

A Pilot Project Exploring the Feasibility of Enlisting Health Information & Support  
Networks to Enable Health Information Seekers, Using Semantic Web Middleware

By

Jesse William Gardner,  
MLIS, University of British Columbia, 2006  
BSc, University of Victoria, 2010

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

MASTER OF SCIENCE

In the School of Health Information Science

© Jesse William Gardner, 2019  
University of Victoria

All rights reserved. This thesis may not be reproduced in whole or in part, by photocopy  
or other means, without the permission of the author.

A Pilot Project Exploring the Feasibility of Enlisting Health Information & Support  
Networks to Enable Health Information Seekers, Using Semantic Web Middleware

by

Jesse William Gardner,  
MLIS, University of British Columbia, 2006  
BSc, University of Victoria, 2010

## **Supervisory Committee**

Alex Mu-Hsing Kuo (School of Health Information Science)  
**Supervisor**

Andre Kushniruk (School of Health Information Science)  
**Departmental Member**

## Abstract

### Supervisory Committee

Alex Mu-Hsing Kuo (School of Health Information Science)

Supervisor

Andre Kushniruk (School of Health Information Science)

Departmental Member

My Thesis posits a novel method of utilizing emerging web semantics, through HTML5 markup; to improve experience of Health Information seekers through a framework for creating functional, tailored Health Information Resource Collections potentially hosted by their own Health Information Support Networks; and based upon long-standing principles of online Information Retrieval. Most such organizations have websites, with links to useful Resources. This research exemplifies how to design and to present the Resource *Collections* as pathfinders to existing online Health Information, adding context to each link, to directly address the needs of each community served. The research appeals to a Needs Analysis process rooted in Everyday Life Information Seeking research methodologies, especially Participatory Action Research. As a pilot project, the Needs Analysis focuses necessarily on the Spina Bifida & Hydrocephalus community – with which the author of the Thesis is intimately familiar as a person living with Hydrocephalus, making the choice of a Participatory Action Research framework ideal – and enlisted just one National (Canada) and one Regional (British Columbia) Association for the same rationale. Results of the Needs Analysis were used to identify necessary Resources, but also to select familiar web tools and technologies for design of the Resource Collection and Resource Cards. At completion, there is a functional Collection of Spina Bifida & Hydrocephalus Resources for researchers, caregivers, or patients with Spina Bifida and/or Hydrocephalus – not limited to members of any organization, but best suited by design to the two through which analysis was done.

## Table of Contents

Supervisory Committee .....	ii
Abstract.....	iii
Table of Contents.....	iv
List of Tables .....	vi
List of Figures .....	vii
Acknowledgments & Dedication .....	viii
Chapter 1: Introduction .....	1
Implementing a Resource Collection as Response to User Needs .....	2
A Brief Introduction to the Problem Area: Spina Bifida & Hydrocephalus.....	3
Resource Collection as Solution to Wider Problem Domain .....	8
Thesis Question.....	10
Chapter 2: Methods.....	12
Data Collection Methodology – Needs Analysis.....	13
Confirmation of Data Source .....	13
Participatory Action Research (PAR).....	14
Everyday Life Information Seeking .....	18
Implementation Process.....	24
Data Collection.....	28
Technical Methodology – Resource Collection .....	28
Metadata Standards .....	28
Semantics & the Medical Web.....	34
Chapter 3: Results.....	41
Demographic Data .....	42
Questions Which Establish Respondent’s Reason for Membership .....	44
Questions Concerning Information-Seeking Behaviour .....	47
Questions Concerning Information-Seeking & Formats.....	52
General Information Seeking Habits.....	53
Consulted Information Resources (Print, Electronic, or Human) .....	58
Questions Concerning Information-Seeking Experience .....	61
Chapter 4: The Resource Collection.....	74
Implementation Process for the Resource Collection .....	74
Established a Resource Collection Interface.....	74
Added a Feedback Feature .....	76
Established Resource Categories.....	77
Populated the Resource Collection with Resource Cards .....	79
Used the <i>tags</i> feature to cross-reference Resource Cards.....	82
Out of Scope: Link members of Associations to the Resource Collection.....	84
Out of Scope: Assess Response to the Resource Collection.....	84
Chapter 5: Discussion and Conclusion .....	86
Expected Contributions .....	86
Research Constraints and Limitations .....	87

Future Directions .....	88
Approaching the Wider Problem Domain .....	88
Collecting More Survey Data to Improve Reliability.....	89
Automated Acquisition & Inclusion of New Resources .....	89
Conclusion.....	90
Bibliography .....	93
Appendices.....	100
Letters to the Associations seeking Participation.....	100
Responses from Associations Confirming Participation .....	104
Letters of Information for Implied Consent.....	106
Surveys .....	108
Ethical Approval Form.....	123

## List of Tables

Table 1: Chapter 1 Summary .....	1
Table 2: Chapter 2 Summary .....	12
Table 3: Use of Ethical Approval Period.....	28
Table 4: Key Concepts of RDA.....	31
Table 5: WEMI Principle for defining RDA fields.....	32
Table 6: An RDA formatted Record Template for Web Resources.....	33
Table 7: Chapter 3 Summary .....	41
Table 8: Demographic Data Sources.....	42
Table 9: Analysis of Demographic Data .....	42
Table 10: Analysis of Demographic Data Regrouped .....	43
Table 11: Questions which Establish Respondent’s Reason for Membership .....	44
Table 12: Analysis of Membership Rationale .....	45
Table 13: Questions Concerning Information Seeking Behaviour .....	47
Table 14: Analysis of Information-Seeking Behaviour .....	48
Table 15: Additional Analysis of Q12 - Resource Types.....	51
Table 16: Questions Concerning Information Seeking & Formats .....	52
Table 17: Available Data on Information-Seeking & Formats .....	53
Table 18: Kind of Information Sought.....	54
Table 19: Questions Concerning Information Seeking Experience .....	61
Table 20: Analysis of Experience – Usable Responses.....	62
Table 21: Analysis of Experience – How Parents Describe their Experience.....	69
Table 22: Chapter 4 Summary .....	74
Table 23: Chapter 5 Summary .....	86

## List of Figures

Figure 1: Resource Collection as Middleware .....	9
Figure 2: One example of a HTML5 Semantic Structure Map .....	39
Figure 3: Resource Collection Main Page .....	76
Figure 4: Comment Structure .....	77
Figure 5: Sample Categories Page.....	79
Figure 6: Generic HTML5 Resource Template .....	80
Figure 7: A Resource Collection Page based on the HTML5 Template.....	81
Figure 8: Finding a tag on a Page to Follow it into cross-referenced Resource Cards .....	83
Figure 9: Following the Tag to a Page of cross-referenced Resource Cards .....	84
Figure 10: Personal Letter to Spina Bifida & Hydrocephalus Association of Canada .....	100
Figure 11: Letter for Approval to Spina Bifida & Hydrocephalus Association of Canada.....	101
Figure 12: Personal Letter to Spina Bifida & Hydrocephalus Association of B.C. ....	102
Figure 13: Letter for Approval to Spina Bifida & Hydrocephalus Association of B.C. ....	103
Figure 14: Response from Spina Bifida & Hydrocephalus Association of Canada.....	104
Figure 15: Responses from Spina Bifida & Hydrocephalus Association of B.C. ....	104
Figure 16: Implied Consent, Spina Bifida & Hydrocephalus Association of Canada.....	106
Figure 17: Survey of the Spina Bifida & Hydrocephalus Association of Canada .....	108
Figure 18: Survey of the Spina Bifida & Hydrocephalus Association of B.C. ....	122
Figure 19: Ethical Approval Form.....	123

## Acknowledgments & Dedication

I wish to acknowledge the assistance of each of the following Professors, Medical Professionals, Librarians and community members whose input and expertise greatly shaped my work on this Thesis and its subsidiary Projects.

*My Supervisor, Alex Kuo, and Department Advisor, Andre Kushniruk:* for their support and guidance with technical and methodological aspects of the Thesis

*Rebecca Raworth, Liaison Librarian for Health Information Science and Island Medical Program Librarian:* for regularly providing ideas for research and resource collection

*Luanne Freund, Associate Professor at UBC's iSchool (School of Library, Archival and Information Studies) and Director since 2015:* for providing methodological suggestions and guidance, and connections to iSchool students engaging in informative work in Health Information Seeking Behaviour

*Frances Foster:* for moral and technical support of the Thesis write-up

*Bonnie Hidlebaugh, National Manager/Communication & Development Coordinator of the Spina Bifida & Hydrocephalus Association of Canada; and Pauline Dooley, last contacted Office Manager for the Spina Bifida & Hydrocephalus Association of British Columbia:* Each for their efforts in recruiting subjects to provide data, and regularly promoting the ongoing availability of the data collection tool during its deployment

*Dr. G Stuart Cameron and Dr. John C.L. Sun, Neurosurgeons:* For being, ultimately, the root of my interest in the subject matter that forms the bulk of my Thesis, and without whom I'd not be present to complete it.

# Chapter 1: Introduction

Table 1: Chapter 1 Summary

This Chapter introduces my Thesis, including its two major Sub-Projects.

The second Project by chronological order but actually the first one conceived, a Resource Collection, follows modern web app conventions of metadata and semantics to provide users of the Spina Bifida and Hydrocephalus Associations of Canada and British Columbia with an organized and curated collection of web-accessible Resources. It is meant to help answer questions users might have during the course of living with one or more of the medical conditions on the spectrum served by the Associations; and to provide a community platform for engagement to fill in the blanks left between current resources through shared experience. Here, I realized that through Action Research I could actively engage the member base of both Associations in the development of both the Resource Collection interface and the specific Resource Cards. So, a Needs Analysis had to be conducted before the Resource Collection Design could fairly begin; following a Participatory Action Research method embedded within the wider methodology of studying Everyday Life Information Seeking Behaviour.

Before getting there, though, it is necessary to also describe – as briefly as possible – the medical conditions represented in the Resource Collection; as well as to illustrate why there are certain necessary restrictions to how data could be collected and why expectations for returns of Needs Analysis surveys had to be low, in short because there's no way to predict the number of high functioning or low functioning potential participants as that is too personal a piece of data to have been tracked.

The Chapter ends by noting how this project leverages certain technology concepts such as **semantic web middleware** to potentially serve within a wider domain of health information resources; as its core concepts can be repeated within other medical condition and consumer health information domains.

The intent of the Project underpinning this Thesis is to explore the feasibility of, and to develop as far as appropriate, a template and framework for retrieving and enhancing the presentation of consumer health information from the internet. This will be accomplished through a **Resource Collection** organized according to recognized rules of classification found in the 'Library Sciences' sub-discipline of the Information Sciences. The proposed collection would achieve this goal by repurposing existing Search Results to appeal to a more targeted audience in need of less generalized search results or findings, considering their role in a community of like-minded **Consumer Health Information** (CHI) seekers –which, instead, should be defined as **Everyday Life Information Seeking** (ELIS) *individuals interacting with resources within a Consumer Health Information domain*. Terminology will be explained in subsequent discussion.

### ***Implementing a Resource Collection as Response to User Needs***

The pilot **Resource Collection** provides the answer to the main thrust of my Thesis Question (now included at the end of Chapter 1, on Page 9) immediately following its launch to the intended user base: the needs analysis provides answers to this question, and the resource collection is designed according to the answers given.

In the process of developing this Thesis document I determined that the scope of creating such a resource collection for a *generalized* set of consumer health information is too broad and would not allow in-thesis and post-thesis exploration of use and usefulness of the system to a *specific* user population. Considering *each* different subject area in greater detail when evaluating the overall impact of the system could provide a *career* worth of tangents. This is the genesis of the first of my inquiries to support the Thesis Question: in recognition of necessity to reduce the scope of investigation to a manageable degree, the document presents a pilot project narrowing the scope to a single **Health Information Resource Provider & Support Network** (*note that this is a term I have coined for my Thesis, based on similar terms in the literature. Its meaning is exactly as written: an organization that provides both information resources and social support to clients*); and concerning a single spectrum of closely-related

medical conditions. The possibility remains open to engage future research into other conditions or other international jurisdictions' organizations.

Furthermore, its design – introduced below in the **System Design Principles** section and elaborated further in its own Chapter of the Thesis Document – allows constant updates meant to continually improve perception of the value of the resource. As long as updates are maintained indefinitely, the *perception* of value (meaning findability and usability as above) can be similarly maintained indefinitely; and methods to address that perception can be built into the System.

### **A Brief Introduction to the Problem Area: Spina Bifida & Hydrocephalus**

In Chapter Two my data source is revealed to have come from the member community of the Spina Bifida and Hydrocephalus Associations of British Columbia and Canada. I have a vested interest in these organizations, as I myself have Hydrocephalus of one particular form. It's important to provide a primer on the organizations involved and the medical conditions that they support, here; as well as to disclose that I am highly familiar with all material presented in this section. It directly informed my data collection method and analysis process. However, as the reader will appreciate on completing the next Chapter, the methodology that I have chosen (*Participatory Action Research* embedded within an *Everyday Life Information Seeking* framework) **entirely mitigates any possible bias**, transforming my participation in the data collection instead into a source of experience and expertise.

The Spina Bifida & Hydrocephalus Association of Canada was established in 1981 and later affiliated with the International Federation for Spina Bifida & Hydrocephalus (<https://www.ifglobal.org/en/>). It represents a federation of thirteen Provincial and Territorial Associations that work on behalf of Canadians with spina bifida or hydrocephalus (one of which is the Spina Bifida & Hydrocephalus Association of British Columbia). It aims to be the leading voluntary health organization in Canada; and focuses on promoting independence of persons living with either condition while seeking to reduce the incidence of both conditions through public awareness,

education, advocacy and research (SBHAC, 2018). The organization provides a member newsletter and public website for these purposes, and to promote public events and provide member and publicly-accessible resources on the subject of the conditions and their diagnosis, treatment, management, and lifestyle concerns. The Spina Bifida Association of British Columbia, our Provincial Member of their federation, echoes the statement of purpose of SBHAC:

*Our Mission: is to improve the quality of life of all individuals with spina bifida and/or hydrocephalus and their families through awareness, education and research (SBHABC, 2016)*

**Hydrocephalus:** The majority of cases are congenital in nature; which is to say they developed prenatally and were diagnosed either in foetal stage or shortly after birth based on observable signs and symptoms. Hydrocephalus is, in laypersons terms, a disorder of the nutrient-rich water-based fluid that normally sits like a liquid cushion between the brain and the inside of the skull and passes down the spinal column (called *cerebrospinal fluid*). Under normal circumstances it circulates through the cerebrospinal column and out into the body to be flushed away by normal internal processes. A person with the condition, untreated, experiences either an excess buildup in the brain ventricles (called *non-communicating* or *obstructive* hydrocephalus) or the rarer reverse, it flows away too rapidly from the ventricles (*communicating* or *non-obstructive*) and gets blocked somewhere on the spine. Either form must be surgically managed since there is as of yet no known cure for the disorder given little research has been done to establish its causes. Fortunately, the management solution, as with the diagnostic tools used to identify the abnormal CSF levels, applies identically regardless of which form is had by the patient.

Diagnosis may be done by a doctor or, preferably, neurological specialist (neurologist or neurosurgeon) based on any of a wide array of signs and symptoms; which are then managed surgically, until the surgical solution wears down in effectiveness and the signs and symptoms emerge again, indicating need for a surgical revision (and so on).

Symptoms vary with age, disease progression, and individual differences in tolerance to the condition. So **it is important for any Resource Collection to include information on signs and symptoms**, but especially because of the individual tolerance each patient or caregiver's observation of these signs and symptoms may vary wildly from one patient to another, or across a single patient's entire experience of the condition (which, incidentally, is my experience: from one incident to the next I've never once had totally consistent symptoms with any prior need for medical intervention). For examples: on infancy, the most obvious indication of hydrocephalus is often a rapid increase in head circumference or an unusually large head size. Other symptoms may include vomiting, sleepiness, vocal irritability, and observable optical issues (crossed eyes or downward drift called 'sun setting'). Symptoms in children and adults may include headache followed by vomiting, nausea, blurred or double vision, sun setting of the eyes, problems with balance, poor coordination, gait disturbance, urinary incontinence, slowing or loss of developmental progress, lethargy, drowsiness, irritability, or other changes in personality or cognition including memory loss. It's important to note that I have experienced all of these symptoms at one time or another during each period culminating in surgery. The most common current treatment of hydrocephalus, which has been standard medical practice since its invention over half a century ago, is the surgical introduction of a flexible plastic tube made up of a shunt, a catheter, and a valve. The catheter is inserted into one of the ventricles inside the brain or directly into the cerebrospinal fluid [CSF] that's outside the spinal cord – mine is in the third ventricle, right side. The other end is typically placed in the abdominal cavity and identified as such as a *ventriculoperitoneal* (from the ventricle to the peritoneum) shunt but may be led to any other safe place for CSF drainage and absorption such as around the lungs or near one chamber of the heart. A valve located along the catheter maintains one-way flow and regulates the rate of CSF flow. The valve in some recent models is magnetic, allowing for slight external adjustments of the desired pressure without the need for invasive additional surgeries by using a device made up of a small magnet and an electronic pressure monitor. As with most mechanical devices, this

device's use as treatment method is temporary and may require multiple surgeries (called 'revisions') over a lifetime to provide replacements for part or all of the device. As the need for a revision looms, signs and symptoms return; though in their absence, or in conjunction with their appearance, a range of diagnostic tools may also be employed. Specialists may request a battery of medical imaging tests from X-rays to Computed Tomography [CT], to Magnetic Resonance Imaging [MRI] and even Positron Emission Tomography [PET] as are available. One or several of these methods may be employed to look at things like: the size and shape of ventricles, in case of dilation by CSF; whether or not the shunt itself is obstructed or just not communicating as expected; or other diagnostic abnormalities. As a general rule there is no single prognosis with respect to hydrocephalus, so one can't expect any resource collection to have much relevance in the category of lifestyle with respect to hydrocephalus: one person's experience immediately following surgery or in the much longer term may be vastly different from another's'. It differs as consequence of presence of other disorders, timeliness of diagnosis, success of treatment (which is generally very high but not without exceptions). One definite change in both academic literature and in consumer health resources on the topic is the effective abandonment of any preconceptions that hydrocephalus *will* lead to cognitive and physical impairments; instead favouring warnings that it *could* lead there, but not to make any judgements since many children who were initially diagnosed with the condition in past decades have gone on to lead lives with few limitations – provided that they were given the support of a solid network of interdisciplinary medical, rehabilitation and educational care providers. This implies that I and any other searcher should expect to find few specific resources for living with hydrocephalus since it's too personal an experience for a one-size-fits-all approach, but that I should try to incorporate resources which emphasize the Care Team based nature of not only diagnosis and management, but also lifestyle support as a team effort.

**Spina Bifida:** originates as a neural tube defect in which the spine fails to close properly during early foetal development. Specialists will perform surgery to close the newborn's

spinal opening immediately after birth to minimize the risk of infection and to preserve existing function in the spinal cord; but any prenatal nerve and bone damage is irreversible. Spina Bifida is subcategorized according to severity and extremity of deformation; presented here in order of decreasing severity:

1. **Myelomeningocele:** spinal cord and its covering (meninges) protrude at birth
2. **Meningocele:** only the covering protrudes
3. Various closed-tube defects in which the spine is pressed by malformations of bone, fat, or the meninges
4. **Occulta:** none of the above occur but one or more vertebrae are malformed

Most infants born with **spina bifida** are likely to have **hydrocephalus** as well; though there hasn't been enough research done to conclude or even speculate at the probability that it develops as a coincidental defect or is more deeply related.

Unlike hydrocephalus no provision needs to be made to anticipate an acquired form in any Research on a group of patients or caregivers, as all forms of spina bifida are generated by a prenatal defect only. Recent medical literature and consumer health recognizes a trend in adult and later-life diagnosis of *spina bifida occulta* because it's the mildest form and its appearance in medical imaging can be easily missed if its tell-tale defects are not being actively sought; but this should not be confused with an acquired form. The distinction between these forms was built into the data collection tool; but, as seen in that later Chapter, results of that question were ultimately discarded as not significant enough to establish one user's needs as different from another's when they had different forms of the same condition. Instead it emphasized their compatibility. Treatment for the variety of effects of spina bifida may include surgery, medication, and physiotherapy. Many individuals will need mobility assistive devices. Ongoing therapy and medical care including surgical treatments may be necessary to manage or to prevent complications throughout a patient's life. As with hydrocephalus there is no single prognosis after surgery or in later development: prognosis is poorest among those with complete paralysis (typical of the most severe form) or other congenital defects;

however, properly managed spina bifida with an adequate support network can overcome even these challenges. This is where resources on spina bifida may differ greatly from hydrocephalus: the condition is chronic and ever-present; it's not being managed by a device that a person can almost learn to ignore (as I did). It seems very important that the vast majority of resources for spina bifida in a resource collection for their benefit concentrate on lifestyle and ongoing management of spina bifida. Patients know their diagnosis but need to focus on current needs rather than dwelling on that diagnosis – except perhaps where new research on causes might lead to new ideas on treatment and management.

