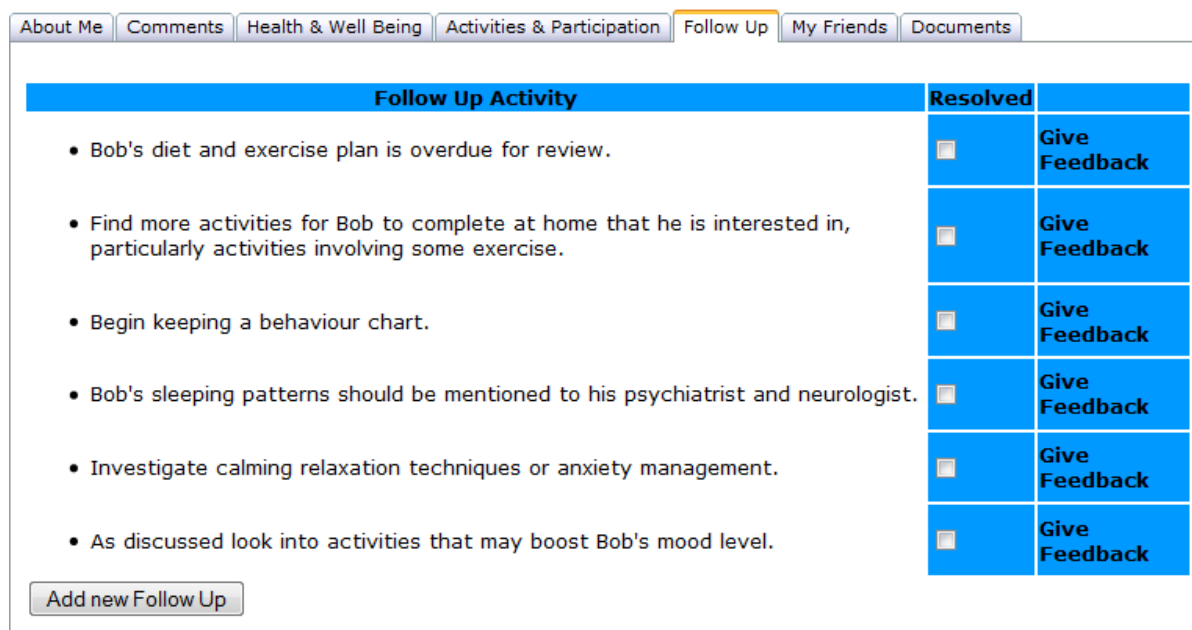
[Stephan Rupert](#)

 Hi Bob,  
I noticed that you are using Medicine XY and you believe it is helping your progression. I'm very interested in this. Can you tell me more about how it's working for you?

[Cynthia Smith](#)

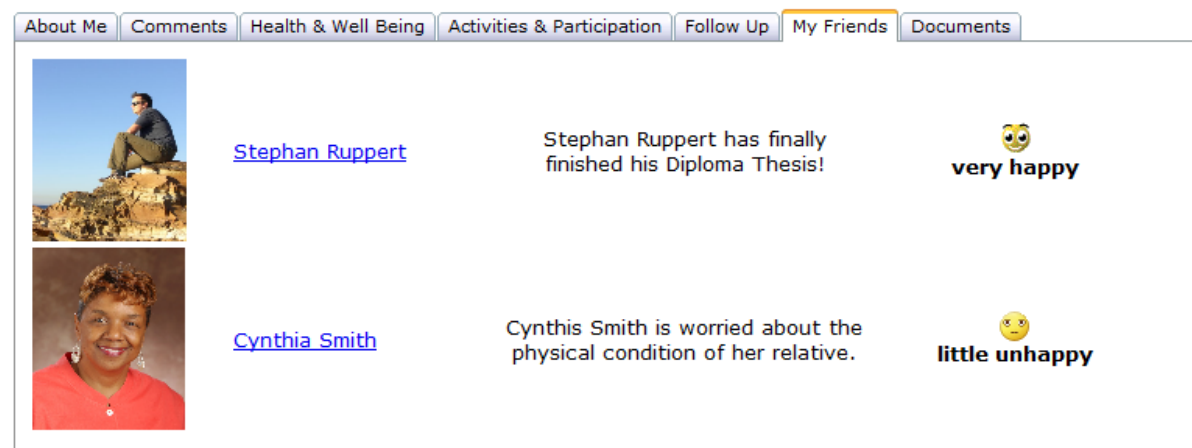
**Figure 7.5:** The Comments tab in I-CAN 5.0

The Follow Up tab (Figure 7.6) is created automatically for every user P1, P2, P3, and P4 as well and only in their profiles available. This tab shows all Follow Up activities that are planned for this person and represent a kind of “to do” list. When an activity is “done” and no more necessary, the manager, staff, or family/friend user can activate the checkbox. The responsible manager gets a message to confirm this and if the manager confirms, the follow up activity disappears from the list. The “Give Feedback is available in this tab as well.