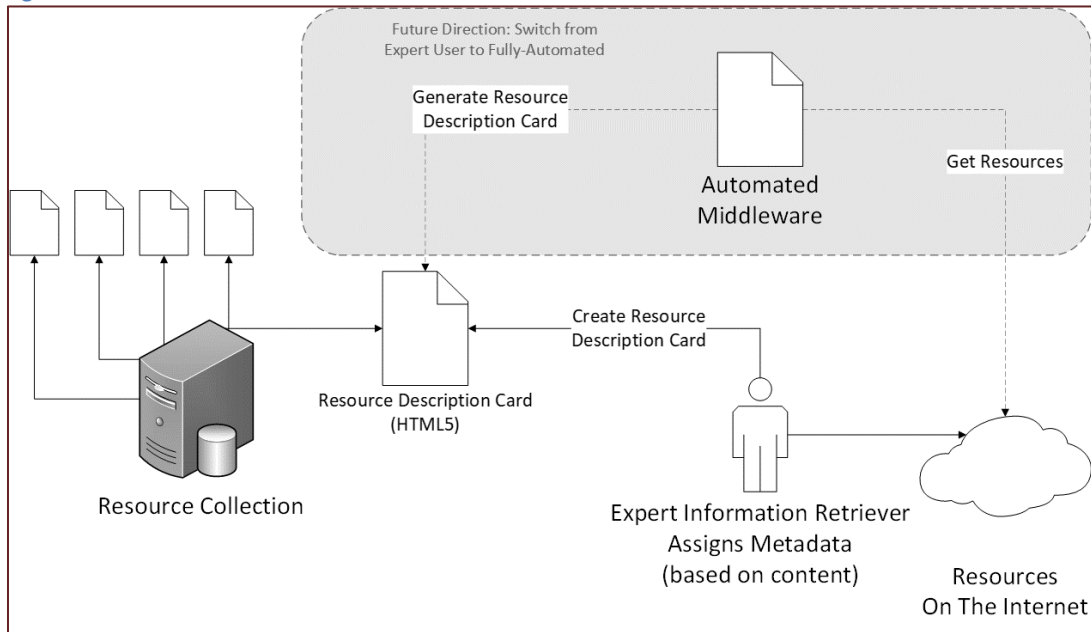
### ***Resource Collection as Solution to Wider Problem Domain***

According to these specifications, the secondary purpose of the pilot project is to provide a model framework to be applied to health resource and support networks defined by *other* medical conditions, or even the same condition but as experienced in other international jurisdictions; with the overarching intent being a wide-reaching model for the practical indexing of consumer or *everyday-life* information online, at least via an authoritative and end-user-approved subset of the information set. Implementation, however, is explicitly a Future Directions concern.

The ***Resource Collection*** design involves a back-end collection of resources presented to a user by a categorizing and cross-referencing ***middleware*** that adds extra layers of detail and context that are not available in a simple Search Results page. The pilot version of the Resource Collection is populated by an Expert Information Retriever rather than an automated ware, in order to first test acceptance of the pilot model before more investment of time and resources into developing an automated version, left as Future Directions. The term ***middleware*** is used here to denote its position in the middle of the framework between interface and database, rather than to more specifically connote an automated process as is included in some definitions. The design as presented, however, allows an automated process to be swapped in at a later stage

of update and/or redesign simply by replacing the Expert Information Retriever with the middleware tool.

Figure 1: Resource Collection as Middleware



The Resource Collection **design framework** adds a different process of *both* organization *and* information enhancement upon the results of an Internet search, which is intended to be more user-friendly than the Search alone. It sits in the middle between the collected Search Results and the Resource Collection itself, finding appropriate resources for inclusion then creating a resource collection description card in HTML5 based on found metadata. This middleware program presents these results in a database from which an electronic **catalogue** of search results can be generated. The catalogue elaborates the relationships between data points, whether relationships between the results themselves or relationships between their *metadata* which it provides at a glance for any retrieved **resource**. With this metadata content on display for each record, the middleware functions as a WebCrawler for compatible resources in a more nuanced way than search engines which use semantics to perform a similar function. This process allows natural subcategories and groupings of the results of a higher-level search to organically derive from the major subject heading; and does not

require the use of a formal semantic web framework (such as RDF) be fully implemented.

### ***Thesis Question***

*Would a customized solution for enhancing consumer health information retrieval **within the domain of Spina Bifida & Hydrocephalus resources** prove an effective tool in the improvement of findability of appropriate **Spina Bifida & Hydrocephalus resources** - from the perspective of the intended audience for (or performer of) such health information searches, **persons whose special needs include information and support for their lifetime experience with spina bifida and/or hydrocephalus?***

To answer this Thesis Question, I must address two subqueries which, through affirmative answers, lead the main Thesis question to a similar affirmative answer:

1. *How can system **design** influence user **perception** of findability and usability of retrieved resources so that it improves over the standard method?*
2. *What way of measuring user satisfaction with findability and usability of resources could be implemented in such a system?*

It proves not to be necessary to actually *quantitatively* measure how consumer satisfaction is enhanced, given the Thesis' focus on everyday life information seeking experience – in which perception of an improvement ensures greater interaction (and thus higher satisfaction) with the results of information seeking. So, too, any method for measuring user satisfaction need only observe use and adjust the system according to newly communicated wishes or requirements from the user population.

One final sub question may be addressed, in the interest of Future Directions only:

3. *Can the design process be generalized from one health resource provider to a framework for other similar organizations to do the same?*

My Thesis project will not, itself, be generalized; but rather the technical method chosen should be generalizable to any other condition. Further Chapters will elaborate if this question can or can't be answered affirmatively given the design I've chosen.

## Chapter 2: Methods

Table 2: Chapter 2 Summary

This Chapter introduces the Methods used within each sub-Project; first describing the processes chosen to define the data collection methodology for the Needs Analysis Subproject, now noted first in reference to its chronological order; then describing the Technical Methodology used to develop the Resource Collection given an array of design and implementation choices, tools, and technologies.

The Needs Analysis Subproject is defined by choice of the Spina Bifida and Hydrocephalus Associations of British Columbia and Canada as data sources. The Chapter justifies a web-based survey as a natural data collection tool following the appropriately chosen Participatory Action Research methodology. It steps outward to the encompassing methodology for researching Everyday Life Information Seeking Behaviour, noting Participatory Action Research as a vital part. Then the Chapter specifies the implementation process for the online Needs Analysis Survey, with a brief summary of the Data Collection which will lead into Chapter 3 (representing Survey Results and analysis thereof).

The Resource Collection is defined by its design and functional components, taken as a whole to be the complete Technical Methodology. This part of the Chapter includes discussion of the historical metadata standards employed in Consumer Health Information Resource Collections, the evolution of metadata standards for the web in general, and the convergence of Library and Information Sciences cataloguing standards with modern web metadata standards in the form of the Resource Description and Access toolkit for cataloguing online resources (while adhering to XML, RDF, and therefore also HTML5 standards). This dovetails with the subsequent discussion of the explorations into the use of Semantics on the 'Medical Web' that eventually lead here to how HTML5 can be used to leverage both metadata and semantic requirements of the intended Resource Collection.

The Thesis Question is evinced by a process that culminated in the development of the Resource Collection Interface and planned subsequent use of the Resource Collection by members of the Spina Bifida & Hydrocephalus information-seeking community, who will be directed to it by the Canadian Association. Assessing intended user's attitudes toward the Resource Collection will follow; but is envisioned as a long-term goal which will be begun during system design, so is not assessed within the scope of this Thesis.

### ***Data Collection Methodology – Needs Analysis***

#### **Confirmation of Data Source**

The first major step in the process was collection of data to be analysed. This was accomplished through engagement with a representative group of health information seekers with membership in a known and reputable national level **Health Information Resource Provider & Support Network**. In the interest of full transparency of method, it should be noted that parties interested in replicating the results of this Thesis Project for other such organizations should either have (a) one specific **Health Resource Provider** ready and willing to participate well in advance of the Project's proposed starting date; or (b) be prepared to send out multiple Letters for recruiting participation to multiple organizations. Based on my experience, the number who say 'yes' will be a high percentage of those requested. This will allow a choice between several, but only if a decent number are approached to start. While I only approached three, they were three I was fairly certain would all be willing (a presumption proven correct). See Appendices for letters mailed to Spina Bifida & Hydrocephalus Associations.

In early 2013, the Spina Bifida and Hydrocephalus Association of Canada expressed their commitment to supporting my thesis from their end, in terms of hosting or distributing my proposed Data Collection Tool at least, and optionally also hosting the completed Resource Collection, although that option would limit timely updates as proposed. My contact, Bonnie Hidlebaugh is a national Manager and Communication & Development Coordinator for SBHAC (See Appendices for Bonnie's response to Request for Participation). Our communication indicated that the Spina Bifida and Hydrocephalus

Association of Canada are, in fact, contemplating an as-yet-undefined and unscheduled upgrade to their website which may include an expanded Resource Collection similar to the one this thesis describes. As such they – via Bonnie – offered to support the data collection tool, provide expert resources to fill in any unexplored needs, and support the stage following design of the data collection tool: seeking Ethical Approval to utilize it.

I later received a letter from the Spina Bifida and Hydrocephalus Association of British Columbia. Following review by their Advisory Committee their Office Manager, Pauline Dooley, sent confirmation contingent upon approval from the SBH Association of Canada (**see Appendices for Pauline Dooley's response to request for Participation**).

Rather than differentiating between these two groups regionally, since both were expected to produce a low response rate individually; results were pooled as though all came from one single pan-Canadian source, the decision to do which was aided by the fact that the BC Survey's respondents proved often to be members of other Province's Associations as well, having moved but not severed older memberships.

### **Participatory Action Research (PAR)**

Development of the Resource Collection requires, first, an assessment of the intended users' needs and attitudes in order to differentiate itself from a simple System Design project. The approach used to collect *and to then analyse needs data* was envisioned from the start as a modified exercise in Participatory Action Research.

**Action Research** *"is identified with research in which the researchers work explicitly with and for people rather than undertake research on them ... Research design must be continually negotiated with participants, and researchers need to agree upon an ethical code of practice with the participants."*  
(Meyer, 2000).

This statement justifies the detail to which I communicated the Ethical Review process with potential participants, up to and including permanently posting the 'Letter of

Informed Consent and Invitation to Participate' on the portal to the Survey, as well as *always* using the Survey tool for anonymized data.

Action Research requires that rich contextual details are explored and reported. I interpret this as meaning that simply *reporting* participants' information needs is insufficient given the methodology. Identifying *motivations* for fulfilling those needs; and their methods, process, and actions to answer those needs goes further toward reaching a solution which addresses the rich context of their activities. This in turn produces a much more robust end product: when implemented according to the participation of the intended user base, the Resource Collection Interface becomes a holistic response to not only the specific information needs, but also the information seeking *contexts* of users and a way to address the deficiencies that they see in design of current information retrieval technologies. The latter can provide more meaningfulness to the Resource Collection. This in turn will drive perception of improvement, which is how I chose to ultimately judge the success of the program.

**Participatory Action Research (PAR)** is a newer variation on Action Research with a substantially different attention to participant as contributor and even researcher as participant; both of which traditional Action Research methods eschew. Action Research was defined as a methodology in the 1940s (Lewin, 1946), but PAR has more recent theoretical groundwork (Freire, 1982, etc.). It was shaped in part via new thinking from the 1970's onward that traditional educational pedagogy was being inherently one-sided and limiting the input of the participants. A new critical pedagogy was advanced by Freire and by contemporaries (Hall, 1975, 1992, 2005; Horton & Freire, 1990) and has drawn theoretical strength and validation from – and spread out as a legitimate research method toward – “adult education, sociology, political economy, community psychology, community development, feminist studies, critical psychology, organizational development [etcetera]” (Hall, 1992) as well as even more recently health education and information literacy (Wallerstein & Bernstein, 1988; Nutbeam, 2000; Kickbusch, 2001; Borzekowski, 2009)

Participatory Action Research redefines the role of the Action Researcher and primary data collector to permit them to add their expertise to fill in the blanks in data presented by non-researcher participants: it requires a researcher who is participant, stakeholder, *and* facilitator (Chevalier & Buckles, 2013; Meyer, 2000) in PAR research. Action upon findings must be done *with* people, and not *for* or *on* people to their exclusion as participants (Chevalier & Buckles, 2008, 2013; Kindon, Pain & Kesby, 2007; Meyer, 2000; Swantz, 2008) and assumes that participant agency in the process of defining and redefining methods and data is paramount. For instance, one set of responses to each Survey created for Needs Analysis is my own – anonymously entered, of course, but subsequently shared in detail to help motivate participants who may be unsure how to respond so that they may take agency of their own information needs.

Participatory Action Research is, as defined by Minkler (2000) and others (Cornwall & Jewkes, 1995; Duhl, 1996; Fawcett, 1991; Freire, 1982; Green et al, 1995; Israel, Schurmer & Hugetobler, 1992; Schulz et al, 1998; Wallerstein, 1999), inherently compatible with community-based health research of the kind evinced by this Thesis: "Systematic investigation, with the collaboration of those affected by the issue being studied, for the purposes of education and taking action or effecting social change" (Minkler, 2000). The Participatory Action method as used in community-based health research may also be seen in: Israel et al (1998), assessing partnership approaches to improve public health (e.g. between similar Health Information Services providers); Giachello et al (2003) and Wallerstein & Duran (2010), concerning means to reduce health disparities within communities with common medical experiences; and Rains & Ray (1995) for general community health promotion. Most recently: Boote, Wong & Booth (2015) provide a bibliometric review of the whole literature of public involvement in health research, finding Action Research and Participatory Action research dominate among empirical methods (400/417, including 130 reviews), though they note that publications peaked in 2006.

In some cases, the literature notes a deliberate combination of the method and the sphere of interest into a new group identified as Community-Based Participatory Action Research (CBPAR); which may alternatively be called Community-Based Action Research or Community-Based Participatory Research, with the missing word in each identifier implied through context of use. In fact, a MEDLINE search of the Consumer Health Information literature conducted without even specifically requiring “Community-Based” research found the majority of PAR studies in MEDLINE, EBSCO interface, refer to a Community-Based approach. Some even specifically name it CBPAR (or variants).

For instance: Gibbon (2002) provides an early attempt at a framework for CBPR projects; Carlson et al (2006), Khan et al (2009), and Mahrer-Imhof et al (2014) each concern development of online health information exchanges or web platforms for health promotion; Ochocka, Janzen & Nelson (2002) and Knightbridge, King & Rolfe (2006) use PAR to develop complex Community-based mental health programs and service delivery methods; and Brown et al (2008), Culhane-Pera et al (2010), Ford, Rasmus & Allen (2012), Giachello et al (2003) and Minore et al (2004) describe Community-based initiatives designed for health improvement with the participation of their target minority immigrant (Brown; Culhane-Pera; Giachello) and indigenous populations (Ford; Minore), either of which appeal to the egalitarian principles of Freire and other early contributors to the international PAR literature.

In one critical case for my methodology: Basu & Dutta (2008) investigate the role that community participation has on health information seeking (and vice versa) through the specific lens of health information orientation by the consumer and has on efficacy as defined by the resource, in a pair of health information survey studies. This article provides a perfect segue to the other fundamental part of my own methodology: their focus on explaining the interaction between information orientation (in this case to health information) and information seeking is fundamental to the Everyday-life Information Seeking (ELIS) research methodology advanced by Savolainen (1995) and others, working from a Library & Information Science perspective rather than Health

Information Science one. Yet the article cites neither Savolainen nor any of the authors in the following section who follow the ELIS method. That Basu and Dutta fail to notice the Library & information Science precedents to their research furthers my contention that this (at least) is one silo between disciplines which *must* be disassembled, there justifying my bringing together the two into a single methodological framework.

### **Everyday Life Information Seeking**

ELIS, as previously noted, is the overarching information-seeking behaviour domain in which this Thesis is situated. This position was identified because there is a logical link between ELIS and Participatory Action Research, even where a used method akin to the latter is not explicitly identified as PAR. Indeed, the link is unfortunately not generally spelled out in any easily-accessed LIS literature about ELIS; instead it is more often implicit in the choice of method for determining *how* and *why* Information Seekers looked for health information online, or in some cases *what* kind of information was sought and *what* was found. That logical link is exactly why the data collection and analysis methods described in this chapter follow a Participatory Action Research method: it is the most consistent one with literature found in Health Information Science and/or Library & Information Science journals when investigating ELIS, even where not made explicit. The Library Science literature most often identifies the problem domain as ELIS, and without naming it sets up a Participatory Action Research method for determining the “*how, why and what*” as noted upward in this paragraph.

The foundational modern work in this area traces to one individual, much as with Eysenbach and consumer health information: the aforementioned Reijo Savolainen. Although it should be noted his is by far not the first study of information seeking in a non-work context such as may be called everyday-life (for instance Chen & Hernon, 1982 or Dervin et al, 1976, which are both cited by Savolainen), he gave that name to the area of inquiry through a proposed framework. In *Everyday life information seeking: Approaching information seeking in the context of way of life* (Savolainen, 1995) the author develops this framework for the study of everyday life information seeking for

the purpose of ‘mastery of life’, with every-day life as contrasted with workplace information seeking – the literature for which the author saw as vastly overshadowing non-work information seeking activities (though arguably the explosion of non-work information online thoroughly subverted that focus over the last twenty years).

ELIS as an Information Behaviour model emphasizes the legitimate nature of non-work contexts. The ELIS model has two focuses: ‘seeking of orienting information’ and ‘practical dimensions’. *Orienting* information is the lifetime of information which the seeker draws from in order to understand the interrelated nature of way of life (the order of things) and mastery of life (keeping things in order). Way of life, as such, is environmentally-dictated, and fixed but interpretable. Mastery of life – the practical dimension – is only met when a person successfully orients toward needed information, then conceptualizes and utilizes information in a manner consistent with their own understanding and organized for optimal usefulness. Practical dimensions which moderate ELIS delve further into modifying personal (e.g. severity of condition) and environmental limitations (e.g. availability of resources):

*Similarly, the identification of the type of mastery of life may not necessarily reveal, in detail, how a person seeks information in the context of **everyday life** [emphasis mine]: the nature of mastery of life describes the tendency to adopt a certain information-seeking strategy in problem-solving situations... In order to analyze more exactly the information-seeking behavior associated with problem solving it is also necessary to take account of the specific features of the problem situation, for example, the repertoire of information sources available and the acuteness of the problem (Savolainen, 1995)*

Savolainen demonstrates the framework through an empirical study in the same article. Two populations are observed: the Finnish middle class (represented by teachers) and working class (factory workers to be specific) of 1995. Data was collected via theme interviews focusing on way of leisure time use as well as practices of seeking information from various media – which the author further probed for specifics of

information seeking behaviour and the nature of information sought. One important early finding that justifies the ELIS framework is that, while way of life “directs practices of information seeking... the latter may also affect the former.” (Savolainen, 1995). Without ever explicitly acknowledging it, Savolainen is utilizing an Action Research model – perhaps not noted as such because at the time Action Research literature tended to be siloed in other disciplines than Library Information Science.

It’s important to reiterate that ELIS does not limit itself to a subdomain of information seeking behaviour – unlike consumer *health* information – but that authors are free to utilize the framework within the health information domain. By contrast, the Health Information Science literature in which there is a growing body of works with Action Research (including PAR) explicitly stated as the methodology utilized for investigating Information Seeking Behavior tends to use the term *consumer* health information. And this may be the case even as the authors could just as easily mean a health subdomain of *everyday-life* information seeking, since there isn’t an implication one way or the other of the information source targeting *consumers* specifically.

As consequence, it appears at too cursory a glance to be incompatible with Library & Information Science literature – in which, in a direct reversal of the omission seen in the Health Information Science literature, ELIS is mentioned as the guiding principle for information research but the methodology is not often named. Looking closer at a few of these LIS papers, though, one sees that they are using a modified Participatory Action Research model without naming it as such.

Some scoping surveys, such as the one conducted by Greyson (2014, 2015) may help to find collected examples of ELIS studies which are only now clearly defining their *data collection and analysis* method, whether as action research or as something else. Greyson identifies that of 89 Health ELIS articles selected for final Review, 61% have an identifiable method – most frequently following either the Savolainen model of participatory interviewing for data collection or Wilson’s model of Information-seeking behaviour (Wilson, 1997, 1999, 2000, 2005). Wilson’s model promotes the evolution of

an information system according to how it is used, rather than designing it to meet the need at launch. Here the fundamental query is that, the system having already been built, is it addressing the user's information needs adequately (Robson & Robinson, 2013). This latter model will be important for the expected future revisions of the Resource Collection, but is not within the scope of this Thesis document.

Carey, McKechnie & McKenzie (2001) provide one of the earliest criticisms of the ELIS literature as tending to at least not name and at most *not even share* methodological details of how ELIS was incorporated within prior studies in the LIS literature – and they do so within the subordinate context of *health information* seeking behaviour. While arguably, lack of transparency of method continues to be problem, this article may be pointed to as a turning point in creating more openness in Library & Information Science with respect to deliberate use of and description of ELIS as a core part of their methodology. Specifically, the authors describe three ELIS studies using ELIS as a starting point for methodologically sound investigations, categorized as follows:

1. **Researcher as Insider:** concerning the information behaviour of pregnant women of twins, by the one of three authors who was herself a mother of twins
2. **Researcher as outsider:** observation of a support group for persons with a chronic auto-immune condition, no authors having such a condition
3. **Researcher as insider and outsider:** a study of children's and their mothers' library use by a librarian and mother of a young child (outsider to child group)

Two of these three studies quite explicitly concern everyday-life health information seeking behaviours, so are of most relevance to my Needs Analysis modelling. While the second one speaks to a more relevant medical information domain (a chronic condition) the first stands closer in the sense that the researcher is an insider: she, a woman of twins observing, interviewing and interacting with mothers of twins; and me, a person with a condition on the hydrocephalus / spina bifida spectrum collecting data from members of a health information & support group for persons with those conditions. Although a case could be made easily that I am both insider (hydrocephalus) and

outsider (spina bifida). In any case, because all three studies are explicit about their methods it is entirely possible to map these to participatory action research even though none of the three authors even once refer to that term – meaning it doesn't come up in indexing or metadata. If there's one like this, maybe there are many more.

The author of the second study, the lone male of the three (determined by elimination: the other two, as noted above, were undertaken by two women of young children), states the following about his choice of ELIS as theoretical basis:

*Previous research into the health information needs of various populations has frequently exhibited an emphasis on institutional perspectives. The overt purpose of much inquiry in this vein has been to identify patients' information needs and to recommend ways these needs can be better met by information systems for health care professionals. Such studies have implicitly tended to support positions that preserve the power and privilege of the biomedical establishment. A preponderance of work, for example, has focused on encounters between physicians and patients in the belief that improving communication practices in these situations will minimize noncompliance with medical directives. This type of approach neglects ways in which the everyday reality of illness is understood and shared by the chronically ill and, moreover, ignores the political nature of health information exchange (Carey, in Carey McKechnie & McKenzie, 2001)*

Parsing this statement, and using slightly more recent publications to help translate some of the language above (along with intentional reference back to the participatory action research literature via use of the word 'agency'): Carey has distanced himself from the *consumer health information* label, because it is loaded with an institutional perspective that denies agency of the patient in the identification of patient information needs (Carey, McKechnie & McKenzie, 2001; Greyson, 2014, Greyson, 2015). Though, according to Greyson (2015) there's perhaps not so much a separation as a need to map from one concept to the other: "following the wave of changes to health information access brought by the consumer health movement and the development of the World

Wide Web, librarians and information scientists have increasingly recognized the importance of [ELIS]" (Greyson, 2015)

It's not a far step from either of these statements – even without my prompting with the word 'agency' – to a justification for a participatory action research method; and although neither Carey in his study nor the other two authors in theirs name their method as such (Carey, McKechnie & McKenzie, 2001) it's quite clear that PAR is what they used. Though only Carey, as above, justifies his method in terms that Freire (1982) or Hall (1992, 2005) would recognize as the motivators for using PAR.

Indeed, researcher #2 – Carey – refers to his method specifically as *participant observation*, in which he attended 14 support group meetings and followed up with interviews of 25 group members; as well as setting himself up as a Librarian for their resource center during the course of his Study. Though intending only to be a participant during the meetings and interviews in which mere observation could not probe deeply enough into conceptualized and articulated information needs of the group members, and as only an observer of information-seeking behaviour in practice during hours as Librarian where surveys could be collected, the author found the latter also developed into another branch of participatory action (albeit less directly).

Researcher #1 – determined to be McKenzie when compared to another citation (McKenzie, 2002) – used various offline social network means to gain access to and connect with various health educators, nurses and public health staff (etcetera) who in turn introduced her recruitment materials to expectant mothers of twins, allowing her to present as a trusted third party in order to discuss her shared insider experience and as consequence gain further access to the everyday experience of her target audience. The author conducted in-home interviews, modified to allow reciprocal exchange of ideas and information – demonstrating a (maybe) unintentional parallel with PAR: research and discovery is done with the participant, not on them.

Further ELIS literature in which the everyday-life information seeking is or includes health information, and which make proper note of their data collection and/or data analysis methods include: McKenzie (2002) which continues her research as presented in Carey, McKechnie & McKenzie (2001). Once again, expectant mothers of twins are interviewed, with the slight difference that here McKenzie modifies the approach with the keeping of a response diary to modify future interviews and questions according to prior interactions. This explicit acknowledgement of the patient as agent of their own (and other expectant mothers') observation methods once again speaks to a participatory action research method in procedure though not in name.

Savolainen and Kari (2004a & 2004b) use ELIS and an unstated participatory action research method using semi-open interviews of information seekers, including of health information, to explore conceptions of the internet itself in two separate research papers. Meyers, Fisher & Marcoux (2009) present a study of teen everyday-life information seeking behaviour informed by ELIS principles, and cite articles by McKechnie for her work with children (1997) and Savolainen (1995) for foundational principles. Multiple research methods were used to triangulate data: two focus groups each with a secondary interview of individual participants were conducted on three separate dates. They matched this research design referred explicitly to the desire to move from research *on* youth to research *with* youth (Meyers et al, 2009). Like Meyers, Fisher and Marcoux (2009), Gray et al (2005) concern perceptions and experiences of adolescents' everyday-life information seeking through focus group interviews, specifically health and medication information online. This definitely is further Participatory Action Research, even though not named as such.

### **Implementation Process**

Each article in the preceding sub-section support development of my own methods with respect to data collection and analysis; with some modification made necessary by present context. For instance, while every preceding article concerning ELIS research in which method for data collection and analysis is described notes the use of either a one-

to-one or focus group interview method (both of which are common to Participatory Action Research), it is not possible to implement with an asynchronous and non-collocated pool of potential respondents, either with pan-Canadian or pan-British Columbian geographic locations. Instead, the Data Collection tool was structured as a mostly-open-ended Online Survey, in a way which is consistent with application of Participatory Action Research to healthcare; Minkler (2000), for instance made an intentional methodologically-consistent “decision to conduct a health survey to obtain baseline data on health behaviors”; and the Review by Israel et al (1998) identified two key citations involving questionnaires or surveys in place of or in conjunction with other data collection methods (Israel, Shurman & Hugentobler, 1992; Schulz et al, 1998).

In order to adhere to requirements that were set by University of Victoria’s Human Research Ethics board for data security and confidentiality, the Thesis Survey was created using an instance of the PHP-based SURVEY™ open source web project, housed on the University of Victoria’s web server (Health Information Science sub-domain) at: <http://web.his.uvic.ca/survey/default.aspx>. Surveys can only be generated by authenticated **Survey Users** – Netlink ID holders who are Students, Staff, and Faculty of UVIC’s School of Health Information Science – and who are furthermore granted access by an Administrative account. Surveys may be accessed from the web by any User directed to a Survey URL which cannot be crawled for inclusion in search engine results. It is only undermined when the private URL is posted on a public website (though spam is generally easily identified).

Developing a Survey prevented *direct* participation in data collection on my part, except where participants emailed me anonymously to ask questions about how to complete certain questions. Instead I provided a sample completed Survey but also encouraged users to complete responses as they saw fit (see **Appendix** for a Letter to potential Respondents that was posted on the Survey Portal), meaning as little or as much information included as they felt willing to impart. Each Survey was designed to collect voluntarily-submitted data about SBHAC (and SBHABC) stakeholders’ specific

information requirements in three distinct time phases of their experience. In keeping with the Participatory Action Research method, even the design of the Survey was open to the Spina Bifida & Hydrocephalus Associations for input and approval, so for instance some Survey responses continued to recommend changes to the questions or order of questions late into the Survey's availability. Some recommendations made their way into either the updated second version of the Survey or into analysing the data in different groups than originally intended.

My interest was the information about stakeholders' recollections concerning past and present information needs, as well as perception of whether or not they might modify their behaviour in the future.

1. Whether or not they perceive those needs having been resolved by their own search is important data to collect to aid justification of the "niche" process as described above
2. Who are the members responding to the Survey? Members include patients (or persons living with the condition), caregivers, or just researchers and allied health professionals. Needs of each group are collected in just *one survey* to design *one system* all participants for two not mutually-exclusive reasons:
  - Differences in Information Use by each group were expected to be few and not significant enough to warrant separation
  - Resources that one group describe a need for may be of use to the other groups even if they don't mention it
3. Data was collected from voluntary participants, made anonymous through the method of distributing the survey (the electronic survey described above)<sup>1</sup>
4. Data was also collected from a Social Media source brought to my attention after the close of the Survey Period; but only content generated *during* the Approved Year could be considered eligible. Ultimately, I decided that this data source will

---

<sup>1</sup> There was an optional print version to be mailed back to the Spina Bifida and Hydrocephalus Association(s); however, even after 1 year no Print surveys were completed by either Association's members

not be included in this iteration of design given that its collection can only *artificially* be fit within the context of my original Ethical Review, so instead will be saved for another data source to be included as part of my Future Directions.

Point #3 above was my primary motivator for seeking information through SBHAC and SBHABC assistance: they could potentially point members, anonymously, to the survey. No identifying information was passed to the researcher, and the degree of personal recollections shared varied depending on the respondent's comfort with the promises of anonymity. And so, the degree of *potential* personalization of responses to the Survey needed careful consideration and approximation when brought to Ethical Review; which asserted guidelines to strictly adhere to in the process of data collection, most significant among which was a generous prediction of personal responses. This proved wise given that all complete, unspoiled, and non-negative responses to the Survey were largely very personal – and by extension it may be assumed that the few that more or less 'spoiled' their response surveys felt strongly enough to respond, but not strongly enough to share anything relevant given its personal nature.

All identified information needs were pooled, regardless of perspective (including at different phases such as prevention, diagnosis, treatment, and post-treatment management; as well as social and sociological; or genetic and pharmaceutical; and on). I designed the aforementioned survey to cue the reader to consider the *entire* range of their information needs, but not to lead them to any 'expected' answers or insist upon any sections being necessary to complete. This does, naturally, tend to limit the reliability of the results given; but since the Resource Collection is designed so that new information can be iteratively added as it is presented by future communication with users – even before automation is applied – any omission or deficiency may be overcome in the ongoing lifespan of the Resource Collection.

## Data Collection

Table 3: Use of Ethical Approval Period

Phase	Description	Start Date	Responses	Close Date	Responded
1	Initial Survey	May 2013	May & June	December 2013	20

Data Analysis was done with the intent of deriving information for direct use in the development of the pilot Resource Collection's interface (which is the middleware tool). Rationale for asking Survey questions in the form and order in which they were asked is described in the Tables and discussions that follow in Chapter 3.

Analysis of the data collected in the School of Health Information Science-hosted Survey system may be enhanced by secondary social media sources, which were fed into the survey system after the Ethical Approval period was complete by an unidentified third party. Because this was not included in the original Ethics application this data will only be added while pursuing Future Directions.

## ***Technical Methodology – Resource Collection***

### **Metadata Standards**

Metadata initiatives (e.g. Dublin Core and RDF) originate from the general Information Science sub-discipline called the Library Sciences (LIS). LIS is, notably, not mutually exclusive with the discipline of Health Information Science: this Thesis takes several keys from 'Health Librarianship', which is the point of intersection. These metadata initiatives were originally investigated – in the early years of the previous decade – as tools to more readily and efficiently index the contents of the internet *itself*, though they postulated quite presciently that full automation of the process would require buy-in both from search providers and web developers who would, naturally, have to encode these standards into the HTML/XHTML metadata of their creations. Lack of buy-in for automation, coupled with the direction of industry toward one dominant Search Provider, led to ongoing research in this area having been dropped to the back-burner in priority behind less work-intensive strategies (*paraphrased from*: Singer, Norbistrath & Lewandowski, 2012; Eastin, 2001; Eysenbach & Kohler, 2002; Eysenbach, Powell, Kuss & Sa, 2002; Metzger, 2007; Shepperd et al, 1999).

Past grand ideas of cataloguing and/or indexing the whole Internet have generally been, at least gently, subverted by the success of search engines' concerted movement toward limited nods to semantic web technology. This in turn simplifies search processes and results to a "query-response" strategy of immediate gratification, often sacrificing true relevance to the Information Seeker. For instance:

*...Today's search systems are mainly designed to follow the "query-response" or short look-up concept. Search engines usually offer their users only a simple query interface. Users enter queries into those search systems and receive ranked lists of search results. Search engines support basic types of search tasks that can be solved with a simple query/result pairing. These search tasks usually happen in the context of question-answering and fact-finding... (Singer, Norbistrath & Lewandowski, 2012)*

This is in part because time and progress have somewhat subverted old adages about how not every question can find a corresponding answer online, although even where answers are present the authority and other appropriateness of the result may be questionable at best (Eastin, 2001; Eysenbach & Kohler, 2002; Eysenbach, Powell, Kuss & Sa, 2002; Metzger, 2007; Shepperd et al, 1999).

The latter statement (*"where answers are present the authority and other appropriateness of the result may be questionable at best"*) remains consistently truer, and ironically increases in tautology as the proliferation of consumer health information continues without uniform quality standards applied. In fact, the statement functions as significant motivation for both projects within my thesis: seeking authoritative answers to health questions is exactly the motivation stakeholders have in following or becoming members of the **Health Information Resource Provider & Support Networks** most relevant to their own needs or lives, so providing methods to ease the process ought to be welcomed, as was the case in my conversations with SBHAC/BC.

Information presented by these organizations carries higher authority for persons with covered conditions (Wright & Bell, 2003; Brashers, Goldsmith & Hsieh, 2006), even if the

information comes from a secondary source. But, given the sheer current depth of the World Wide Web, it becomes increasingly possible to *appear* to find the answer to any question; which in turn seems to undermine the first half of the adage for all users except those users at the very top of the **Information Literacy** ladder, who tend *not* to be included in the population targeted for this Thesis.

Problems arise when subjects fail to recognize the importance of assessing authority and reliability of an informational resource which they found based only on apparent relevance to the answer, as in a typical Search Engine's results page. This issue provides rationale for including investigation during the Resource Collection Development phase into whether **RDA: Resource Description and Access [RDA]** can be used to add depth to result Views. RDA is a cataloguing standard developed following the library profession's long-term standard Anglo-American Cataloguing Rules. The primary distinction between RDA and AACR is structural. RDA is organised based on the ***Functional Requirements for Bibliographic Records*** (FRBR). These principles identify both the 'user tasks' which a library catalog should make possible and a hierarchy of relationships in bibliographic data. Descriptions produced using the instructions of RDA are intended to be compatible with any coding schema, including the data environments used for existing records created under the AACR2 rules (Oliver, 2010)

RDA provides a set of guidelines and instructions on formulating descriptive data and access point control data to support resource discovery. The first two Key Concepts of RDA are expressed as follows:

Table 4: Key Concepts of RDA

<ol style="list-style-type: none"> <li>1. Resource: A Resource is an identifiable information object. The object may be either tangible or intangible in nature.</li> <li>2. Resource discovery: ...encompasses the following generic user tasks: <ul style="list-style-type: none"> <li>• FIND – resources that correspond to the user’s stated search criteria</li> <li>• IDENTIFY – confirm that the resource described corresponds to the resource sought, or to distinguish between two or more resources with similar characteristics</li> <li>• SELECT – choose a resource that is appropriate to the user’s needs</li> <li>• OBTAIN – to acquire or access the resource described (Danskin, 2009)</li> </ul> </li> </ol>
--

The expression above (Point 1) proves that RDA is directly and obviously applicable; in that results of a search are identifiable information objects. It also (through Point 2) justifies the exploration to enhance the Resource Collection Interface via RDA: its purpose is not just to help *find* resources, but to aid in the identification, selection, and obtainment of *appropriate* resources.

- RDA is designed to leverage technology and be web-friendly *and* user-friendly. RDA tool-kit instructions are organized around a principle with the acronym WEMI: Work, Expressions, Manifestations, and Items; respectively identifying ‘work’ as the content, the expression as its physical or digital format, specific manifestations such as distinct editions with differing publication dates and designs, and miscellaneous items being information that helps find the item in-collection such as the URL (Gunther, Blythe & Spurgeon, 2013).

Table 5: WEMI Principle for defining RDA fields

**Work** may require some or all of the following parts, noting that RDA is always true to the original source and never includes things that require separate lookup (like finding out who wrote it if it's not printed on the resource):

- Creator, other person involved, family or corporate body; including co-creators
- Preferred title
- Date of Work preferred over Publication Date, but whichever is shown
- Place of origin
- Other distinguishing characteristics

**Expression** means: the language of the resource, the language of the content if different, the script if notable, the date of publication (if not repeated) and the content type. Expression is made available through **Manifestation**, its carrier:

- Proper Title
- Production, Distribution or Publication information
- Extent of the work
- Type of content, media and container (for instance if it's a website, container is the internet)
- Numeric or alphanumeric designation for finding the resource, such as a catalogue number, standard number, etcetera.
- Source of the record, which is also **Item** (Gunther, Blythe & Spurgeon, 2013)

For instance, RDA provides guidelines for classifying or cataloguing web resources using a standard template based on the WEMI principle; an example of which follows:

Table 6: An RDA formatted Record Template for Web Resources

<b>Name of Field</b>	<b>Content Recommended</b>
<b>Title</b>	<i>Is a Proper Title, taken directly from the Resource</i>
<b>URL</b>	<i>Is the location of the Resource</i>
<b>Variant Title</b>	<i>What else is it known as?</i>
<b>Place of Production</b>	<i>Refers to place of Production, Distribution, or Publication</i>
<b>Name of Author</b>	<i>...Or Name of Producer, Distributor, or Publisher</i>
<b>Year of Production</b>	<i>May substitute Last Edit or Publication Year</i>
<b>Mode of Issuance</b>	<b>Integrating Resource</b>
<b>Note on Title</b>	<i>Explains how Title was found</i>
<b>Note on Issuance</b>	<i>Last Date resource was accessed by Resource Collector</i>
<b>Media Type</b>	<b>Computer</b>
<b>Carrier Type</b>	<b>Internet Resource</b>
<b>EXTENT</b>	<b>1 Webpage</b>
<b>Language of Content</b>	<i>Primary language in which content is written</i>
<b>Illustrative Content</b>	<i>Does the resource have images (Yes / No)?</i>
<b>Color Content</b>	<b>Color</b>
<b>Work Manifested</b>	<i>Title and URL may be repeated</i>
<b>Other Persons Attached</b>	<i>Additional credits for content displayed on the Webpage</i>
<b>Relationship Designator</b>	<b>Issuing Body</b>
<b>Summary of Content</b>	
<p><i>A description on multiple lines. RDA prefers Document Body as authority on content, Source Code for metadata only used as last resort. For example:</i></p> <p>‘This Record is a Sample of the Resource Card Template including RDA-compliant Headings and content explanations. Some content is the same for all Records, such as Mode of Issuance above (notice: these are colored black) whereas others depends on the specific Record (these are italic in the current Template).’</p>	

Furthermore, RDA is explicitly interoperable with both its underlying conceptual models (e.g. FRBR, see last page) and related to two XML metadata models – the **Dublin Core Metadata Initiative’s Abstract Model** and the **<indecs> Metadata Framework**. Note that Dublin Core may be expressed in RDF, implying a conceptual link between RDF and RDA is established; and explains why the former can be comfortably left out of current design, as a later enhancement of the Resource Collection Interface. To adhere to standards, all Resource Collection items are represented following the RDA Template format above and encoded in HTML5 using *extensible and descriptive attributes*; so that even the *markup structure* of the Record matches RDA recommendations.

## Semantics & the Medical Web

The crux of this section of my thesis begins beyond proof of concept of the technology – the point at which the work and practical output of Roudsari et al (2002, etc.) leaves off with discussion of future considerations – and factors in the impact of having directly involved a stakeholder group of health information seekers *throughout the design process* rather than as voluntary respondents only to the finished product. This intent has been briefly mentioned already, explained in further detail in the Participatory Action Research and Implementation Process sections of the Data Collection Methodology section. A concise explanation is that members of the selected Health Resource and Support Network were presented with a means to communicate to the researcher (me) their information needs throughout their whole experience of the medical condition that the Health Resource Network supports.

*While traditionally of interest primarily for healthcare providers, the emergence of the Internet and other networked technologies within healthcare delivery settings has resulted in a growing need to provide access to consumer-friendly health information. Additionally, the growth of publicly available information networks has resulted in a like need to create resources that cater to multiple user levels as well as a variety of specialty areas. (Lorence & Spink, 2004)*

This statement succinctly describes the subset of Health Information and Library Science literatures which spurred my interest in the topic. While it doesn't quite use the term **consumer health information** let alone **everyday-life information** (neither one being codified in the literature just yet), it may be noted both terminologies were in use within the HIS and LIS literature a decade ago: the former, *consumer health information*, having been coined and established a few years earlier by Gunther Eysenbach et al (Eysenbach & Jadad, 2001; Eysenbach, Powell, Kuss & Sa, 2002) and the latter even earlier (Savolainen, 1995; as cited in Carey, McKechnie & McKenzie, 2001).

Also consider the importance of Savolainen's contribution to terminology – given that further in this Thesis document an argument is made that consumer health information

is not the best term for what the Resource Collection aims to collect, my contention based on Savolainen's research being that a health-concerned subset of *everyday-life information* is much closer in principle. Nonetheless, Eysenbach's work proves seminal in transitioning the use of a codified metadata structure to facilitate a semantic or an *extensible-to-semantic* search of health information (as in the case of RDA without full RDF compliance) on the World Wide Web (Eysenbach et al, 2001a/b) from just theory into practical application. But we should note that the term *semantic web*, like *consumer health information*, was not yet fully codified in the literature by that year. Seminal, exemplary, work in the area includes development of the HIDDEN (Eysenbach, 2005) system which "as an XML application ... [and which] conforms to the W3C's RDF Specification" (Eysenbach et al, 2001a).

Utility of these systems in Information Retrieval is made evident in each discussion, and supported by additional Reviews, e.g. **Semantics & the Medical Web: a review of barriers and breakthroughs in effective healthcare query** (Lorence & Spink, 2004), and **an introduction to the Semantic Web for health sciences librarians** (Robu, Robu & Thirion, 2004). Robu et al (2004) provide a simple introduction to the Semantic Web, using examples at a junction between health informatics and health sciences librarianship; given that the latter is a career often founded on providing indirect access to appropriate health information resources, the bridge is an inherently natural one.