**Figure 7.6:** The Follow Up tab in I-CAN 5.0

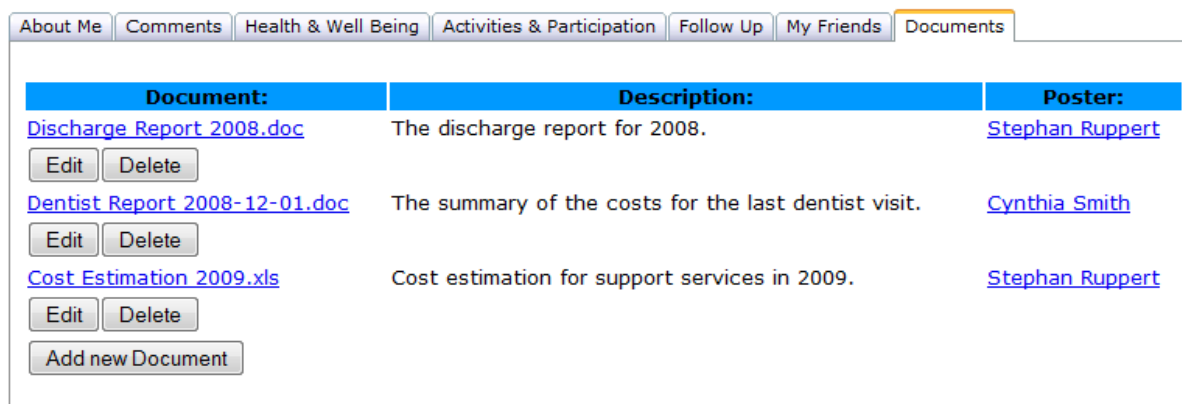
The My Friends tab (Figure 7.7) lists all the friends this user has in its system. Beside the profile pic, and the name of the friend, the user can see the current status of his friend as well.



**Figure 7.7:** The My Friends tab in I-CAN 5.0

In the Documents tab (Figure 7.8), the user can save their important documents about the person. The document name can be seen on the left side. By clicking on the name, the document opens in a new window. It is also possible to edit the document. Here, the document opens in a new window and the changes done in it will be saved and the file is updated. The “Delete” button deletes the file. There is

also a description available for any document stating what the content of the file is, and the person who posted the file is shown on the right side of the screen.



**Figure 7.8:** The Documents tab in I-CAN 5.0

### 7.3 Discussion

One of the biggest problems with a social networking feature like introduced above is the privacy issue. Even though the participation is on a completely unsolicited basis, there are access and privacy issues involved in such a tool. Who can see which information? What does it mean when a person can see information that he should not see. Especially in the health sector, this is a much discussed topic. The question is, how I-CAN can set up access and privacy rules to prevent any problems? The access rights in chapter 7.1 are a good solution to cope with this problem. The default rights are very strict, but it is possible to change access rights for users at any time. It could be for example the case that a person with disabilities has unresolved issues with one of his family member and does not want to grant him any more access to his profile. Or the other case could be that the person with disabilities wants to share more information with people he does not know. In both cases, I-CAN must have the option to grant/deny access for any user at any time.

A special situation is given for I-CAN as well. Only about 10% of the current people supported with I-CAN are able to use a computer. Why should I-CAN create a social networking tool so that the disabled persons can connect with each other? How big is the success of such a system and is it worth to proceed with the development? P4



users for example are categorized as not able to use a computer and have therefore no access to the system, while a P3 user has at least basic computer skills. P2 users are considered able to use a computer but have some limitations in the system because of their behaviour, attitude, etc., while only P1 users have full access to the system and are able to fully benefit from it.

The benefit from such a tool is mainly for the support services and the family members/friends of persons with disabilities. They can have access to all the information and keep up to date with changes in their relatives' situation. They can share information with other relatives in the forum and do not feel alone in their situation. The support services of course benefit from the feedback they get from the family/friends and can react quicker and provide better services.

Another aspect that should be considered before the start of the development is how to attract family member or friends and support services to use a system like this and keep using it over time. How big is the interest of, for example, family members to participate? How big is the interest for the staff of the support services? How much time per day can they sacrifice to look at all their e-mails and to answer them. There could be a problem of resistance at the staff of support services to use the system. It is therefore necessary to point out the extra benefit of these tools.


From a business perspective, the development of such a tool would be a great idea. The publicity that the launch of this site could get would be very beneficial for the Centre for Disability Studies and would attract more customers for the system. The development, of course, would need investments, but in the end I-CAN would be attractive for more potential customers and would be a beneficial investment.

### 8.0 Conclusion

The development from Web 1.0 to Web 2.0 brought many new possibilities, even though many elements of Web 2.0 are actually no new phenomenon. User can not just generate content; but social networks create completely new markets as well. In this thesis we looked at the development of Web 2.0 and pointed out the advantages of this approach to both the consumer and the companies offering these services. Medicine 2.0 is an application of Web 2.0 and can be described as Web 2.0 technologies combined with e-health. Despite the issues with Medicine 2.0 like privacy issues, information inaccuracy, loss of control over information, etc. it is the approach of the future in the health sector.

The Centre for Disability Studies, the creator of I-CAN, wants to benefit from Medicine 2.0 too, and is looking for options to extend their current system and implement Web 2.0 features. In chapter 4 and 5 we introduced Medicine 2.0 and currently available applications. We concluded that the Second Life, Medical Wiki, Medical Search Engines, Medical Blogs and Blog Carnivals, as well as Medical Podcasts and Videocasts approach are not the best option for I-CAN to start with. The best solution would be a combination of social networking tool, user based site, and/or community. The design proposal introduced in chapter 7 combines all these approaches and would be a great feature for I-CAN. However, the disadvantages of such an approach are also obvious and have to be taken into account as well. The next steps for the CDS would now be to do surveys at their current customers and ask them about their willingness to participate into a social networking feature introduced in chapter 7. Depending on the results of these surveys and the available funds, the development of I-CAN 5.0 could start.

# Appendix A




**CDDS**

Centre for  
Developmental  
Disability  
Studies

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## I-CAN Individual Support Needs Report



**Name:** Bob 'De-Identified' Lawson

**Address:** 15 Smith St,  
Wentworthville, NSW 2150

**Phone:** 9643 4567

**Mobile Phone:** 0414 745 243

**DOB:** 07-08-1972

**Age:** 35 years

**Date of Interview:** 30-01-2008

**Participants:** Judy (mother), William (Support staff)

**Facilitator:** Samuel Arnold

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**Reason for Assessment**

Bob is participating in his annual person-centred support planning and review process.

**About Me**

Bob is an avid footy fan and supports the Sydney Rabbits. Bob has recently left his job and is enjoying time away from work. He likes to hang out with his mates over a beer and bbq and talk about sport and betting on the horses. He doesn't like people who boss him around too much.

**Long Term Goals, Dreams and Aspirations**

Bob dreams of attending more football matches, joining a football team and having more BBQ's. He would like to go to Adelaide again.

**Current Life Situation**

Bob has been living at his current address for 2 years now and has been supported by Angel Accommodation Services for 10 years. Bob's brother was recently married and Bob enjoyed his holiday to Adelaide to attend the wedding. Bob is in good health and plays indoor soccer weekly with the recreation program at Angel Care.

**Support Network**

Bob is supported by the staff at Angel Care Accommodation Services for most of his needs. He also is supported by his family, and will speak to his parents on the phone several times a week. Bob has friends that he talks with at his current residence and through the Angel Care recreation program and organised functions.

Bob is a person with informal supports for legal matters.

**Day and Night Support**

Bob currently receives 4 hours of formal support per day, informal support during the week and passive night support. People involved in this assessment estimated that Bob requires the same amount of formal and informal day support as currently received although he does not require support at night. Bob may be left unsupported for up to 6 hours. His support network was described as consistent and stable.

**Background Information**

Bob currently lives with three other people in a domestic scale supported living setting at Smith St. Bob has never married or been in a defacto relationship. Bob participates in a recreation

program at Angel Care Accommodation Service. His primary source of income is the Disability Support Pension. Bob was born in Australia and is of Australian descent. Bob completes less than two and a half hours of moderate intensity physical activity each week, physical activities he participates in include walking to the shops, bus stop and indoor soccer.