In discussing the concept of Semantic Search, Lorence and Spink (2004) cite Hendler (2003), the aforementioned Boulos & Roudsari (2002), and Berners-Lee, Hendler, and Lassila (2001) concerning the Semantic Web as a general concept. Importantly pertaining to the proposed Resource Collection Interface, the authors discussed several other developments in Web Search as promising directions, not strictly limited to semantic web, labelling them as **metasearch**, **niche search**, and **peer mediated** (or peer validated) **search**, as follows:

1. **Metasearch:**

*“...involves identification and labeling of various medical terminologies. A terminology is by definition a kind of ontology; and [it] should ideally preserve the relationships between numerous terms. By labeling or tagging a resource with clinical codes, it automatically establishes relationships between this resource and related, tagged resources available through the Internet.”* (Lorence and Spink, 2004; paraphrased from Deacon, Smith, and Tow, 2001)

Boulos and Roudsari work explicitly folds the concept of metasearch into their semantically searchable database by means of ICD-9-CM coded health and medical web resources, and a resource index using Top Level categories. Since my **Resource Collection Interface** has at least one top level concept (for instance: hydrocephalus), and at most a small range of non-mutually exclusive ones (for instance: spina bifida, hydrocephalus and related conditions) that can be handled by multiple non-mutually exclusive categories, a fully ICD-9 (or 10) compliant metasearch is not necessary. However, working with one health support network at a time as dictated by the Framework describing the generalization of this Thesis Project to other **Health Information Resource Provider & Support Network** domains also allows exploration of whether or not ontologies exist for each specific health or information subdomain, and if any of these are already in use by the Network.

2. **Niche Search:** Numerous articles (e.g. Muramatsu & Pratt, 2001; Marable, 2003; White & Roth, 2009; Langford, 2010; Singer, Norbistrath & Lewandowski, 2012) indicate that the majority of studies of Web searching using commercial search engines highlight the frustration with search engines that return a number of Web pages that are of no use or relevance for that user.

*“A niche search engine, in contrast, can zero in on specific topics and different levels, such as healthcare, mental health, or a specific mental disorder. Niche search engines bypass unrelated data, making it possible to find the information sought far more efficiently. Niche search engines cater to a specialized*

*community or sub-population. As such, they can be designed to find and index documents about e-health, medical treatment, or related resources. In a niche search, the search engine trawls the websites of defined healthcare entities to retrieve and catalogue a variety of information resources. One specialized version of a niche search used in healthcare is the subject gateway approach. While the foundational concept of gateway searching and of organizing access to Internet resources has long been used in computer and information science, there has been rare application to health-specific searching. The fundamentals of this approach involve Internet resources that are selected for their quality and relevance to a particular target audience. They are then reviewed, and resource descriptions are created and stored, generally with the associated metadata, in a structured database. The consequence of this effort is to improve the recall and especially the precision, of Internet searches for a particular group of users.”*  
(Lorence and Spink, 2004; paraphrased from Flake et al, 2002)

The importance of this discussion to the Thesis cannot be overstated: the pilot project approach had, by definition, found a niche to explore. It is a process which, as described, is half automated (the initial search for concepts) and half hands-on (the librarian or informatician’s role in the assessment of appropriate resources to be collected). Better resource control, for example stricter adherence to programming proper semantically-searchable metadata, might permit the process to be fully automated. But automation hinges entirely upon the full adoption and utilization of metadata standards by web programmers, and until then remains more or less beyond the scope of this Thesis.

3. **Peer mediated / validated search**, according to Lorence and Spink (2004), may overlap with both concepts of metasearch and niche search. It is defined by circumstance in which the search is conducted by another person familiar with the subject area, and results presented in a particular form for the end user.

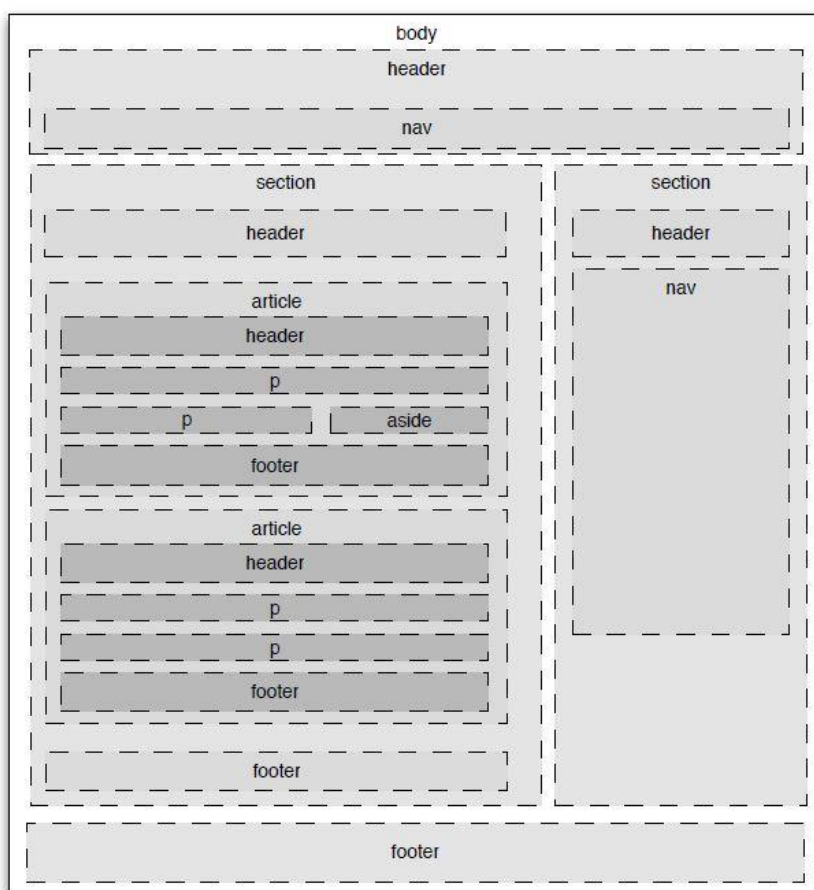
This definitely overlaps precisely with the last piece of the discussion on niche search, above, when the ‘peer’ is a librarian or health informatician’s versed in the subject area.

## HTML5 and Web Semantics

There is a relatively recent development that is fundamental in distinguishing the technical specifications of the Resource Collection Cards, which represent each individual record, in my prototype from its historical precedents: past projects such as Eysenbach's HIDEEL (2005; Eysenbach et al, 2011) and Kamel Boulous and Roudsari's HealthCyberMap (2002; Kamel Boulos, Roudsari & Carson, 2002a) were developed in an era in which metadata initiatives were thought to be the one true path to the semantic web. Semantics were to be built into the head tags of HTML documents and where semantic *searchability* didn't necessarily mean semantic *structure* of a document, but rather how well did the head tag follow one or another of the metadata initiatives. The problem with this approach was, as previously discussed, one of buy-in: if web developers didn't adhere then their web page failed one or another metadata initiative's test of semantic searchability. It turned out that there was a better way to do things than clutter a document's markup with multiple initiatives' metadata requirements.

Soon after HTML5 was introduced as a living standard so was the idea that HTML5 itself could be extensible in much the same sense as XML had been, but in a slightly stricter way: HTML has always had defined tags, and HTML5 simply introduced a set of semantic structure tags to help define the body structure of an HTML5 semantic web page (Kurtuldu, 2012; Lee, 2016; W3C, 2018).

Figure 2: One example of a HTML5 Semantic Structure Map



(Lee, 2016)

In fact, any tag that tells both the browser *and* the human who is inspecting the HTML markup, in plain language, what is its function is a semantic tag. So that if a ‘tag’ wasn’t doing something semantic, it is just good practice to replace it with something that *does* describe its function. For instance, one of the more commonly seen sectional HTML4 tags ‘div’ or ‘span’ might now be meaningless; but could be *extended* into having a semantic meaning by including a class attribute like **subject heading** which tells the browser and the markup inspecting human what it means, how it’s to be interpreted, and most importantly how it can be searched. It’s then up to the markup creator to ensure that the div class ‘subject heading’ has some specific meaning, appearance, and structure that distinguishes it from other div. This is meaningful for my development of the Spina bifida & Hydrocephalus Resource Collection because it means I was able to look to existing XML-based, RDF-compliant, collections of resources for guidance on

how to structure a record; translate from their XML into a semantic HTML5 card; then adapt *it* according to what RDA suggests and made sense for each of my Resource Collection records. I also found it useful to consult HTML5 and CSS semantic libraries such as Bootstrap to replace ambiguous CSS classes with unambiguous semantic ones.

## Chapter 3: Results

Table 7: Chapter 3 Summary

This Chapter follows chronologically from the first major section of Chapter 2, concerning the Needs Analysis Subproject; and is used to inform the Resource Collection development because of the way the two Projects have been intertwined by preceding discussion: every Result described in this Chapter should and in some cases absolutely *must* have been used to influence the design, implementation, and contents of the Resource Collection. Even some of the discussion in the second half of Chapter 2, on the Resource Collection's technical design, is influenced by the findings in *this* Chapter because their chronological order made it possible or necessary.

The two surveys that provide the data for the Needs Analysis generated 20 surveys; but with up to 60 data points for some questions because they were repeated for three different time periods (before diagnosis, immediately after, and longer term). Survey sections allowed all self-identified and voluntary responses in the form of categories: demographic Data (and membership rationale); reasons for seeking information; habits for finding information, formats used and the participant's own assessment of their utility and usefulness; and experience of the search process, which was left large and open ended to allow users to provide lots of qualitative data to motivate flexible and attentive development of the Resource Collection.

All responses in this first section are quantitative, so frequency analyses could be done (and charted) if desired. If the response sample had been large enough for statistical relevance, these questions would give meaning to comparison by Province of residence (and the Rural/Urban distinction could be used to explain resource availability); however, because it wasn't done, this is mentioned only for Future Design reference.

## Demographic Data

Table 8: Demographic Data Sources

How Survey Questions Refer to Demographic Data	CAN#	BC#
Member of the Spina Bifida and Hydrocephalus Association of Canada	N/A	1
Province/Territory of Primary Residence	1	N/A
If Province has its own Association, respondent is member of it as well	1A	N/A
Respondent is member of other Provincial or Territorial Associations	1B	1A
Specified 'other' Provincial or Territorial Associations	1C	1B
Respondent Resides in Urban or Rural location	2	2

All 20 respondents' questions were included in analysis of demographics; as nothing in this section was left unanswered or spoiled with a third option. That lack of spoiled data is ensured exactly because no print surveys were included: the online survey system *required* one or the other answer to continue.

Table 9: Analysis of Demographic Data

Demographic Data	Yes	No	Total
Member of the SBH Association of Canada	17	3	20
If Province has its own Association, respondent is member	17*	3	20
Respondent is member of other Provincial Associations	2*	18	20
Respondent Resides Urban (Yes) or Rural (No) Location	15	5	20

One respondent who is a member of an Association outside of their home Province is a member of the Nova Scotia Association, but a resident of rural Newfoundland. This is interpreted through later responses by the same individual to have been a necessary circumstance and not a deliberate choice (since neither necessity nor choice was explicitly acknowledged by the respondent as motivator, PAR allows for interviewer re-assessment based on additional data available of the four Maritime Provinces, only Nova Scotia and P.E.I. have Associations). The respondent can't be a member of his home Province *because it doesn't have one*. Fortunately for the individual none of the Provincial Associations in Canada impose residency restrictions for membership.

The other respondent self-identifies as being from the B.C. interior, and is a member of both the British Columbia and Alberta associations. As with the previous case, rationale for being a member of multiple Associations (including the Canadian one) is not pursued

directly, given limitations of the method of data collection; but based on similar responses it is interpreted for current design purposes that residents of rural locations put more effort into finding physical resources that are further afield. This interpretation is made despite certain expectations the researcher had of the reverse being true (with geographic proximity being preferred to limit expense) because it is definitely worth investigating with a larger sample size in further research. Because it is more advantageous for present synthesis to assume this trend true in general, the digital Resource Collection should consequentially include a few pointers to *brick-and-mortar* resources such as Associations' headquarters, Clinics, and Libraries; which can in turn point to print and other resources not included in the Resource Collection. And more may be added over time if those included are appreciated by the user base.

**Table 10: Analysis of Demographic Data Regrouped**

Province	Region	Total	SBHAC Member	Province Member	SBHAC Only	Province Only	SBHAC & SBHABC
BC	Urban	13	11	11	2	2	9
BC	Rural	4	4	4	0	0	4
AL	Urban	1	1	1	0	0	1
MB	Urban	1	1	0	1	0	0
NL	Rural	1	1	1*	0*	0	1*
		<b>20</b>	<b>17</b>	<b>17</b>	<b>3</b>	<b>2</b>	<b>15</b>

This table represents another way to group the respondents. In this view of the small respondent population it's clear that rural-residing members are inevitably members of both the Canadian Association *and* the most geographically proximate Provincial Association – whether or not their home Province has an Association to join. Reasons for joining both having an apparent association with rural residence could be an interesting pattern to pursue with a larger sample size and proportionately similar representation from Provinces without an Association of their own (Ontario, Newfoundland, New Brunswick) as Provinces with one. If the finding repeats with a larger sample it could directly bolster the other observation that rural residents also seem to seek more physical (and social) interconnectivity with the SBHAC research and

patient community at greater distances from their home locations. I took from both observations a clear requirement that the Resource Collection function as a platform to enhance interpersonal and inter-organizational connectivity (in addition to its basic goal to provide information). This finding *will* repeat itself in later Tables, as evidence builds.

### ***Questions Which Establish Respondent's Reason for Membership***

**Table 11: Questions which Establish Respondent's Reason for Membership**

<b>Question Spelled Out</b>	<b>Q#</b>
Why are you a member of the Spina Bifida and Hydrocephalus Association?	3
What is the nature of your diagnosed condition(s) / the conditions of the individual(s) in your care?	4
Explain your responses to the previous two questions	5

Questions in this second section and all subsequent questions are asked identically in both surveys, so that the surveys responses can be combined into one data sheet. Additional rationale for the combination is due to a post-Survey Period revelation that the National Association had additionally been recruiting members through *all* Provincial Associations (B.C. included): meaning that the National data set is *itself* a comparison between Provinces, but far too small a sample size (average between one and two responses per association) to correlate to those others. Future Directions may include pursuing larger sample sizes directly from other Provincial Associations.

Q3 and Q4 are quantitative, so frequency analyses could be done if the sample size is large enough. Additionally, if the sample size is large enough, responses (to subsequent questions) could be analysed in categories according to the responses from Q3, which specify the member type. Q4, though similar, will *not* be used to compare responses. Its frequencies influence the distribution of items in the proposed Resource Collection for each user population. It is meant to prompt users to consider all subsequent responses to questions in the context of the medical condition specified in Q4 and needs which arise from that condition.

Q5 is qualitative. Analysis involves mining responses for additional context and guidance on designing the Resource Collection prototype to suit member needs, especially if respondents do not provide enough of a list of specific information needs for inclusion.

**Table 12: Analysis of Membership Rationale**

<b>Member Type</b>	<b>All</b>	<b>Hydrocephalus</b>	<b>Spina Bifida Meningocele</b>	<b>Spina Bifida Myelomeningocele</b>	<b>T</b>
Patient	0	2	2	2	6
Parent	0	3	5	5	13
Researcher	1	<ul style="list-style-type: none"> <li>• Daily support to all SBHAC Members</li> <li>• <i>Exclusive</i> reliance on Internet for support work</li> <li>• Categories: Treatment and Management</li> </ul>			1
<b>Total</b>	<b>1</b>	<b>5</b>	<b>7</b>	<b>7</b>	<b>20</b>

The 2 Hydrocephalus Patients (respondents #11 and #16) concur on a lack of resources for their parents just after diagnosis at birth, except attending neurosurgeons. Both note increased autonomy for medical decision-making and availability of Internet-based resources with the launch of Internet Service Providers in their respective communities.

One of the patients diagnosed with Spina Bifida Meningocele indicated an atypical experience: no mobility handicap. This compares to a parent's comment in another Survey that not all outcomes are the worst case predicted by resources. I interpret this as justification for Members to temper the "worst case scenario" leaning Resources in the collection with their own more positive experiences. A Comment Section allowing anonymous (but human) responses to Resources will serve this purpose.

Responses from Patients or Parents were focussed on providing additional clinical context that can't be used for analysis or synthesis given the sample; but often reflect a need and desire for ongoing clinical, informational, and social support networking (surveys by respondents #1-5 and #13 especially). All responses indicated congenital diagnoses. Consider, though, that the distinction between acquired and congenital cases makes sense only for hydrocephalus: even when not diagnosed at or before birth, Spina Bifida is assumed to have developed prenatally.

Having this subdivision included in Question 4, in fact, led to an elderly Patient with Spina Bifida Myelomeningocele (respondents #8 and #9) responding in Question 5 with confusion and insistence that since the Survey was not written exclusively for them, and reiterating a perception that the Resource Collection would not help them either, they would not provide any further data. So, there are more spoiled responses to that respondent's two Surveys, though neither Survey Response set is excluded: all information – no matter how brief – is important to a Participatory Research method. Respondent #8 is needed to clarify a few responses to #9, and vice versa.

To account for this observation the revised Survey used in Data Collection Phases #2 includes a simplified Q4 listing just the three conditions (Hydrocephalus and the two Spina Bifida onset variants) instead of attempting to distinguish sub-condition classes such as acquired versus congenital conditions or obstructive versus communicating Hydrocephalus. Whether the diagnosing clinician noted additional issues like Agenesis of the Corpus Callosum or an Arnold-Chiari Malformation, each of which contribute to the development of Spina Bifida or Hydrocephalus, was initially recorded but not carried forward through analysis (or synthesis). The small sample size necessitated removal of these findings as unreliable for deriving meaning; as did the fact that some entries included one or the other of Agenesis or Malformation in cases where that made no diagnostic sense given additional details provided. My assumption is that Survey respondents just ticked everything that sounded familiar, even if not actually relevant.

Respondent #10's answer to Question 5 relates that initial information provided by a clinical team was *literally* her worst case: her child was not expected to survive delivery. However, I have interpreted this as consequence of emergency delivery which was also noted in detail, and not specifically due to a Spina Bifida Meningocele diagnosis. So, this is not the 'worst case scenario' which is alluded to above by respondent #7; nor the confirmation of a similar concern that come from #11 (Q9, 13, 18), #6 (Q8, 18) as detailed in later Table summaries. These indicate concern that resources tend to predict the worst-case scenario of the *symptoms and long-term effects of diagnosis* – inherently

following survival with the condition into youth, young adulthood, and beyond. More about those responses are included within subsequent analysis.

### ***Questions Concerning Information-Seeking Behaviour***

Table 13: Questions Concerning Information Seeking Behaviour

<b>Questions Spelled Out</b>	<b>SE Q</b>	<b>Q#</b>
Did you or someone who helps you seek any information about Spina Bifida or Hydrocephalus before you were (or the person in your care was) diagnosed with a specific form?	1	6
What was your motivation for seeking information previous to diagnosis? Did your search turn up results later reflected in the medical diagnosis?	1	7A 7B
[After a diagnosis was provided] when, and in what context did you seek out additional information?	2	9
[After a diagnosis was provided] how had your process of looking for health information concerning the medical condition changed (if at all) compared to the scenario in the previous time frame?	3	12

Sequence indicates whether or not a question is from the section for pre-diagnosis searching (1), post-diagnosis searching (2) or long-term and ongoing searching (3).

Questions 6, 9, and 12 refer to the act of searching for information. Q6 is purely a yes or no, to be elaborated upon by Q7. Answers “No” skips the section completely.

- Is Sequence 1 favoured by persons with an acquired condition or persons caring for an individual with a condition? (Note that no other groups make sense)
- Did information seeking behaviour change or add new media and formats between Sequence 2 and 3?
  - Did strategy or the process evolve?
  - Were new resources required or discovered?

Answers will be used to shape the **design** of the proposed Resource Collection; and the type (e.g. media or format) of resource included as appropriate.

Table 14: Analysis of Information-Seeking Behaviour

SEQ	Q#	Useful Patterns
1	6	Only 3 respondents indicated resource consultation before diagnosis: <ul style="list-style-type: none"> <li>• #12: Parent of an infant with Spina Bifida Myelomeningocele</li> <li>• #13: Parent of an 18-year old with Spina Bifida Meningocele</li> <li>• #16: Patient with Congenital Hydrocephalus reported Parent's search</li> </ul>
1	7A	Parent's motivation for seeking information before diagnosis: <ul style="list-style-type: none"> <li>• #12 &amp; #13: Coping, self-information, treatment &amp; management, anticipating future needs</li> <li>• #12: need to relay info to another parent</li> <li>• #16's Parents: Need for social, educational, medical support</li> </ul>
2	9	Context for information seeking after diagnosis: see text below
3	12	Long-term changes in information-seeking behaviour: see text below

Question 6 responses provide the first indication that a few Parents interpreted Sequence 1 as an opportunity to discuss their needs between prenatal prognosis of Spina Bifida or Hydrocephalus and postnatal diagnosis of the condition covered by Sequence 2, which the majority acknowledged being where they began seeking information. This was my intent as Researcher and Survey designer; but I hadn't anticipated that *no* Patients other than myself understood that Sequence 1 could be answered by their Parent or Guardian, even given my own two examples. Granted, the elderly respondent had no such opportunity; which likely exacerbated their insistence that the Survey was not tailored to their needs. To correct this oversight the distinction between Sequences was dropped when the Surveys were simplified between Data Collection Phases 1 and 2 (see Appendices for comparison).

Responses to Question 7A were initially mined just for those who had answered 'YES' to 6; which are included in the Table above. However, respondent #17 must also be included. Instead of conducting a search before diagnosis of their first child (the patient with Spina Bifida), they consulted resources before the birth of their *second* child in the event that he or she was also diagnosed. Although not how I intended the question answered, the value of their input was clear enough to appeal to the flexibility of Action Research data collection and analysis to include it anyway: the respondent was motivated by need to understand genetic predisposition and to gain personal contacts

and information, in their words “now that we knew Spina Bifida was part of our family” whether or not a second diagnosis was made. This is an important lesson for Resource Collection development: it further evinces the requirement that the collection foster social engagement by individuals and agencies on top of its core goal of providing information. However, it also demonstrates that specific resources for families are as important as for the patient or individual care provider, which can also be seen in respondent #12’s response about the need to relay all the information she found to her spouse (in her words the father of a youth with Spina Bifida).