**Diagnosis**

Intellectual Disability with Extensive Support Needs

Epilepsy

Mild Cerebral Palsy

Vision: Bob's vision is corrected by prescription glasses which he wears most of the time.

Depression

**Medication current as at 30-01-2008**

Bob has no known allergies

**Epilim** - 800mg

**Frequency** Bedtime: 1

**Appearance:** Large round light purple tablet **Route:** Topical (eg. cream)

**Reason for:** Epilepsy

**Prescribing Dr:** Dr Jordan **Data Prescribed:** 10-01-2007 **Review Date:** 10-07-2008

**Zoloft** - 50mg

**Frequency** Breakfast: 1

**Appearance:** Small yellow oval scored tablet **Route:** Oral

**Reason for:** Depression

**Prescribing Dr:** Dr Lanley **Data Prescribed:** 10-12-2007 **Review Date:** 10-06-2008

**Medication Procedure**

Bob takes medication from a webster pack with supervision.

**Brief Medication History**

Bob has been taking only Epilim and has recently been started on Zoloft. He has been on Haliperidol previously, this made him very lethargic and subdued.

**Assessment Observations**

Bob attended for the full assessment and participated partially.

**Test Description**

The Instrument for Classification and Assessment of Support Needs (I-CAN) (Llewellyn, Parmenter, Chan, Riches, Hindmarsh & Arnold, 2007) is designed to assess, classify and describe support needs conceptually based on the ICF framework. For further information and psychometric properties please see [www.i-can.org.au](http://www.i-can.org.au)

**Results**

**Statistical Summary**

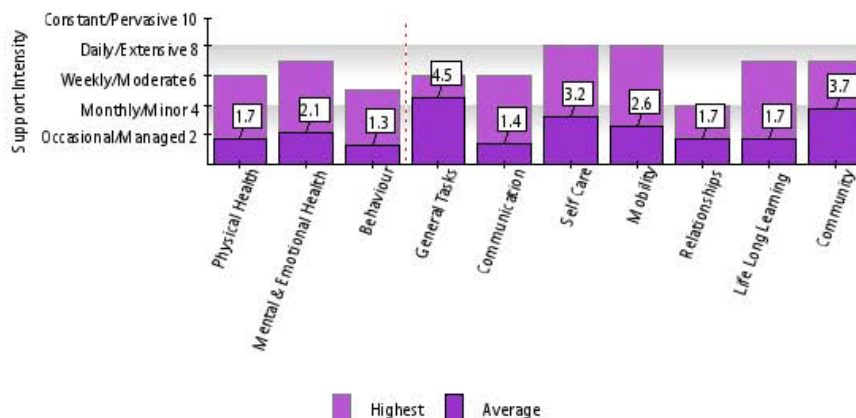


Figure 1: Highest and Average Support Intensity

Raw Scores	
Health & Well-Being total	Activities & Participation total
55/260	117/340

Rating Scales		
Frequency of Support	Level of Support	Combined Support Intensity
5 Constant	5 Pervasive	10 Constant/Pervasive
4 Daily	4 Extensive	8 Daily/Extensive
3 Weekly	3 Moderate	6 Weekly/Moderate
2 Monthly	2 Minor	4 Monthly/Minor
1 Occasionally	1 Managed	2 Occasional/Managed
0 Never	0 No Support	0 No Support

Questions in the I-CAN are rated using two 0-5 point scales. The Frequency of Support required asks how often support is needed. The Level of Support required asks how much support is required. These two scales are added to give a 0-10 Combined Support Intensity scale. Figure 1 shows the average support intensity within each domain in the darker shade. The highest support intensity gained on any item is also displayed in the lighter shade.

On this assessment the domain with the highest support intensity on average is Applying Knowledge, General Tasks & Demands. The data represented here is yet to be normalised and may be reanalysed online once normative data are available.

### Support Needs Breakdown - Health & Well Being

#### Physical Health

##### epilepsy or seizures

Daily  
Managed

Please see Bob's epilepsy management plan. Bob's epilepsy is well controlled with medication and he has not had a seizure for over 2 years. He requires 6 monthly review with a neurologist.

##### vision or eye problem

Occasional  
Minor

Bob has a vision problem but can see well with his glasses on. Every year Bob has his vision checked and occasionally needs prompting to clean his glasses.

##### weight problem

Daily  
Minor

Bob is over weight and gets less exercise now that he doesn't travel to work each day. Our goal is for Bob to lose about 5-10kg. He enjoys sports and other activities if he has the opportunity. Bob requires staff to monitor his diet and ensure when he is cooking that appropriate amounts of oil and butter are used, and that he packs a sensible lunch and doesn't buy too much junk food when in the community.