Question 7B was answered clearly only by one (non-researcher) respondent, who confirmed that information provided at diagnosis was vague and not-comprehensive but at least accurate. The lesson for synthesis is to avoid vague or too-specific resources when adding to the Resource Collection; but always to provide an opportunity for users to assess resources as a community. For instance, one could use either the mentioned planned built-in Comment system or a Feedback page or link could be included; although the latter lacks transparency and community interaction, so might be included *with* the Comment system and not *instead* of it.

For Question 9 I included ***when respondents first sought information*** in the event that I had a larger data pool and could group things according to era (expecting more physical resources pre-internet, for instance), but observations cannot be grouped meaningfully given the small sample: of the 20 respondents, less than half provided a year (let alone month, which was included only once). Otherwise the question referred only to *context* of information-seeking, not further defined because I wanted to leave interpretation of what context meant to each respondent open to interpretation. Respondents who did not spoil this question or leave it blank were typically, but not exclusively, from the Parent/Guardian group as anticipated: patient respondents would have had to find their own parent or guardian to fill in this question or know their parents’ information-seeking context from prior discussion considering that all patient cases were congenital.

New parents wrote of the immediacy of finding resources, whatever they might be, right as they returned home from the hospital.

Initial human sources for parents included pediatrician (1), neurosurgeon or specialist (3), nurses (3), doctors and other unspecified clinical professionals (4), support workers (1); all of which were consulted 'in hospital' in the perinatal period. An array of text-based information sources was concurrently consulted by parents, including: books, textbooks, and medical journal articles from university or hospital libraries; and the Internet, including university and hospital pathfinders – collections of relevant links on the subject. Parents consulted both online and offline sources whenever possible (for instance: all of those who said they did not initially consult the web *could not have done so anyway*, as their child was born before the advent of the Internet).

Answers to how respondents' process of looking for health information concerning the medical condition changed over time (Q12) were in-depth and contained abundantly useful data, but not as initially intended. Removing blank, duplicated or "no change" non-responses left just over half of 20 useful responses; and each appeared at a glance to provide significantly more data for mining given that each response was paragraph-length and multifaceted. Making use of the extra data, though, required a change to the analysis plan: although belonging to the group of questions originally intended only to help shape the design of each resource collection *record*, only one obvious resource design lesson common to all responses was found: metadata must include headings that can be cross-indexed to find all similar results among all headings (headings which will be more obvious after additional analysis of further questions).

I found, rather, that responses clearly would be useful in shaping the other two aspects – on the one hand suggesting specific *resource categories* for inclusion, and on the other hand enhancing the meaningfulness of the resource collection to the user. Addressing meaningfulness, as with previous and upcoming analyses, impacts the design of layers *other* than the specific records. This alteration to the analysis plan can be made by appeal to the flexibility of the Participatory Action Research Method.

Table 15: Additional Analysis of Q12 - Resource Types

Survey	Variation from Prior Search Habits	Resource Types
5 10-12 17	Sought more medical community and/or parent experience	Online & Brick-and-Mortar support networks; especially with clinical and parent support groups
13	Everyday items adapted to infant with SB/HC; Early childhood development and education resources <i>- Query: do latter resources differ greatly from non-SB child?</i>	- Adaptive technologies - Toys, clothing (incl. how to sew own) - Early Childhood: cuddling, engagement, pattern repetition - Other Early Childhood Education
11 16	- New importance of Self-Care - Direct consult with care providers	Signs and Symptoms, Treatment, Management
10		Physiotherapy, Appointment Management
20		Medications
6 13 18	Information needs constantly evolving: currently researching (2 infant child, 1 age unknown)	(Spina Bifida related) - Bowel and Bladder issues - AFOs, Botox (child non-mobile)
1-3 11 16 20	More attention to Library Resources as those increased in sophistication (and availability from Internet) <i>- Observation: More interest in academic resources than anticipated</i>	<b>Resource &amp; Interface:</b> - Link to other Libraries/Collections? - May include 'academic' resources (in addition to consumer health ones)

A few of the survey responses have definite lessons for interface design; for instance, respondents #5, 10-12 and 17 lead me to deduce, through their greater reliance on medical community and parent experience, that similar users would benefit from a Resource Collection which is designed both to foster or enhance existing interpersonal and inter-organizational connectivity and social engagement by individuals and agencies on top of its core goal of just providing information. If this statement looks familiar, it's because it follows a recommendation of how to analyse demographic data seen in Table 8 combined with observation about making use of responses to questions 7A from the discussion following Table 10. That in turn is rationale for recommending the same kind of technical enhancement of the Resource Collection Interface as was mentioned there:

a page-dependent way of adding comments to the interface of individual records, opening each resource to discussion and value-enhancement by users.

Likewise, given the possibility of intended users having infants with constantly-evolving needs, as in surveys by respondents #6 and #18 (and to lesser degree #13) the Resource Collection's design in general requires a way for user to request or even to *recommend* new resources and resource categories that could be manually added to the Collection. A simple Feedback page would be sufficient given the current design parameters end at manual (human-moderated) evaluation and inclusion of users' suggestions; and is already planned given discussion about Question 7B's solitary response in this section. As in the discussion following that finding, there is value in also monitoring resource recommendations and requests made by the community in the Comment system which will be attached to each Resource page. But regularly applying Comment Section input as new records for the Collection might require a higher degree of moderation of the Resource Collection site than I can provide (unless taken over by the Spina Bifida and Hydrocephalus Association, which is possible) so will be applied on a case-by-case basis, as brought to my attention, until a better moderation process can be implemented in a consistent manner according to the principles of ongoing Participatory Action Research.

### ***Questions Concerning Information-Seeking & Formats***

Table 16: Questions Concerning Information Seeking & Formats

<b>Questions Spelled Out</b>	<b>S1</b>	<b>S2</b>	<b>S3</b>
What kind of information did you seek?	7	11	14
What sort of PRINT information sources did you consult?	7C	10A	15A
What sort of ELECTRONIC information sources did you consult?	7D	10B	15B
What sort of HUMAN information sources did you consult?	7E	10C	15C

These questions address specific **format** findings and will be reflected by updated *electronic* resources in the collection on the same subjects. Each Survey response generates three distinct data entries, which may be marginally to mutually exclusive.

Even though there were only 20 Survey participants, asking the same question three times for three different sequences returned more data for each possible inquiry –

although the large number of spoiled or blank entries reduced usable responses to well below 60 each. One valuable observation with respect to responses is that there isn't an obvious preference for one type of Resource over another within each sequence, but at the same time there's an increase in reported consultation of *all three* resource types between the period before diagnosis and the two post-diagnosis periods. This was expected, but it is highly validating to see it reflected in the data.

**Table 17: Available Data on Information-Seeking & Formats**

<b>Questions Spelled Out</b>	<b>S1</b>	<b>S2</b>	<b>S3</b>
What kind of information did you seek?	7	13	11
What sort of PRINT information sources did you consult?	6	11	9
What sort of ELECTRONIC information sources did you consult?	4	11	9
What sort of HUMAN information sources did you consult?	8	15	11

When exploring the kind of information that persons sought, without further specifying the resource type (print, electronic, or human); it's worth differentiating between the three sequences. "Kind" tended to be interpreted by parents as meaning something akin to subject areas, though not specifically defined subject headings. Responses evolved from more general in the earliest sequence to more specific in the later sequences, and more focussed on the methods and sources that provided most relevance for information seekers. This observation supports the ELIS model of information Seeking Behaviour put forward by Savolainen and advanced by others that not only does information seeking behaviour have impact on information seeking experience (with respect to success finding answers *and* satisfaction with answers) but information seeking experience will moderate future information-seeking behaviour.

### **General Information Seeking Habits**

Initial analysis plan for questions 7, 11 and 14 was to include them as checks and balances for the questions mining information sources utilized by respondents – in print, electronic, or human form – and to only use that information to recommend specific Resources categories for inclusion in the Collection. But on further discussion with experts about the findings seen in the full data extraction, and in reference to the flexibility of Participatory Action Research analysis, I decided to refer in more detail a

discussion about how information-seeking habits changed over time (as indicated in the Table below), and to use that information to guide the general Design of the Resource Collection's interface. All responses that filled in less than two of the three questions provide no means of comparison, as that requires at least two to be filled in. So, for instance, surveys by respondents #2, 4, 7-9, and 15 are left out because all three answers are left blank; but also #14, 16 and 19 only had one entry. Fortunately, in each of these one-entry cases, that one response was repeated in more detail by the questions oriented to the form of the resource, so no data was lost.

Many respondents, especially #13, provide quite a few specific Resource ideas for the Collection; but more importantly they provide a human Everyday-Life Information-Seeking context for each potential Resource's inclusion, which would not otherwise be evident from the Print, Electronic, or Human resource specifying questions.

**Table 18: Kind of Information Sought**

#	What kind of information did you seek?
1	<p><b>Before diagnosis, 1980:</b> most people involved were extremely surprised. Luckily, one physician, his grandfather, realized that something was irregular. Within a few days, we were seen at a central hospital where early tests using CAT scanning confirmed the diagnosis. There was very little information shared with us except we knew that these early scans were sent to Toronto for confirmation.</p> <p><b>After diagnosis, in the 1980's:</b> [we felt that] patients and their caregivers were not supposed to search for answers but were to believe the experts and not question the diagnoses or prognoses.</p> <p><b>Long-term:</b> [search undefined because] as the person with the condition is now an adult, he manages his own care. <i>This can be compared to recent Patient responses, who provide far less data (intentionally?)</i></p>
3	<p><b>At diagnosis:</b> I needed information about care and long-term needs.</p> <p><b>After diagnosis:</b> Any special care that would be needed, not yet accounted for by previous information. Information provided to, not searched by respondent.<sup>2</sup></p>
5	<p><b>After diagnosis:</b> We were given a complete lesson all about spina bifida, excellent help, no better clinic than the one at [BC] Children's Hospital.</p>

<sup>2</sup> Surveys by respondents #1 & #3 share an attitude that early care was paternalistic. Information was provided to them by professionals; independent search was not accepted. But their other responses suggest this changed for the better as the Patient took over their care. This is possibly a matter of timing: the patient in both cases was a teenager as Internet emerged in their respective jurisdictions.

	<p><b>Long-term:</b> search involved whatever came our way [from BCCH contacts].</p> <p><i>Change: Early success with information provided led to respondent becoming an information-collector rather than a dispassionate information-seeker, in line with ELIS expectations.</i></p>
6	<p><b>After diagnosis:</b> I didn't seek any information until after my son was diagnosed. Then I sought articles through UBC, textbooks, doctors, and medically verified internet sites.</p> <p><b>Long-term:</b> locating a support group for parents on the internet; speaking with specialists at greater length.</p> <p><i>Change: Greater interest in medical professional and layperson resources, after their general questions were resolved by earlier text searching with some human input by a doctor.</i></p>
10	<p><b>After diagnosis:</b></p> <ul style="list-style-type: none"> <li>• Would have liked other families with whom to discuss common experience</li> <li>• Couldn't find a social worker for needs associated with diagnosis</li> <li>• New mom felt in the dark in new city, no idea where to start looking</li> </ul> <p>"We had brochures for looking for a room to stay for a week. Not knowing where to go and what our baby would now need medically was really scary there was not enough info out there."</p> <p><b>Long-term:</b> Educational information; Accessibility information; Equipment and new technology; Respite; Bowel and bladder information</p> <p><i>Change: respondents initial worries were alleviated by membership in an Association and the human resources to which it connected. Longer-term searching evolved into typical, specific information needs for a new parent with a child with Spina Bifida – by their own estimation, but supported by other respondents.</i></p>
11	<p>Patient with condition. <b>Long-term</b> only; as earlier phases handled by Parents:</p> <ul style="list-style-type: none"> <li>• What exactly is [condition] and how does it differ from other forms?</li> <li>• What Associations or social organizations for persons with [condition] are available in my region (and country)?</li> <li>• What kind of resources do they offer?</li> </ul>

12	<p><b>After diagnosis:</b></p> <ul style="list-style-type: none"> <li>• Contacted the spina bifida association for information on managing condition (also spoke to a pediatrician about what to expect)</li> <li>• What kind of care would be required?</li> <li>• Sociological: how caring for child would affect the family</li> </ul> <p><b>Long-term</b>, as child reached school age:</p> <ul style="list-style-type: none"> <li>• Fostering independence</li> <li>• School/learning aides</li> <li>• Equipment and equipment sources</li> </ul> <p><i>Change: Little difference in resource types sought. Comparison to other responders indicate this user has a higher confidence with their own internet searching; their searches trend from general to more specific over time, and are primarily about childhood development and coping instead of just clinical responses.</i></p>
13	<p><b>At Diagnosis:</b> My son was diagnosed at 32 weeks, so once we knew it was spina bifida, I went to the [Spina Bifida and Hydrocephalus] Association of NL [Newfoundland], and also went to the pediatric hospital to meet the transportation team, see the ICU, etc. I would be in another hospital and I needed a place to 'see him be' in my mind. I researched spina bifida exhaustively - which was a little harder than now [in 1994, internet not being what it is now]. My son was not expected to live and indeed to this day I am told that his specific condition is not compatible with life.</p> <p><b>After Diagnosis:</b> how to stimulate him, how to get him to suck as he didn't have that ability, feeding information, ways to help him thrive... At 2.5 months of age, I had him sucking and feeding on his own. He was saying mom-mom and dad-dad at 8-10 months old, playing with a truck while lying on his side, laughing, etc. Not bad for a kid with a 'not compatible with life' scenario!</p> <p><b>Long-Term:</b></p> <ul style="list-style-type: none"> <li>• I looked for ways to comfort him</li> <li>• When he came home, I looked for ways to stimulate, comfort, play with, live with, encourage</li> <li>• When he continued to live, and grow I looked for the perfect toys, the most caloric and fat filled soft foods I could find to help him thrive, adapted his clothing because of the size of his head, adapted his toys</li> <li>• As he reached his milestones, I looked to find ways to stimulate and integrate, ways to deal with each new medical condition as it cropped up and find out what they were all about. I bought my own medical reference books, and kept seeking information</li> <li>• When feeding tube was introduced, I found out how to dress it, how to keep it [operational and safe]; when scoliosis and lung disease cropped up, I got information and life experience on that. When 6-hour seizures took most of our energy and lives, I found out ways to deal with that. Etc.</li> </ul>

17	<p><b>At diagnosis:</b> Wanted to know why myelomeningocele was not diagnosed immediately at birth. No satisfactory answer provided.</p> <p><b>After diagnosis</b> (SB with rare Spinal Disorder called ‘hydromyelia’): we got most of our information from the neurosurgeon and other parents that we knew.</p> <p><i>Change: laypersons (other parents) used as new resource, connected via SBHABC. This was possibly a negative reaction to the poor initial diagnosis turning the respondent off clinical resources generally, but the neurosurgeon is still a noted trusted resource because of their expertise.</i></p>
20	<p><b>After diagnosis:</b> Anything that would prepare me for what to expect when my son was born and then what I could expect when he would be growing older</p> <p><b>[Long-term]:</b> Effect of medication; cognitive ability in a child with spina bifida; bowel and bladder management plans.</p> <p><i>Change: initial general search habits were much more general than later ones. Longer-term searching evolved into typical and sometimes specific information needs for new parent of a child with Spina Bifida.</i></p>

The respondent to Survey #18 is a Researcher who interacts with stakeholders of the Spina Bifida and Hydrocephalus Association of Canada on a daily basis. His or her response to this question is not included in the Table above because it can’t be assessed for a ‘change’ in search habits. Their input in the three phases relates to whether or not her *clients* are seeking information at a diagnosis, after one, or at a much later phase in life. So, for instance, her clients who just received a diagnosis in the family may request:

*Background information about the condition, how it is caused, how it is diagnosed (prenatally and after birth), if it can be prevented, finding specialists who can assist with the conditions, what other assistance and/or organizations can provide funding and/or services.*

Those who are looking for information following a less-recent diagnosis seek that which is most pertinent to current living and coping with the condition: clinical treatment of symptoms; methods for home management of the condition; new medical procedures that are being used to correct the condition’s side effects; and locating support networks and medical professionals within their geographic region who can assist. Long

term information needs, other than variations on the near-term ones just listed, include any [grey literature *or* academic sourced] news on new procedures for therapeutic surgeries, including perinatal surgeries, and their success rates.

The researcher lists diagnosis of “later-onset” forms of hydrocephalus and how it compares to the congenital forms of the condition as a chiefly long-term interest; though in this case I interpret their submitting this as long-term only in that it’s not something that troubles clients who have received a past diagnosis for themselves or their child of a congenital form. To that end, I have also interpreted her use of the term “later-onset” to refer either to trauma-acquired or to normal-pressure hydrocephalus, both of which affect adults in later life, and have no evident link to early childhood susceptibility to neural tube disorder (unlike all congenital forms).

### **Consulted Information Resources (Print, Electronic, or Human)**

Individuals who reported consultation of Print resources at any phase list the use of booklets and pamphlets from their local clinic, video and speaker transcripts, medical reference books, and journal articles. When reported, libraries and clinics were the major source (more or less in equivalent measure) for this sort of information. That observation supports an earlier finding that parents – especially in the pre-internet age – consulted anything and everything possible to find in print, so long as it carried authority as either a trusted clinical resource or a trusted information organization. In fact, at least one respondent’s entire answer to one of the three Print Resource questions was “anything I could get my hands on”. Print resources were by and large consulted only when electronic resources (such as the internet) or human ones were not handily available. Two responses in particular speak for the other respondents in that respect, first, in response to 15A (third sequence):

*[#18:] I have not (lately) located new information in print form. I hope that the newest information will be available on internet.*

Preference for internet-accessible information, even given availability of print resources, follows a trend of their consulting Print Resources only because those were what was available early in the lifespan of the patient. Their response to the second-sequence (10A) noted that, post-diagnosis, one of their preferred “print” sources was second-hand information printed off the Internet. Respondent #17 indicated similar use of quite a range of Print resources (library resources, association pamphlets, newsletters, and transcripts of speakers at public forums) but felt strongly enough about higher usefulness of human resources to repeat the content of another question’s response:

*With our second pregnancy, which resulted in a child who did not have spina bifida, we did obtain considerable information... Now that we knew spina bifida was a part of our family, we felt it was our responsibility to find out as much as possible. We... have read much but think that the personal contacts of this process are most helpful.*

My primary takeaway from these observations is that the Resource Collection may move entirely past cataloguing physical resources; so for instance there is no point in including a record based on the solitary Survey turned in during the second Phase of Data Collection, as its content was essentially a detailed request to include a catalogue record for a video series with print supplements on Spina Bifida care and lifestyle management; which is only available in physical format through one particular Spina Bifida and Hydrocephalus Association. Survey respondents who did mention consulting similar resources did not identify ‘video’ as an Electronic resource if it came with print materials. If on its own, however, they might have (but as will be shown in the analysis after Table 13, would also be passed over in favour of Internet-accessible resources).

Nearly all respondents who used electronic resources during any of the three phases of information needs indicated the Internet as their primary source. One respondent (#5) phrased this as “always looking online for new ideas” then, akin to several other respondents, further specified their search tool being Google. Several other users listed Spina Bifida Association websites’ contents for all except their most recent search

habits. One user followed a combination of these two general search habits for the first two phases, then zeroed in on a particular strategy during the third. Their most recent search habits had tuned specifically to researching solutions for mobility and disability issues (in online magazines, journals, and manufacturer's websites) given earlier research had satisfactorily resolved their other concerns. Others specified their internet search habits as seeking not just Association websites' content or just whatever Google had to offer, but targeted various combinations of: e-journals, reputable healthcare provider networks other than Associations (for example hospitals or health authorities), newsgroups, blogs and community forums for parents with children with Spina Bifida or hydrocephalus, social media resources, and online library catalogues as portals to deep web resources not immediately accessible from Google (other than Google Scholar).

Traditional Health Information and Support Networks' web-portal based collections of resources follow an old Print metaphor of text-and-image-only information resources, provided as static and unchanging (except when deliberately edited), and at most hyperlinking to go between pages. The lesson for synthesis that emerges from coupling this status quo observation with analysis of Electronic Resources is this: the resource collection *may* have records for information pages that are all just traditional text and image content, with at most hyperlinks, representing a mildly changed paradigm from old Print resources; but in parallel with the movement toward Web 3.0 being the emergence of socially engaged websites, a growing portion of collected Resources must be similarly social. Blogs, forums, and social media resources need to be prominent in the Collection. Traditional static internet resources may be preferred if they provide built-in methods for providing interactivity, but it's not a deal-breaker if excluded: the interface built around each Resource summary card in my Interface will include the Comment system that allows even static resources to become social ones.

Nearly all respondents to the questions about Human resources indicated reliance on medical professionals (including doctors and specialists, nurses, allied healthcare professionals at all phases of information seeking. I think this speaks highly to the

willingness of parents and patients to accept the help of qualified medical experts; but doesn't diminish the desire to seek other opinions and not-strictly-clinical support from lay individuals who have had, or are going through, similar experiences. Indeed, a number of survey respondents also mentioned seeking non-medical professional experts in their communities; which included other parents of children with the conditions and/or adults with the condition. Some were contacted through existing Associations; others were simply encountered through offline connections. Survey respondents increased reliance on human resources other than medical professionals (especially in the later phases of everyday life information seeking) feeds back into my contention that, first, the Resource Collection design provide social interaction and second, Resources collected include a substantial number of social and social media pages so that social interaction can also continue externally to the Resource Collection.

### ***Questions Concerning Information-Seeking Experience***

**Table 19: Questions Concerning Information Seeking Experience**

<b>Questions Spelled Out</b>	<b>S1</b>	<b>S2</b>	<b>S3</b>
Regardless of whether search results matched your diagnosis: How satisfied were you with the results of your searches? <ul style="list-style-type: none"> <li>• Could Find</li> <li>• Could Trust</li> <li>• Other Comments</li> </ul>	7S	10S	15S
What was your overall experience concerning looking for health information concerning the medical condition?		8 <sup>3</sup>	13
Given experience from your previous information seeking, are the resources you will continue to use likely to change significantly?			16
Do you expect to continue to seek information about your (or if you are a care provider, your charge's) medical condition in the future?			17
Do you have any other Closing Comments that you feel would be useful to this Survey's Researcher, or to other clients of the Spina Bifida and Hydrocephalus Association of Canada?			18

<sup>3</sup> Note: Q8 and Q13 were interpreted by participants as asking the same question despite the wording being slightly different in each case. They are presented in Results as sequential versions of the same Question.

These questions were analysed to explore how to give resources **meaningfulness** to participants. The design of the Resource Collection is adjusted accordingly.

However, note that because of the deliberate openness of the Participatory Action Research method, any and all responses that clearly shape more than one of **design** of resource pages, **type** of resources, *or* **meaningfulness** of the system to its users may deviate from the above division of questions which answers only one of three.

**Table 20: Analysis of Experience – Usable Responses**

Survey	7S	10S	15S	8	13	16	17	18
1				x	x		x	x
3 <sup>4</sup>				x	x	x	x	x
4							x	
5	x			x		x	x	
6	x	x	x	x	x	x	x	x
7						x	x	
9 <sup>5</sup>							x	
10	x	x	x	x	x	x	x	x
11				x	x	x	x	x
12	x	x	x	x	x	x	x	x
13	x			x	x	x	x	x
14	x			x		x	x	
15				x				x
16		x	x	x	x	x	x	x
17		x		x	x	x	x	x
18				x	x	x	x	x
19				x		x	x	x
20			x	x	x	x	x	
T=18	6 (/18)	5	5	15	11	14	17	12

#### **Satisfaction with Information Sources (Q7S, 10S & 15S):**

Respondents #6, 10, 12 and to lesser degree 16 (who left Question 7S blank) are ideal candidates to look at for mapping the evolution of satisfaction with information sources given understanding of patterns that emerged in the prior analyses. Seekers will usually start with what seems like the most relevant source of abundant information, typically

<sup>4</sup> In the case of these questions, respondent #2 can be effectively considered a duplicate of #3; because it's word-for-word identical except where left blank compared to the other response. #8 also duplicates #9.

<sup>5</sup> See last footnote. These two surveys have self-identified as the same respondent, but #2 and #3 are unclear.

professionals; then expand outward as they acknowledge the expertise of ‘non-professional’ resources as developed through shared experiences, and generally find new resources that prove useful and relevant to their needs (so that, in addition, human resources will only be later shunned if they proved initially unhelpful or contradictory). The only limitation to doing so, as seen repeatedly in the data, is whether or not other information sources are even available to the users. Once it is available, they’ll gravitate toward it as one more resource in their information-seeking toolkit: if you build it, they will come. The following paragraphs are the result of pooling results for all three Satisfaction questions for each of these four respondents, in some cases compared to responses from some who filled in only one of the three questions.

One difficulty, often encountered, is that seekers might never find that first successful entry point into positive information-seeking. Respondent #6 (and beyond this group of three, respondent #20 too) had this experience. #6’s response across all three search periods revealed a lack of satisfaction with presented information resources, being too vague and not well-tailored to her experience or current needs, leading to relying heavily on her own instincts as a mother to address concerns rather than expressly consulting *any* kind of resource for advice. Based on her other responses this self-reliance fortunately excludes emergency situations, in which professional advice and intervention is necessary, but that her instinct can lead toward.<sup>6</sup>

Respondent #10 fits the profile of an individual who branched out from comfortability with clinic doctors and nurses working with her, toward more frequent networking with the spina bifida and hydrocephalus community and its collected resources – as necessitated through a mid-range desire just to “be a parent” and finding that difficult given that she “didn’t really understand the resources needed at the time [for] ... a child with high medical needs”.

---

<sup>6</sup> Respondent #20 expressed similar dissatisfaction with information resources, but only as noted with respect to longer-term satisfaction (15S). It’s not directly comparable, but worth a footnote.

Respondent #12 worked slightly inversely compared to #10 who moved from human resources to others: she, instead, began with internet searching but failed to find anything relevant to the unique case of her child; then found success working with a pediatrician in a spinal cord clinic to *accurately* address her needs; but acknowledged a return to a nuanced approach for long-term Internet searching (which I interpret as continued consultation of clinic resources with added internet searching given new understanding of what to look for and how to find it). Despite no comparable “at diagnosis” experience to speak of, respondent #16 indicated his similar strategy for searching had evolved through early successes communicating with medical professionals, adding internet as it became available, and applying lessons learned from professionals to help guide his own future search; with the added benefit, with respect to relevant medical-information acquisition, of being a medical professional himself.

A few respondents only completed one of the three Satisfaction questions: one is a very recent case and can only speak to satisfaction with resources at the Children’s’ Hospital spina bifida clinic in her jurisdiction as a general rule, not tied to any information-seeking after diagnosis since she hasn’t had that experience yet; two others had lots of answers for *other* post-diagnosis questions but concerning satisfaction left all but ‘at diagnosis’ blank. These two indicated degrees of dissatisfaction and information avoidance: one felt she was misinformed by prenatal information resources, so didn’t look for anything further; the other felt pressured not to even look for information given that their child’s survival after a complicated birth was in doubt, and priority was on making sure he pulled through. In fact, she was told to hold off on seeking information because “it was not a priority” but also it was not even “deemed needed”. Interestingly, this most negative experience led to the respondent developing the most robust information-seeking behaviour of all survey respondents (utilizing all three types of information resource as thoroughly as possible), and in the long-term having one of the more positive information-seeking experiences. But this is clear only when other responses to other questions are taken into account. Without them, since she left 10S and 15S blank, this would not be as evident. The last two respondents, who only

responded to one question expressed their satisfaction with resources as very much dependent on what they could find: one (respondent #20, see most recent footnote) directly expressed dissatisfaction with the perceived non-specificity of resources she sought; the other said she did careful research and triangulated all findings to ensure that any resource she used was of value. I felt it necessary to look outside this subgroup of questions to her answer to Q18 for more guidance on how to address this statement in my Resource Collection design:

*I recently tried to access some up to date information regarding pregnancy and those at higher risk of spina bifida. I did not see anything that was helpful [from] either the local or national association; and [I] received no response to emails from either group.*

The respondent relies upon the Association for information, as is evident from this and other responses. This totally justifies having a better, more user-tailored resource collection as I am developing with this Thesis; and incidentally speaks to another category of information resource that might be available on the Internet, but not immediately obvious and not currently found in the Associations' respective current web link pages. It will be added to the list of Resource categories to add to the new Resource Collection; as will the previously mentioned comment system method for ensuring that help from the community can overcome delays caused by, for instance, "no response to emails from either group". Doing so should also help diminish the concern expressed by respondents #6 and #10 for when found resources aren't sufficiently tailored to the information-seeker's own experience; although it will be up to Future Directions of post-Thesis analysis to determine how true that assertion is.

I expected few responses concerning satisfaction with searching *at or before* diagnosis (resulting in a low response rate to Q7S) as opposed to afterward (Q10S, 15S) given the significant size of the subgroup of respondents for whom those questions were irrelevant. Patients with a congenital or prenatal condition, being the whole patient group, instantly reduced the eligible respondent pool to 13 Parents and one Researcher.

**General Experience (Q8, 13, 18):**

The fact that question 8, about overall search experience in the immediate aftermath of a diagnosis, was answered by nearly every respondent whether or not they were even capable of searching for their own purposes *almost* contradicts the former expectation that persons who can't speak to their own needs at diagnosis wouldn't do so. However, three (#7, 11 and 16) who were diagnosed at or near birth share a rationale for their responses that resolves the seeming contradiction, namely that a past information seeker conducted searches for information that would serve them. Respondents wanted that past information seeker's experience to be on the record as prefacing their own.

Respondent #7 indicated that all information seeking was done only by medical professionals; and that consultation (presumably with their parents') of those human resources had generally positive results. The respondent left no data in Q13 for direct comparison between experience summaries (Q8 versus Q13); but their responses to other questions indicate that once they came of age enough to assert control over their own medical care they consciously diversified their information-seeking to all manner of human, internet-based, and traditional print resources – with preference for digital equivalents of what would have formerly just been print resources, for example articles and books.

The other two respondents referred specifically to their parents' experience:

*Respondent #11: It wasn't my experience at the time, rather my parents. From what I've been told their understanding and emotional reaction to information offered varied greatly depending on the information source (all of whom were medical professionals, as no other resources were known to them).*

*Respondent #16: [My parents experience seeking information was] the same at diagnosis as before it, but with added immediacy during any emergent situations. Resources remained fleeting and oriented mainly to human information sources.*

In Q13 both respondents acknowledge a later experience much like Respondent #7: once they came of age enough to take responsibility for their own medical care and information needs, both made use of a much wider array of information sources, keeping the old but adding new ones as they became available. Within all three respondents' statements is an explicit acknowledgement that emerging technology played a part in determining the ready availability of appropriate resources. This is an example of negative information experience (the experience of limitations to availability of information) moderating behaviour until the negative is resolved (it becomes available through the emergence of new technology), allowing new behaviour to create new experience; which in turn affects new behaviour, and so on. One respondent stated this experience as follows:

*I appreciate the [difference in] available resources from limited (my own family and caregivers) to wider scope.*

*However, I am ambivalent about [usefulness] of these resources. With the exception of ... this Association, I am concerned that ... clinical information available [on the internet] is not taking advantage of [people's experiences]. What if it deals too heavily in the 'worst-case scenarios' that are not a part of my experience, without giving me context from other experiences or voices. Can I still [use] its other information, or will that come with the bias too?*

Both respondents indicate early reliance on human resources by their parents that evolved to include a wide array of others as they took over their own care; which is consistent with past findings about the evolution of information-seeking behaviour. These findings are supported by expectations set forth by the ELIS methodology, namely that information-seeking behaviour is as shaped by information-seeking experience as information-seeking experience is impacted by information-seeking behaviour. Human resources will invariably be the first point of contact with health information for new parents. Resource utilization will gradually expand to include other methods whether or not the initial point of contact provides accurate, meaningful, and helpful information;

but will differ in nature depending entirely upon positive or negative experience. Positive experience tends to keep that resource in the toolkit even as new ones are found (and sometimes new ones are found *through* the old ones); whereas those who have negative experiences with human resources will tend to move away to different ones more readily as they find those alternatives.<sup>7</sup>

The latter observation concerning Patient information-seekers is mostly corroborated by Parent respondents; however, their responses to Q8 and Q13 are not generally directly comparable to responses by patients, so this has to be assessed on a response-by-response basis. What causes the incomparability of the totality of the data set is as follows: the patient group responded to these two questions strictly in terms of what they looked for, how they looked for it, and where (as can be seen on the previous page); whereas parents related experience in much more emotional terms of the toll that diagnosis, scarcity of information at diagnosis, or even outright misinformation at diagnosis had on their attitudes toward information-seeking as a general practice. The following Table demonstrates Parent's responses to one or both of the questions, where complete responses were given, using their response to question 18 (which elicited any additional comments) to add details or frames of reference as needed.

---

<sup>7</sup> Findings imply that information-seeking parents will keep positive human resources in their future toolkit, and discard the negative ones. While this might seem obvious, anecdotally, it's good to find support for that conjecture both in the ELIS literature *and* in findings from the Survey.

Table 21: Analysis of Experience – How Parents Describe their Experience

S#	Q8: After Diagnosis	Q13: During Ongoing Care	Q18: More Comments
1	<blank>	I would have liked more information from the medical profession. Now, there is a wealth of information available on-line for parents, this is a good thing but there needs to be a guide. Speaking from experience, if I had believed everything I was told by "experts" then the outcomes could have been very different.	I believe that this information needs to be filtered somehow... There is so much information available to parents and caregivers it is probably over-whelming and perhaps harmful. Too little information may in fact be less harmful than too much unfiltered information.
3	In 1980s, there was little information and support for parents of children with this condition.	I wondered if my own experience was reflected at all in the literature. There was none.	There was a lack of information on these conditions in the 1980s and I was expected to believe the medical experts (although they were sometimes incorrect). There is now an explosion of information. But I believe that a huge amount of unmonitored information can be almost as damaging as too little information.
6	My son has a less severe case than most [but] the whole time I was pregnant, I was expecting the worst. I found I should have left the research until after he was born.	I am leery because I have realized that each child or diagnosis is very different from the next. I have learned to go circumstance by circumstance with my child.	I find majority of the information on Spina Bifida goes right to the worst-case scenario; while I do understand [that] this is important, it made me a paranoid mother the first few years of my son's life.
10	Was in shock and looking for any information on SB we could find and the clinic gave a few pamphlets but not enough detail info was on hand at the time it was too overwhelming	Still find it difficult to gather information at the transition stages at 5 years 12 years and 16-18 very hard to follow the needs of changes equipment and needs of the individual changes socially is more difficult also need more info about life skills and adaptations and recreation	
12	Much [prenatal information] I got was inaccurate according to my child's pediatrician. I showed him some of the written info I received and he said it was at least 10 years outdated... At about 24 weeks' pregnancy, when my son's ventricles were growing in his brain... I was told my child "might not have any brain matter". But my child's pediatrician told me later he had never seen such a thing.	Networking with professionals is paramount, knowing who to ask for what help you need is important. I am still meeting new people and learning about new things all the time. Human contacts are the most useful. Health care professionals with experience with other children with spina bifida are the MOST valuable resources!	I think SBHABC could provide contact info for a medical ethicist to answer questions (especially before child is born). I think it would be helpful if parents with questions could be linked up (phone/web) with parents willing to offer answers based on life experience to date.

13	Looking up information immediately after his birth was not a priority, or deemed needed.	I've searched, I've needed through haystacks, I've buried myself in journals, I've asked professionals, I've asked parents, I've figured things out for myself and ended up being called by the professionals to give some talks to med students, give suggestions and help with OT issues, make things for kids & offer solutions.	[My son] is unique and I must mostly find my own way with this one... I have become my own best source of information.
14	Talking with other families who have gone through it before and what to expect in the future as my child ages is important. He has been a unique case within the diagnosis and have gone through more than the regular person who lives with the condition.		
17	Our child was born at a time when some parents were not even told of the existence of a spina bifida medical clinic. We met with a marvellous genetic counsellor, every doctor we dealt with was exemplary in their contributions of information, nursing staff was very helpful.	Now that we are in the age of the computer, we make good use of that tool.	I recently tried to access some up to date information regarding pregnancy and those at higher risk of spina bifida. I did not see anything that was helpful at either the local or national association and received no response to emails from either group.
19	My family was well taken care of, information wise.		My daughter had very minor problems as compared to others with Spina Bifida and we have medical professionals in the family. She is now in university and functioning very well. She/we are very much on the lucky side concerning the condition.
20	The doctors overwhelmed me with the negative things that could happen to my son and all the things that could go wrong. I was overwhelmed with the variety and intensity of information on spina bifida.	My son is a special case as he doesn't have hydrocephalus and he [can walk] without assistive technology. What we look for we generally can't find in academic articles/internet because the former is what seems to always be discussed.	

All parents are interested in continuing to seek medical information to support their child (meaning they answered “yes” to Q17), regardless of his or her current age; though expectations of whether or not the kind of information resources they used could change in the future varied somewhat at the extremes (meaning they also answered “yes” to Q16): new parent #14 felt resources they would seek may change in the future, which is probably quite rightly motivated by their communication with other new parents; whereas two parents who identified as having adult children (#1 and 3) also expected changes in resource use, presumably though use by their adult child. Other parents, who included at least one other parent of an adult child, expected to continue to make use of the same type of resources in the future as they had in the past (‘no’ to Q16); although, given discussion above and below, I interpret that consistent use of resource *types* in one’s toolkit doesn’t preclude differences in rates of use of resources, nor does it preclude amassing different specific resources within each type.

Trends in this data subset differ mainly as a result of experience just after the point of diagnosis (Q8, first column). Experiences which are initially positive (#17 and #19) add to users’ willingness to seek further information at a later stage, although success varies depending on whether or not new information that is not previously sought is needed. Of the two respondents with definitely positive initial experiences, #17, whose response to question 7A above (see p 46) places the timeline of this response to Q18 at just before their second recent pregnancy, had low opinion of the ease of finding information relevant to their new emergent need. This was in spite of the human resources with which they had previously found success; though probably because it wasn’t relevant to use those same resources. I assume they thought that a quick call to the Association or perusal of its information resources would be less of a hassle. So, on the one hand, just providing a resource on that topic would be sufficient addition to support a need addressed in the Survey. But, also consider, if the Resource itself had included a way to discuss the topic with peers who had a similar issue, many of their concerns might be addressed by one who had been looking into it beforehand. If this did

not, though, provide a specific answer, at least it could provide a moral support and create a new networking opportunity.

Experiences which are negative, or at least inconclusive, tend to colour the expectations of parent information-seekers. One respondent reflected previous analysis that parents would prefer resources that avoid the worst-case scenario since all it might do is create unnecessary anxiety for a parent whose child does not later show worst-case-scenario development. Another spoke to a concern that, while having no information made for a negative early experience, having too much unfiltered information was just as disconcerting. The Resource Collection is, by design, meant to address this latter concern directly; but the former can be addressed through careful selection of resources to be included. Resources must avoid worst-case information unless necessary given other valuable page information; and in that case discussion on the resource should be immediately triggered to soften its negativity as thoroughly and as soon as possible.

Some respondents, like #12 and 13, recognize that just because early resource experiences were misleading doesn't mean that others won't be as problematic, given differently nuanced information seeing behaviour can lead to a more positive information-seeking experience.

*Networking with professionals is paramount. Knowing who to ask for what help you need is important. I am still meeting new people and learning about new things all the time. Human contacts are the most useful. Health care professionals with experience with other children with spina bifida are the **most** valuable resources!*

*I think [the Spina Bifida and Hydrocephalus Association of B.C. or Canada] could provide contact info for a medical ethicist to answer questions... I think it would be helpful if parents with questions could be linked up... with parents willing to offer answers based on their life experience to date.*

In addition to making a positive from a negative experience through deliberate and concerted information-seeking behaviour modification, as with respondents #12 and #13; it speaks to a trend of parents having more desire to help other parents by appealing to the experiences (positive and negative) which they had, that can then be turned into learning and teaching experiences to share in various environments:

*I've searched, I've needed through haystacks, I've buried myself in journals, I've asked professionals, I've asked parents, I've figured things out for myself and ended up being called by the professionals to give some talks to med students, to give suggestions and help with OT issues, to make things for kids, to offer solutions.*

Taken together these both support the idea that the Resource Collection can also be a social platform designed to maximize usefulness, meaningfulness, and relevance of included Resources. One represents an individual who thinks that contact with medical professionals and parents is valuable; and the other represents a parent and self-made expert who would be willing to provide information on contact with persons needing informational (or moral) support.

Methods for accomplishing the social platform are suggested above; and the consequent chosen and programmed methodology that defines My Spina Bifida & Hydrocephalus Resource Collection is presented in detail in the following Chapter. It is presented as Synthesis of the Survey Data that was listed and analysed in this previous Chapter. It is realized as the Design parameters for:

1. The Resource Collection interface;
2. Layout of the Collection's individual resource pages & embedded metadata;
3. A preliminary list of subjects and keywords for indexing Resources which must be included at Resource Collection prototype launch;
4. The method by which major subject headings are further specified and keywords are cross-referenced.

## Chapter 4: The Resource Collection

Table 22: Chapter 4 Summary

This Chapter describes the whole implementation process for the Resource Collection; following design parameters established in Chapter 2's second Section, from which it follows in direct chronological order. This includes defining the Resource Collection Interface, for at least this prototype version, as having a blog format; which allows the use of UVIC's own blog instance, keeping the project inside the UVIC systems scope. This wasn't mandated by UVIC's Human Research Ethics Board, but would surely be appreciated as even further mitigating the assessed minimal risks of the Project. Given the Needs Analysis made clear that users would appreciate a means for feedback to communicate with one another and with the Blog administrator (currently myself) this is described and shown next. How Resource Categories are defined and displayed follows; and demonstrations of Resources included within Categories, and how tags can be used to cross-reference Resources at a level more specific than Categories. The Chapter also notes two current (near) Future directions of the Resource Collection Project, which are out of Scope for this current Thesis but will be developed into a distinct Project at a later date: linking members of the Spina Bifida and Hydrocephalus Associations to the public version of the Resource Collection, and longitudinally assessing their response to the Resource Collection in both the feedback forms and interactions with other users in reference to the Resources.

### *Implementation Process for the Resource Collection*

#### **Established a Resource Collection Interface**

...Such that the Resource Collection Interface adheres to User Requirements which were exemplified in the Needs Analysis Chapter.

Although not explicitly backed up by collected User Data, I believe there is a preference for electronic resources that use *familiar* web designs. My evidence is the preference for familiar resource *types* as found in the Needs Analysis. For that reason, a **blog** format

was chosen for the Resource Collection Interface; surely it is a familiar web design for most users, whether novice or otherwise. Using a blog template also allows the Resource Collection prototype to be designed and managed within UVIC-owned and managed web technologies: UVIC has its own WordPress instance, the *Online Academic Community* (<https://onlineacademiccommunity.uvic.ca/>), which is...