##### nails

Occasional  
Moderate

Bob attends a podiatrist for nail care with support once every two months.

#### Mental and Emotional Health

##### depression

Daily  
Moderate

Bob requires emotional support from staff, such as encouragement, praise and someone to talk to. He can become confused or upset by minor things and want to talk to staff about it. He often looks to staff for direction on what to do and should be encouraged to find positive activities he can complete at home or engage in physical activities. Our goal is to find three new interesting activities for Bob to do while at home. Bob takes anti-depressant medication that is reviewed by a psychiatrist every six months.

##### frustration / agitation, emotional outbursts

Monthly  
Moderate

Approximately monthly Bob's emotions become quite intense, either becoming very upset and crying or becoming angry and frustrated. It doesn't help if people boss him around. When Bob becomes emotionally tense staff should talk with Bob, if he wants, to see if they can help him sort out any of his problems or suggest activities that might make him feel better.

##### hoarding / stealing food

Weekly  
Moderate

Bob often hoards junk food in his room and may leave crumbs and mess about. Bob cleans his room each Sunday with prompting, supervision and some assistance. Bob should be encouraged to eat healthy foods given his growing weight problem.



<b>waking early</b>	Weekly Minor
Bob often wakes very early and may need sleep over staff to ask him to return to bed if it is earlier than about 6:00am	
<b>panic attacks, phobia / fears</b>	Monthly Moderate
Approximately monthly Bob will have a panic attack. Common triggers include crowds, small enclosed spaces and loud noises. During a panic attack staff will need to provide close supervision for Bob and reassurance. Bob can calm down easily by moving to a new location. Our goals is to reduce the frequency and severity of Bob's panic attacks by developing a desensitization program.	
<b>Behaviour</b>	
<b>repetitive behaviour</b>	Monthly Minor
Bob can become repetitive in his conversations with staff if he becomes focused on one topic or event. Staff can find this annoying at times, and after discussing the topic with Bob if he raises it again suggest an alternative activity or tell Bob that you have already discussed this topic with him.	
<b>verbally abuses others</b>	Monthly Moderate
Bob can become verbally abusive to staff during an emotional outburst. During these times if Bob does not want to calm down or if Bob is particularly targeting one staff member it may be best to leave him for one to two hours and then readdress the issue Bob was upset by.	
<b>Health and Support Services</b>	
<b>GP</b>	Monthly
Bob sees a GP primarily for an annual checkup, prescriptions or if he catches a virus.	
<b>Dental</b>	Occasional
Bob sees a Dentist every six months, this can be quite distressful for him and though he is ok with some reassurance from support staff.	
<b>Psychiatric</b>	Occasional
Bob is reviewed 6 monthly by his psychiatrist for anti-depressant medications	
<b>Neurology</b>	Occasional
Bob sees a neurologist 6 monthly to review his epilepsy medication	
<b>Podiatry</b>	Occasional
Bob attends a podiatrist every two months with support.	
<b>Optometry</b>	Occasional
Bob annually has his vision and glasses checked by an Optometrist	
<b>Direct Support Staff (e.g. Educator, Carer)</b>	Daily
Bob receives daily support from direct support staff.	
<b>House Manager / Team Leader</b>	Weekly
Bob has a good relationship with his team leader.	
<b>Accommodation</b>	Daily
Bob lives in a community group home setting.	
<b>Life Skills program</b>	Weekly
Bob attends a life skills program run by Angel Care a few days each week. Last semester he participated in the indoor soccer, tours by public transport and relaxation groups.	
<b>Support Needs Breakdown - Activities &amp; Participation</b>	
<b>Applying Knowledge, General Tasks and Demands</b>	
<b>undertake daily routines, memory for daily activities, learn new tasks, carry out directions</b>	Weekly Moderate
Bob is able to complete many daily activities though for some tasks he needs reminding, prompting, direction to complete. He learns new things well, and currently has a weekly training program to improve the cleanliness of his room and to wash properly with shampoo and conditioner. Bob learned several ADL's effectively over the last few years.	
<b>solve simple and complex problems, makes choices and decisions, insight</b>	Weekly Moderate
Bob often requires support to make decisions or solve problems. Family help with big decisions.	
<b>reading, writing, calculating</b>	Weekly Moderate

Bob can read simple sentences and has poor numeracy and money skills.