*...an initiative of the University of Victoria... The OAC was created after extensive consultation across campus, and meets the personal, professional, and academic needs of UVIC students, faculty, and staff. The OAC has more than 100 up-to-date and customizable themes, allowing users to create their own unique blog or site (UVIC Technology Integrated Learning, 2017c)*

Any blog created on this Site can be maintained so long as a member of the UVIC student body or staff remains the primary administrator. Because I qualify as both, the blog ownership simple changes from being student owned to a UVIC staff owned resource, without changing hands.

The URL for the prototype Spina Bifida & Hydrocephalus Resource Collection, currently accessible to all internet visitors – but restricting direct contributors to UVIC students, staff and faculty – is: <https://onlineacademiccommunity.uvic.ca/sbhcrdemo/>

This is a temporary URL, and will be finalized in the post-Thesis period of development to not include ‘demo’ in the name.

Figure 3: Resource Collection Main Page

**SPINA BIFIDA & HYDROCEPHALUS RESOURCE COLLECTION**  
 Partial Fulfillment of the Requirements for the Degree of MASTER OF SCIENCE in the School of Health Information Science

HOME HYDROCEPHALUS SPINA BIFIDA RESOURCE TEMPLATE ABOUT ME PROJECT BACKGROUND CONTACT

## ABOUT THE RESOURCE COLLECTION

Welcome to the Spina Bifida & Hydrocephalus Resource Collection, hosted by the [Online Academic Community](#) (a WordPress Blog) at the University of Victoria. This Blog is a Project developed in Partial Fulfillment of the Requirements of my Masters of Science degree in the [School of Health Information Science](#) at the University of Victoria (2019). Navigation around the Blog is partially contained in the panel above...

HOME HYDROCEPHALUS SPINA BIFIDA RESOURCE TEMPLATE ABOUT ME PROJECT BACKGROUND CONTACT

- The **HOME** page is the *About The Resource Collection* section which you're reading now
- The next two links navigate to **HYDROCEPHALUS** or **SPINA BIFIDA categories**. Hover both links to see that you can also navigate directly to several **subcategories**, decided based on consultation with members of the [Spina Bifida & Hydrocephalus Association of British Columbia and of Canada](#)
- The **RESOURCE TEMPLATE** is for those of you who are interested in technical details. This site *indexes* useful Resources online via **Resource Cards**, each of which provides some identifying information about its resource according to a catalogue standard called [Resource Description and Access](#)
  - Resource Cards have, internally, another layer of navigation: **tags** allow cross-referencing of several non-subject-related Resources
- **ABOUT ME** provides me a place to give you my background as a person living with **congenital non-communicating hydrocephalus**, and how my own information seeking history and interaction with others doing the same was the primary motivator for this Thesis project
- **PROJECT BACKGROUND** follows from this historical discussion into the initial work that went into the Project; including all of the project's supporting paperwork that may be shared with the Public in non-editable forms
- The **CONTACT** form allows the Resource Collection's community to recommend new resources, new categories, and new Site content (as well as to comment on moderation issues) *directly to me*

**SEARCH**

Search ... **SEARCH**

**ARCHIVES**

Select Month ▾

**HYDROCEPHALUS**

- Diagnostics
- Treatment
- Lifestyle
- Community Events
- Social Media

**SPINA BIFIDA**

- Diagnostics
- Treatment
- Lifestyle
- Community Events
- Social Media

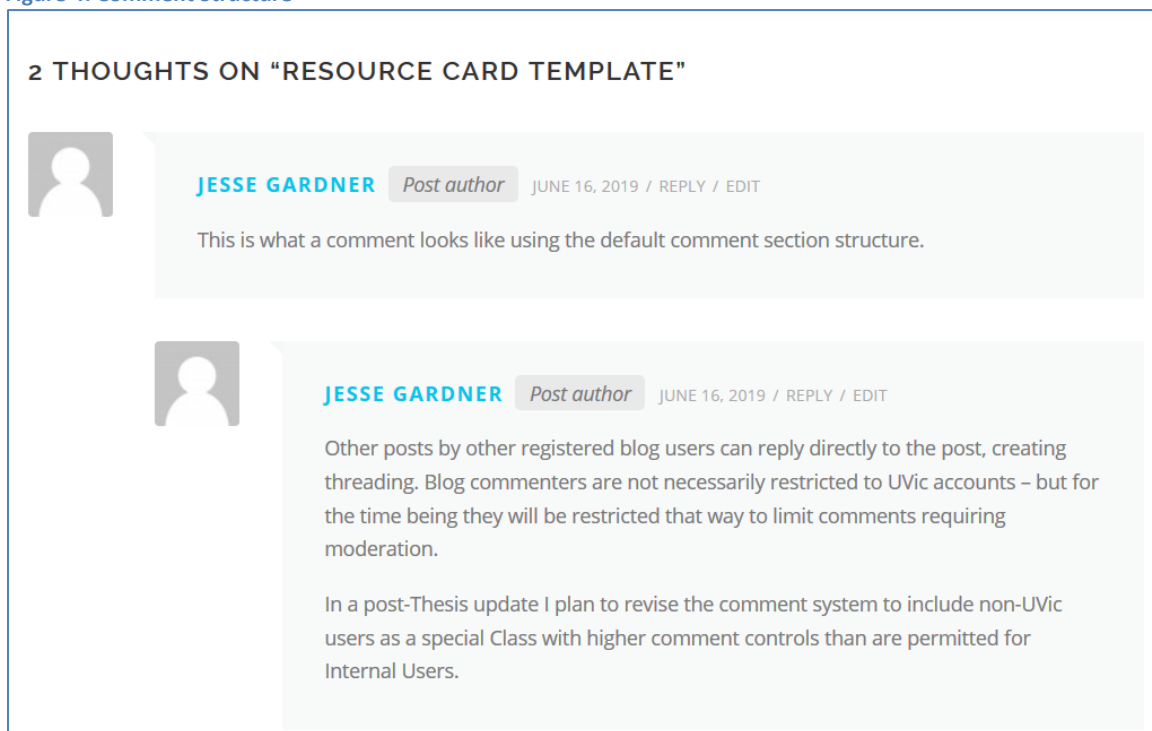
## Added a Feedback Feature

...so that Resource Collection Users have better control over dictating future updates, resource inclusion, and content changes.

Data which speaks to user experience (rather than to specific search terms) are used to inform the visual design and technical add-on features of the Resource Collection Interface, as described in the **Data Analysis** section of the previous Chapter. So, for instance, multiple analysis results speak to the need for a social dimension built into the Resource Collection. The OAC blog system allows the implementation of such a feature: all pages (which may be static or defined by category) and even each post can have a **Comment** feature attached. Comments can be moderated before posting, limited to certain kinds of users, allowing a high degree of control over content posted without alienating the potential user base (UVIC Technology Integrated Learning, 2017b).

Most importantly, since all comments remain on the OAC blog, near future research concerning their content may need only seek Ethical approval from UVIC's own Ethical Review Board, advantaged by not having left UVIC servers let alone geographic borders.

Figure 4: Comment Structure



### Established Resource Categories

I then translated collected data from the Needs Analysis to a set of searchable terms and phrases according to high-level concepts of RDA-compliant bibliographic control, focusing first upon the subject headings. Using a blog interface also simplifies the process of maintaining and displaying resources as grouped by major subject headings: the OAC follows WordPress implementation of **categories** to let 'bloggers group their posts together, making it easier for [a] reader to tell what the post is about.' (UVIC Technology Integrated Learning, 2017a). To avoid unnecessary clutter on the blog interface, only a limited number of non-mutually-exclusive categories are linked on the main interface, though others will be available if enough resources are added that don't adhere to the primary categories but would belong to their own (and not a tag instead).

The visible categories, which were determined through the Needs Analysis project completed in Chapter 2, include the following titles.

1. *Diagnostics* (signs and symptoms, diagnostic technologies, etc.)
2. *Treatment* (medications, therapies and interventions, etc.)
3. *Lifestyle* (assistive technologies, nutritional and exercise needs, etc.)
4. *Information and Support Networks* (associations, medical facilities, etc.)
5. *Social media resources*

Each of these titles are duplicated on the interface with respect to each of **spina bifida** and **hydrocephalus** resources, expecting more than a few will apply to both categories. Users seeking spina bifida resources may find either exclusively spina bifida related resources or mixed ones, and hydrocephalus information seekers can find hydrocephalus related resources or mixed ones.


This needs to be done to avoid giving potential users the impression that the Resource Collection is ‘not for them’ because they didn’t see their medical condition represented in the categories. Consider the patient user case in the data analysis who chose not to productively respond to the survey because they saw that the first few questions dealt with information seeking experience just at the point of a diagnosis of either medical condition (which can’t technically apply to *persons with* either medical condition and was instead intended to reach *parents or prenatal caregivers*) and assumed that they were not the target audience for the survey. Similarly, if a person with *spina bifida* (or caregiver of a person with spina bifida) with this mindset were to open any particular category and find *hydrocephalus* resources at the top of the page, they might not bother scrolling down to find the relevant spina bifida ones. Minimizing this sort of interaction is highly desirable. **Categories** are then manifested as self-updating blog pages, where each one is a *single* category. Cross-referencing is then accomplished using other categories shown *for each post* and by **tags** found inside each individual post – and which have their own grouping pages (see p. 81 for details and a representative figure).

Figure 5: Sample Categories Page

**SPINA BIFIDA & HYDROCEPHALUS RESOURCE COLLECTION**  
Partial Fulfillment of the Requirements for the Degree of MASTER OF SCIENCE in the School of Health Information Science

[HOME](#)   [HYDROCEPHALUS](#)   [SPINA BIFIDA](#)   [RESOURCE TEMPLATE](#)   [ABOUT ME](#)   [PROJECT BACKGROUND](#)   [CONTACT](#)


**CATEGORY: HYDROCEPHALUS**  
All Hydrocephalus Resources



[HYDROCEPHALUS - COMMUNITY EVENTS / HYDROCEPHALUS - DIAGNOSTICS / HYDROCEPHALUS - LIFESTYLE / HYDROCEPHALUS - TREATMENT / SPINA BIFIDA - COMMUNITY EVENTS / SPINA BIFIDA - DIAGNOSTICS / SPINA BIFIDA - LIFESTYLE / SPINA BIFIDA - TREATMENT](#)

**Spina Bifida and Hydrocephalus Association of British Columbia**

Title: Spina Bifida and Hydrocephalus Association of British Columbia  
URL: <http://www.sbhac.org> Variant Title: Spina Bifida & Hydrocephalus Association of British Columbia  
Place of Production: Vancouver, British Columbia Canada  
Name of ...



[HYDROCEPHALUS - COMMUNITY EVENTS / HYDROCEPHALUS - DIAGNOSTICS / HYDROCEPHALUS - LIFESTYLE / HYDROCEPHALUS - TREATMENT / SPINA BIFIDA - COMMUNITY EVENTS / SPINA BIFIDA - DIAGNOSTICS / SPINA BIFIDA - LIFESTYLE / SPINA BIFIDA - TREATMENT](#)

**Spina Bifida & Hydrocephalus Association of Canada**

Title: Spina Bifida and Hydrocephalus Association of Canada  
URL: <http://www.sbhac.ca> Variant Title: Spina Bifida and Hydrocephalus Association of Canada – It's About Life  
Place of Production: Winnipeg, Manitoba Canada  
Name ...

**SEARCH**

**ARCHIVES**

▾

**HYDROCEPHALUS**

- [Diagnostics](#)
- [Treatment](#)
- [Lifestyle](#)
- [Community Events](#)
- [Social Media](#)

**SPINA BIFIDA**

- [Diagnostics](#)
- [Treatment](#)
- [Lifestyle](#)
- [Community Events](#)

## Populated the Resource Collection with Resource Cards

I then used the set of terms or phrases generated during analysis to begin to develop a collection of resources, where each resource is represented by an embed within a single blog post. Each resource record is written in HTML5 with a mind to an XML-like semantic structure, markup languages supported by WordPress and therefore also the OAC. Posts are organized to support RDA rules for resource retrieval (recall that RDA is language independent but that its known XML compliance allows later upgrade to RDF). Addition of Resource Cards to the collection will continue indefinitely, as long as the Resource Collection remains in use and under iterative development.

Figure 6: Generic HTML5 Resource Template

<b>Title:</b>	<i>[Proper Title]</i>
<b>URL:</b>	<i>Hyperlinked URL spelled out, for instance <a href="http://www.sbhac.ca">http://www.sbhac.ca</a> Opens in new Tab</i>
<b>Variant Title:</b>	<i>Variant Title</i>
<b>Place of Production:</b>	<i>Refers to place of Production, Distribution, or Publication (Is-A-Tag)</i>
<b>Name of Producer (Author):</b>	<i>Or Name of Producer, Distributor, or Publisher (Is-A-Tag)</i>
<b>Year of Production:</b>	<i>May substitute Last Edit or Publication Year (Is-A-Tag)</i>
<b>Mode of Issuance:</b>	Integrating Resource
<b>Note On Title:</b>	Proper Title is as seen in Document, Variant Title is from Page Tab
<b>Note On Issuance:</b>	<i>Last Date resource was accessed by Resource Collector</i>
<b>Media Type:</b>	Computer
<b>Carrier Type:</b>	Internet Resource
<b>Extent:</b>	1 Webpage
<b>Language of Content:</b>	<i>Primary language in which content is written</i>
<b>Illustrative Content:</b>	<i>Does the Resource have Images? [ Yes / No ]</i>
<b>Color Content:</b>	Color
<b>Work Manifested:</b>	<i>Repeat Title &amp; Hyperlinked URL</i>
<b>Other Person or Corporate Body Associated:</b>	<i>Additional credits for content displayed on the Webpage (Are-Tags)</i>
<b>Relationship Designator:</b>	Issuing Body
<b>Summary of Resource Content:</b>	<i>Description on multiple lines. RDA Prefers Document Body as authority on content, Source Code on Metadata only used as last resort.</i>
	<i>For example: this Record is a Sample of the Resource Card Template including RDA-compliant Headings and content explanations. Some content is the same for <b>all</b> Records, such as 'Mode of Issuance' above (notice: these are colored black) whereas others depends on the specific Record (these are light blue in the current Template).</i>
	POSTED IN <a href="#">COMMA SEPARATED SUBJECT CATEGORIES THAT HYPERLINK TO EACH CATEGORY PAGE</a>
	TAGGED <a href="#">COMMA SEPARATED TAGS THAT HYPERLINK TO ALL POSTS WITH EACH TAG</a>

The Template demonstrates a full RDA-compliant record of a web resource. Blue italicized text will differ depending on the characteristics of the resource itself but will be presented without either formatting in a true resource – they’re included here only for clarification. Non-formatted text in this image is included exactly as shown for all possible web resources, as required by the RDA template. Some fields are hyperlinked as tags (denoted *Is-A-Tag*), in order to provide deeper cross-referencing than by

category alone. Note also that RDA recommends that if a field is not easily filled in by consulting the resource itself, it should be left blank (without even the heading).

Figure 7: A Resource Collection Page based on the HTML5 Template

## Spina Bifida & Hydrocephalus Association of Canada

POSTED ON [JULY 25, 2019](#) BY [JESSE GARDNER](#)

---

<b>Title:</b>	Spina Bifida and Hydrocephalus Association of Canada
<b>URL:</b>	<a href="http://www.sbhac.ca">http://www.sbhac.ca</a>

<b>Variant Title:</b>	Spina Bifida and Hydrocephalus Association of Canada – It's About Life
<b>Place of Production:</b>	<a href="#">Winnipeg, Manitoba Canada</a>
<b>Name of Producer (Author):</b>	<a href="#">Spina Bifida and Hydrocephalus Association of Canada, SBHAC</a>
<b>Year of Production:</b>	2019
<b>Mode of Issuance:</b>	Integrating Resource
<b>Note On Title:</b>	Proper Title is as seen in Document, Variant Title is from Page Tab
<b>Note On Issuance:</b>	Last Date Accessed by Resource Collector = July 25, 2019
<b>Media Type:</b>	Computer
<b>Carrier Type:</b>	Internet Resource
<b>Extent:</b>	1 Website; 20 Webpages
<b>Language of Content:</b>	English
<b>Illustrative Content:</b>	Yes
<b>Color Content:</b>	Color
<b>Work Manifested:</b>	<a href="#">Spina Bifida and Hydrocephalus Association of Canada</a>
<b>Other Person or Corporate Body Associated:</b>	<a href="#">Tim Nicholson, XtremelySocial (WordPress Page Theme Author and Host Site)</a>
<b>Relationship Designator:</b>	Issuing Body

**Summary of Resource Content:**

Spina Bifida & Hydrocephalus Canada is a federation of 13 organizations working collectively on behalf of people with Spina Bifida and/or Hydrocephalus. [Their] volunteer national board of directors is comprised of representatives from member associations across the country. Their mission is to improve the quality of life of all individuals with spina bifida and/or hydrocephalus and their families through awareness, education, advocacy and research, and to reduce the incidence of neural tube defects.

The Spina Bifida and Hydrocephalus Association of Canada strives to be the leading national voluntary health organization, setting the standard for education, public awareness and research of spina bifida and hydrocephalus. [They] aspire to reduce the incidence of spina bifida and hydrocephalus and to promote independence of people living with spina bifida and hydrocephalus.

The website is a compendium of resources relating to the organization and activities of SBHAC; opportunities for donations and fundraising; bursary funding for members; research opportunities and results; advocacy, information and education; and community-building resources both online and offline.

---

POSTED IN [HYDROCEPHALUS - COMMUNITY EVENTS](#), [HYDROCEPHALUS - DIAGNOSTICS](#), [HYDROCEPHALUS - LIFESTYLE](#), [HYDROCEPHALUS - TREATMENT](#), [SPINA BIFIDA - COMMUNITY EVENTS](#), [SPINA BIFIDA - DIAGNOSTICS](#), [SPINA BIFIDA - LIFESTYLE](#), [SPINA BIFIDA - TREATMENT](#)

TAGGED [2019](#), [ADVOCACY](#), [BURSARIES](#), [CANADA](#), [COMMUNITIES OF HEALTH](#), [COMMUNITY](#), [EDUCATION](#), [FEDERATED ORGANIZATIONS](#), [FUNDRAISING](#), [INFORMATION](#), [MANITOBA](#), [MEMBERSHIP](#), [PUBLIC AWARENESS](#), [QUALITY OF LIFE](#), [RESEARCH](#), [SBHAC](#), [SCHOLARSHIPS](#), [SPINA BIFIDA AND HYDROCEPHALUS ASSOCIATION OF CANADA](#), [TIM NICHOLSON](#), [VOLUNTEER](#), [WINNIPEG](#), [WORDPRESS](#), [XTREMELYSOCIAL](#)

### Used the *tags* feature to cross-reference Resource Cards

Each HTML5 Record 'Card' is embedded in a single Post in the Blog interface of the Resource Collection, and each are organized by **category** and wherever possible are further cross-referenced by RDA-compliant concepts (Subject, Author, Keyword, Location, etcetera) using OAC's **tags** feature.

Since 'categories are typically broader than tags.' (UVIC Technology Integrated Learning, 2017a) **tags** are used – in a way which is consistent with this statement – for identifying specific bibliographic metadata like subject subheadings, authorship, locational data, and so on and cross-referencing resources that share them. But more importantly, tags provide cross-referencing of resources by keywords that apply to multiple resources in different categories, which is at once both more and less specific than a subject heading; but is entirely consistent with the above concern over sensitivity and specificity. Keyword tags must be sensitive enough to pick up semantic relationships but specific enough so that there are as few as possible that recall the *same* set of resources.

For instance, within the social category resources are and will continue to be collected on the specific *subject* subcategory of 'twitter', possibly further subdividing into tags for patient-oriented twitter versus practitioner-oriented twitter. Tags will be subdivided as accurately as possible given content of the resource into two sets – one for each condition represented: categories appear on the main page so require the differentiation, but a list of posts in a blog that is generated by a single tag (in the Resource Collection case, the Resource Cards) and is only visible *when you follow that tag* doesn't as immediately obviously require differentiation; except to main consistency. A searcher confronted by a bunch of tagged resources may be savvy enough to recognize those that don't suit his or her condition as not useful and move on to the ones that do suit his or her needs; but I have made the decision that the Interface itself should differentiate for their benefit. Tags that further specify the *subject area* represented by a category may or may not inherit the top level subdivision by condition as is necessary; so for instance the tag *spina bifida - twitter* is a **tag** found in the category

**spina bifida - social media** and not related to **hydrocephalus** – unless the resource includes information relevant also to a patient with hydrocephalus, in which case it must either **also** have that tag or just a general *twitter* tag. Tags which are not subject-related but rather one of the other RDA categories (for authorship, source of publication, geographic place of the resource, etcetera) are and will continue to be subdivided by medical condition wherever possible as they are added to the Resource Collection, while a resource that applies to both medical conditions is given a non-differentiated tag.