**risk of abuse, handle stress and crises, safety, safety in crowds** Weekly Moderate

Bob is generally safety aware. Bob can become quite upset and hysterical if something triggers a panic attack, as can happen when he is crowds. Investigate anxiety management.

**Communication**

**discuss events, engage in conversation, phone, computer** Weekly Moderate

Bob loves to chat and can require prompting or assistance with his conversations. He can also become focused on one topic and need reminding that the topic has already been discussed. Bob can use the telephone with support to dial the number. Bob does not have many computer skills, though does enjoy a few xbox games.

**Self Care & Domestic Life**

**shower** Weekly Moderate

Bob is independent with most hygiene and grooming activities. Bob is learning to shampoo his hair properly. Our goal is for Bob to be independent in shampooing his hair thoroughly in 2 months. Staff support him on the weekends only with a showering / shampoo program.

**medication management** Daily Extensive

Bob requires daily assistance to administer medication

**prepare simple meals, main meals** Weekly Minor

Bob can cook several meals although is not completely independent and requires some assistance and supervision. Bob is on a cooking roster where he cooks for the entire house twice a week. Bob likes to learn new meals and requires several training sessions to master a new recipe.

**cleaning, use home appliances safely, household maintenance** Daily Minor

Bob requires reminders to complete regular cleaning activities, and some supervision when using electric appliances.

**Mobility**

**arm and hand use** Occasional Moderate

Bob has some minor difficulties due to mild contractures of his hands.

**use public and private transport, use a motor vehicle** Daily Extensive

Bob can catch public transport with travel training for specific routes. Bob requires a staff person to drive him to the recreation program or activities on most days. Bob would like to start catching a bus to Tuesday woodwork.

**Interpersonal Interactions and Relationships**

**general social courtesies, offer help, taking turns, assertion** Occasional Minor

Bob generally follows social courtesies though occasionally requires prompting. Bob sometimes needs support to assert himself if he becomes anxious in a social setting.

**manage relationships** Monthly Minor

Bob can become focused or distressed about particular relationships and may require emotional support from staff.

**handle jokes, control temper and frustration** Occasional Minor

Bob generally handles jokes well and controls his temper though occasionally requires emotional support form staff

**Life Long Learning**

**choose life long learning options** Occasional Minor

Bob attends a recreation come and try day every six months where he is supported to make decisions regarding what recreation activities he would like to participate in.

**transport** Daily  
Moderate

Bob is currently driven on most days to and from his recreation program by staff

**Community, Social and Civic Life**

**make minor purchases, count change, maintain bank account, budget, risk of financial exploitation, use government services** Weekly  
Extensive

Bob knows to wait for change and can make purchases with minor support and supervision from staff. Our support goal is to help Bob not to spend too much money on junk food and encourage healthy options. Bob has difficulty counting money. All other financial matters are managed by staff and family. Bob is supported to the bank every week to withdraw spending and bill money.

**time management** Daily  
Minor

Bob requires daily prompting to remind him what is on today and to get his day started. Bob understands concepts such as lunch, morning etc. though has difficulty telling the time.

**access community, engage in community life** Daily  
Minor

Bob can access local shops independently and access the community with minor support and supervision, particularly when spending money.

**engage in recreation activities** Daily  
Moderate

Bob enjoys recreation and leisure activities. He requires daily support to access his recreation program.

**engage in spiritual or religious activities** Monthly  
Minor

Bob likes to attend the local church with his housemates most Sundays, ask Bob if he would like to join in.

**political and civic life** Never  
No Support

Bob does not vote or engage in civic life activities.

**Identified Follow-up**

- Bob's diet and exercise plan is overdue for review.
- Find more activities for Bob to complete at home that he is interested in, particularly activities involving some exercise. Support Bob to slowly overcome fears of crowds so he can get more enjoyment from attending football matches - possibly develop desensitization program.
- Begin keeping a behaviour chart.
- Bob's sleeping patterns should be mentioned to his psychiatrist and neurologist.
- Investigate calming relaxation techniques or anxiety management.
- As discussed look into activities that may boost Bob's mood levels.
- Continue with and expand on training programs for ADL's.
- Investigate if Bob is interested in money skills or literacy programs at home or at TAFE.
- Bob would be more independent if he caught public transport to his recreation program, travel training to be investigated.
- Bob could possibly be trained to count change and recognize money better.
- Bob may benefit from a visual diary or support to maintain his own written diary. This could also be a literacy training exercise.



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