Figure 8: Finding a tag on a Page to Follow it into cross-referenced Resource Cards

## Phoenix Attitude

POSTED ON JULY 26, 2019 BY JESSE GARDNER

---

<b>Title:</b>	Phoenix Attitude
<b>URL:</b>	<a href="https://twitter.com/PhoenixAttitude">https://twitter.com/PhoenixAttitude</a>

---

<b>Variant Title:</b>	Phoenix Attitude (@PhoneixAttitude) / Twitter
<b>Place of Production:</b>	<a href="#">Vancouver, British Columbia Canada</a>
<b>Name of Producer (Author):</b>	<a href="#">Phoenix Attitude, Inc.</a>
<b>Year of Production:</b>	2014
<b>Mode of Issuance:</b>	Integrating Resource
<b>Note On Title:</b>	Proper Title is as seen in Document, Variant Title is from Page Tab
<b>Note On Issuance:</b>	Last Date Accessed by Resource Collector = July 26, 2019
<b>Media Type:</b>	Computer
<b>Carrier Type:</b>	Internet Resource
<b>Extent:</b>	1 Webpage
<b>Language of Content:</b>	English
<b>Illustrative Content:</b>	Yes
<b>Color Content:</b>	Color
<b>Work Manifested:</b>	<a href="#">Phoenix Attitude (@PhoenixAttitude) / Twitter</a>
<b>Other Person or Corporate Body Associated:</b>	<a href="#">Twitter</a> (Host Site)
<b>Relationship Designator:</b>	Issuing Body

**Summary of Resource Content:**  
Dedicated to creating tools to empower people, and loved ones navigating the medical system. All tools created by patient who became a practitioner!

Rising from those burned out ashes... we're here to guide you towards a far better experience with 'the system' - gaining more control, efficiency, effectiveness, emotional support and developing the 'Attitude' that will help you, and maybe one day even save you, along your medical journey and in your daily challenges.

---

POSTED IN [SPINA BIFIDA - SOCIAL MEDIA](#)


TAGGED [2014](#), [ACCESSIBILITY](#), [APPS FOR HEALTH](#), [BRITISH COLUMBIA](#), [CANADA](#), [EDUCATION](#), [INFORMATION](#), [INNOVATION](#), [MEDICAL TECHNOLOGY](#), [MOTIVATION](#), [PATIENT AS PRACTITIONER](#), [PHOENIX ATTITUDE](#), [SUPPORT](#), [THERAPY](#), [TWITTER](#), [UNIVERSAL DESIGN](#), [VANCOUVER](#)

Note the *Twitter* tag that appears both in the *Tagged* list and in the *Is-A-Link Other Person or Corporate Body* field. Following this link takes the user to a Blog Page that shows all blog posts – the Resource Cards – that correspond to the tag *twitter*:

Figure 9: Following the Tag to a Page of cross-referenced Resource Cards

**TAG: TWITTER**

---

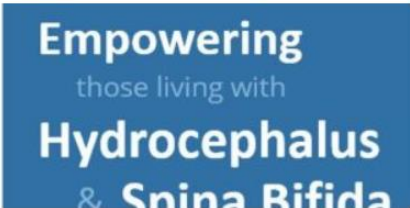


**SPINA BIFIDA - SOCIAL MEDIA**

**Phoenix Attitude**

Title: Phoenix Attitude URL: <https://twitter.com/PhoenixAttitude>  
 Variant Title: Phoenix Attitude (@PhoneixAttitude) / Twitter Place of Production: Vancouver, British Columbia Canada Name of Producer (Author): Phoenix Attitude, Inc. Year of Production: 2014 ...

---



**HYDROCEPHALUS - SOCIAL MEDIA / SPINA BIFIDA - SOCIAL MEDIA**

**Hydrocephalus Canada**

Title: Hydrocephalus Canada URL: [https://twitter.com/MY\\_BRAINWAVES](https://twitter.com/MY_BRAINWAVES) Variant Title: Hydrocephalus Canada (@MY\_BRAINWAVES) / Twitter Place of Production: Toronto, Ontario Canada Name of Producer (Author): Hydrocephalus Canada, formerly Spina Bifida and Hydrocephalus Association ...

### **Out of Scope: Link members of Associations to the Resource Collection**

I intend to provide access to the Resource Collection Interface to members of each of the chosen Health Information & Support Networks: The Spina Bifida and Hydrocephalus Association of Canada, and of B.C. by providing them with a direct hyperlink. *This will be done as the last step within the Scope and Timeline of this Thesis.*

### **Out of Scope: Assess Response to the Resource Collection**

Assessment will be done primarily in terms of perceived improvement over existing Search. *Completion of this step is beyond the Scope and Timeline of this thesis, but it can be initiated closely following Resource Collection rollout in the previous step; as a new and longer-term project to be negotiated with the Spina Bifida and Hydrocephalus Associations.*

There an option to carry on iteratively tweaking and further enhancing Resource Collection & Interface based on input; which I feel is supported through analysis found in the previous Chapter, and the observation that users' needs are highly unlikely to remain static but are generally unpredictable and hard to extract except when a patient or caregiver is completely at ease with providing voluntary input. Evidence of this assertion is that results didn't remain limited in focus even within my small sample. Predicting new users' needs would be unproductive compared to iterative design based on continuous implementation of new findings; so is best left to **Future Directions**.

## Chapter 5: Discussion and Conclusion

Table 23: Chapter 5 Summary

This Chapter wraps up the Thesis, starting with a discussion of expected Contributions of the Resource Collection to the general drive toward a semantic web for pages, resources and apps through contributions more specifically to improving experience of Everyday Life Information Seeking with a Health Information focus. Discussion of research constraints and limitation follow; along with a reminder of the Future Directions previously suggested throughout previous Chapters, in particular how this Thesis can immediately begin to inform other studies within the wider problem domain of *all* Health Information Resources online, the potential to repeat the study with a larger or more engaged and high-functioning participant group, as well as the eventual automated acquisition and inclusion of New Resources into the Collection. The Chapter ends with a general Conclusion to the whole Thesis.

### ***Expected Contributions***

The new ***Spina Bifida & Hydrocephalus Association Resource Collection*** involves all three types of search design described by Lorence and Spink (2004), averting the simplicity and potential frustrations of the call-and-answer process warned against by Singer, Norbistrath & Lewandowski (2012) – not by replacing it, but rather enhancing results through the middleware solution modelled by the Thesis above.

1. An audience was sought from which data was collected about the whole of their experience in learning about their condition, either by necessity or curiosity
2. Results of the data collection are run through a *peer mediated* step, so that contents of the Resource Collection reflect the experience of the user and their *peers*, as organized by yet another *peer* with a related condition (Hydrocephalus)
3. Results, coupled with my own expertise, are used to generate a metasearch and the on-paper conceptualization of the Resource Collection Interface
4. The Resource Collection conforms to RDA standards as a stand-in for future upgrade to full RDF (inspired by [Eysenbach et al](#) and [Roudsari et al](#)), both defined within documents compliant with evolving HTML5 standards.

5. *Peer validation* is initiated immediately at the roll-out of the Resource Collection Interface: at which point a subsequent Project will be able to answer whether or not end-users are more satisfied with search results in this peer-mediated and highly systematized model than a traditional search engine's call-answer paradigm.

The generalized instance of this model – what might be termed a *scaffolding*, since it does not obscure the original search results so much as create a top-to-bottom and cross-referential hierarchy therein – has as its ultimate goal enhancing reliability of relevant information, where relevance is defined by its users. It helps users make sense of the proliferation of health information online (by viewing them less as consumers and more as *participants* in the system design) and heightens satisfaction with results. It is expected to contribute to the literature not by creating a whole new approach, but rather by advocating use of methods not lately or effectively utilized by commercial web search, modelled in a systematic manner, and applied through deliberate involvement of peers in defining and developing searchable and expandable web resources.

### ***Research Constraints and Limitations***

The proposal for this Thesis suggested the development of an automated 'semantic web'–compatible resource collection to accomplish the process of resource collection without need for human intervention as a middleware substitute, an artifact of which is intentionally left in the title of the Thesis; however, evidence detailed later in this Thesis lent credence to the thought that doing so would create a level of complexity that interested parties *did not need or want* in order to consider the project a success. With that in mind, I propose that this further enhancement of the core Resource Collection be left for future consideration and an upgrade – particularly if suggested as a welcome future enhancement by the Collection's proposed user base.

Concerning the process of gathering potential partnerships for Data Collection, half of the Health Resource and Support Networks previously contacted for requests to participate as data sources – to which surveys would be sent to members – were federal

in scope and headquartered outside of British Columbia. In the end the two organizations selected divided equally on these parameters (one outside B.C. and one in B.C. but not in Victoria). This presented limitation in that all interaction would explicitly be technology moderated – and asynchronous except where arranged otherwise. This did not impact the Data Collection Method or its phase of operation, given that the tool was designed to accommodate asynchronous and not-collocated feedback, but it was anticipated would prevent collaborative development of the prototype.

Having selected the Spina Bifida and Hydrocephalus Association of Canada, which is headquartered in Winnipeg, the above statement about having no possible asynchronous or collocated interaction with the organization – to say nothing of its pan-Canadian members – is reinforced. How this was perceived to impact data collection was acknowledged in the **Data Collection Method** section of Chapter 3.

### ***Future Directions***

Research and results presented here may be expanded upon in quite a few different ways; each of which was alluded to in the preceding Thesis document.

### **Approaching the Wider Problem Domain**

Recall that the secondary purpose of the pilot project is to provide a model framework to be applied to any one of the following different areas:

- Health Resource and Support Networks defined by *other* medical conditions beyond those utilized here (e.g. Spina Bifida, Hydrocephalus, and related disorders served by the Spina Bifida & Hydrocephalus Associations of Canada, B.C. and other Provinces)
- Needs of Spina Bifida & Hydrocephalus Associations as experienced in other international jurisdictions beyond Canada
- Combination of the two: a wide-reaching model for the practical indexing of consumer or *everyday-life* information online, at least via an authoritative and end-user-approved subset of the information set

### **Collecting More Survey Data to Improve Reliability**

In and of itself the small number of *surveys* returned During Phase 1 is not indicative of a small number of data *points*, since interpretation of the Results themselves during with respect to 'meaningfulness' led to considering each Survey's middle sections as actually technically three different Surveys in one; in some cases tripling available data points and potentially even justifying launching three distinct Surveys during a later Data Collection to capture the distinctions between information seeking behaviour with respect to each of pre-diagnosis, post-diagnosis and long-term care more clearly. Even so there remains a Limitation concerning Reliability of the current survey results given their relatively small number compared to optimistic assumptions of volume of responses. This Limitation, though, is entirely mitigated by the fact that the Resource Collection will continue to be iteratively developed even after my Masters Program is complete; with ongoing Participatory Action Research (from surveys to direct interviews) to shape future updates and/or redesigns.

### **Automated Acquisition & Inclusion of New Resources**

With completion of the Resource Collection, launch of the first version for use by members of either Association, and sufficient time to gather User Acceptance data (itself defined in the formulation of the Thesis Question as a future consideration) it may be desirable to update the Resource Collection to better permit an *automated* process of finding and incorporating new resources; rather than having a human moderator decide on inclusion or exclusion – although the automated method must retain approval by community members. This would require one or both of two different processes:

1. A web-crawler to find new suitable resources
2. A way for the community to upload their own suggestions

Either one would only acquire the resource; inclusion in the Collection would occur after community approval. An example of the Community Suggestion module is included in the current Prototype for the system for demonstration; but is left non-functional given

that *using* it is planned for completely distinct Ethical Review and Project that can be launched at a later date with more direct participation of the Spina Bifida Associations.

As it stands the indexing system could potentially be upgraded for automation; first by ensuring that the Resource Template adheres to RDF standards (and not just RDA) and then by adding semantic rules by which either a crawled *or* suggested resource's data and metadata is translated correctly into the Resource Template. The only issue remaining would be that incompletely translatable resources might be rejected if required categories or keywords can't be populated from existing metadata, which could inadvertently reject ideal resources. This limitation can't be overcome until webpages themselves are universally designed to support semantic search, which is a key purpose of the HTML5 living standard; so, it may not be as far in the future, after all, as it appeared to pioneer web semantic thinkers of a decade and a half ago.

### ***Conclusion***

This Thesis began as an idea of how to give back to the community of Spina Bifida and Hydrocephalus researchers, clinicians, caregivers, and affected patients; in its originally planned manifestation only a web app displaying useful resources on the topic, much as can be typically found on any Association's existing website; influenced only by my own experience as an information seeker who happens to have one of the medical conditions on the SB/HC spectrum, specifically a non-communicating form of congenital hydrocephalus with additional agenesis of the corpus callosum – the combination of which technically predicted from a young age that I'd have severe cognitive and developmental disability. It's to the credit of my family, physicians, caregivers, and the information sources available at every step in my development that I didn't let those predictions hold me back from overcoming all obstacles and eventually putting those thoughts and feelings into the very fabric of this Thesis. As I began to develop the idea from a few resources to a wide array of categories of information I myself would have liked to find more readily available; I chanced upon some research about patient engagement and communities of care (both officially organized and just web-based

organic communities). In investigating the latter; I developed the idea to engage specifically with the Spina Bifida and Hydrocephalus Association of Canada, and at their suggestion also the British Columbia-based equivalent. So, my Thesis Proposal was defined as collecting information about the unique Information-seeking habits of a community of like individuals apart from myself but with broadly shared Everyday Life Information Seeking experience with specific mind to Health Information. This in succession prompted turning from a concept, learned during my Undergraduate in Health Information Science, of being led to Consumer Health Information resources online by unknown authorities, and having to find ways to parse reliability from that experience; into instead finding relevant Information resources about Health to be *lived* rather than *consumed*, curated by individuals who have lived similar experiences rather than just being trained to look at things clinically. To really make this possible meant, first, developing a Needs Analysis that would probe the participants for information about their information seeking habits; how and where they found answers to their questions; their findings and feelings about what they found; and how that would inform future information seeking activities. The Needs Analysis, in turn, informed the design and contents of a much more community-driven Resource Collection; with methods built into it for constant updating to meet new or changing user community needs; to collect new feedback and new resources from the community itself; and to foster community engagement with one another and with the resources contained.

In order to make the Resource Collection responsive to these evolving needs, without deviating from valid web standards, a technical methodology was chosen that defined Resource Cards not as an embed of the actual resource (which wouldn't, anyway, easily fit on a screen given the real estate taken up by the blog's navigation panels) but rather as a semantic text-based summary of the resource following a current Library Cataloguing standard called **Resource Description and Access**, the purpose of which is to ensure findability and accessibility of web resources through detailed description of the work, its specific manifestation and expression of that manifestation, as well as the item itself – the URL to find it online. This provides the appearance of a familiar Library

Catalogue interface slightly adapted into another familiar interface, a WordPress blog. Various blog features are fully leveraged to provide additional classification and cross-referencing of Resources; and the Resource Collection stands waiting for the next, most immediate, Project – the first one beyond the scope of this Thesis Document, in which users are invited to use the Blog and longitudinally studied in order to inform future designs, features, or resource additions; as well as to gage overall satisfaction with this method of information gathering and dissemination over less directed web searches as are much more typical of the current web – but perhaps not the future *semantic* web.

There are yet, of course, a number of potential future directions above and beyond this immediate validation of user engagement. These involve, for instance: approaching the wider problem domain and adapting the existing scaffolding that is both the Needs Analysis and Resource Collection to Other Everyday Life (Health) Information seeking domains, or even traditional Consumer Health repositories ripe for reimagining; or revisiting this Project with a much larger or at least more directly engaged and highly-functioning participant population, carefully selected for – for instance – direct interview instead of asynchronous surveying, perhaps from the same Associations, but also perhaps from yet others. For example, there are many more untapped Regional Associations just based here in Canada. Ultimately the most interesting, and likely most work-intensive of the future directions, though, would involve adapting the whole process so that the ‘middleware’ isn’t *directly* a representative Information Professional with lived experience in the particular health information resource domain – such as Spina Bifida and Hydrocephalus as is my case – but rather is only *indirectly* that same representative (or several) training and monitoring an automated script process which has the *direct* ability to acquire and include resources into the Collection. The groundwork for this enhancement has been laid by developing according to existing web and cataloguing metadata (and semantic) standards such as HTML5 and XML, RDA which can be fully adapted to RDF and other online metadata initiatives. The Resource Collection has great potential, which is precisely what I hoped for from its conception.

## Bibliography

Basu A & Dutta MJ (2008). The relationship between health information seeking and community participation: the roles of health information orientation and efficacy. *Health Communication*, 23(1): 70–79

Berners-Lee T, Hendler J & Lassila O (2001). The Semantic Web, a new form of Web content that is meaningful to computers will unleash a revolution of new possibilities. *Scientific American* (May 2001), 25–35

Boote J, Wong R, & Booth A (2015). 'Talking the talk or walking the walk?' A bibliometric review of the literature on public involvement in health research published between 1995 and 2009. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 18(1): 44–57

Borzekowski DL (2009), Considering children and health literacy: a theoretical approach. *Pediatrics*, 124(Supplement 3): S282–288

Brashers DE, Goldsmith DJ & Hsieh E (2002). Information Seeking and Avoiding in Health Contexts. *Human Communication Research*, 28(2): 258–271

Brown DR, Hernández A, Saint-Jean G, Evans S, Tafari I, Brewster LG, & Page JB et al (2008). A participatory action research pilot study of urban health disparities using rapid assessment response and evaluation. *American Journal of Public Health*, 98(1): 28–38

Carey RF, McKechnie LEF & McKenzie PJ (2001). Gaining access to everyday life information seeking. *Library & Information Science Research*, 23: 319–334

Carlson BA, Neal D, Magwood G, Jenkins C, King MG, Hossler CL (2006). A community-based participatory health information needs assessment to help eliminate diabetes information disparities. *Health Promotion Practice*, 7(S3), 213S–222S

Chevalier JM & Buckles DJ (2008). [\*SAS2: A Guide to Collaborative Inquiry and Social Engagement\*](#). Sage India and IDRC, Ottawa and New Delhi. e-ISBN 978-1552504185

Chevalier JM & Buckles DJ (2013). *Participatory Action Research: Theory and Methods for Engaged Inquiry*, Routledge UK. ISBN 978-0415540315

Chen C & Hernon P (1982). *Information seeking: Assessing and anticipating user needs*. New York: Neal-Schuman

Cornwall A, Jewkes R (1995). What is participatory research? *Soc Sci Med*, 4(1): 1667–1676

- Culhane-Pera KA, Allen M, Pergament SL, Call K, Adawe A & Yang TT et al (2010). Improving health through community-based participatory action research. Giving immigrants and refugees a voice. *Minnesota Medicine*, 93(4): 54–57
- Danskin A (2009). RDA Scope and Structure. Letter to the Joint Steering Committee for Development of RDA, 1 July 2009. Last Retrieved 17 April 2018: <http://www.rda-jsc.org/docs/5rda-scoperev4.pdf>
- Deacon P, Smith JB & Tow S (2001). Using metadata to create navigation paths in the Health Insite Internet gateway. *Health Information and Libraries Journal*, 18: 20–29
- Dervin B, Zweizig D, Banister M, Gabriel M, Hall E & Kwan C. *The development of strategies for dealing with the information needs of urban residents. Phase. 1: Citizen Study*. U.S. Department of Health, Education and Welfare, Office of Education, Office of Libraries and Learning Resources, Washington, DC
- Duhl LJ (1996). An ecohistory of health: the role of "healthy cities." *Am J Health Promotion*, 10: 258–261
- Eastin MS (2001). Credibility assessments of online health information: The effects of source expertise and knowledge of content. *Journal of Computer-Mediated Communication*, 6(4): 0
- Eysenbach G (2005). 18: Med CERTAIN / Med CIRCLE: Using Semantic Web Technologies for Quality Management of Health Information on the Web. In: *Consumer Health Informatics*. Springer. pp. 217–226
- Eysenbach G & Jadad AR (2001). Evidence-based Patient Choice and Consumer health informatics in the Internet age. *Journal of Medical Internet Research*, 3(2): e19
- Eysenbach G, Kohler C, Yihune G, Lampe K, Cross P & Brickley D (2001a). A metadata vocabulary for self- and third-party labeling of health web-sites: Health Information Disclosure, Description and Evaluation Language (HIDDEL). *Proceedings of the AMIA Annual Symposium, 2001*: 169–173
- Eysenbach G, Köhler C, Yihune G, Lampe K, Cross P & Brickley D (2001b). A Framework for Improving the Quality of Health Information on the World-Wide-Web and Bettering Public (E-) Health: The Med CERTAIN Approach. *MEDINFO 2001*
- Eysenbach G & Köhler C (2002). How do consumers search for and appraise health information on the World Wide Web? Qualitative study using focus groups, usability tests, and in-depth interviews, *BMJ*, 324: 573
- Eysenbach G, Powell J, Kuss O & Sa E-R (2002). Empirical Studies Assessing the Quality of Health Information for Consumers on the World Wide Web: A Systematic Review. *JAMIA*, 287(20): 2691–2700

- Fawcett SB (1991). Some values guiding community research and action. *J Applied Behavioral Analysis*, 24: 621–636
- Flake G, Lawrence S, Giles C & Coetzee F (2002). Self-organization and identification of web communities. *IEEE Computer*, 35: 20–9
- Ford T, Rasmus S, & Allen J (2012). Being useful: achieving indigenous youth involvement in a community-based participatory research project in Alaska. *International Journal of Circumpolar Health*, 71(0): 1–7
- Freire P (1982). Creating alternative research methods. Learning to do it by doing it, in Hall B, Gillette A, & Tandon R (eds.) *Creating Knowledge: A Monopoly*. New Delhi: Society for Participatory Research in Asia, 29–37
- Giachello AL, et al (2003). Reducing diabetes health disparities through community-based participatory action research: the Chicago Southeast Diabetes Community Action Coalition. *Public health reports*, 118(4): 309
- Gibbon M (2002). Doing a doctorate using a participatory action research framework in the context of community health. *Qualitative Health Research* [serial online], 12(4): 546–558
- Green LW, George MA, Frankish CJ, Herbert CJ, Bowie WR, O'Neil M (1995). Study of participatory research in health promotion: review and recommendations for the development of participatory research in health promotion in Canada. Ottawa, ON: Royal Society of Canada.
- Gunther WK, Blythe K, Spurgeon K (2013). Resource Description and Access: It's Really Not So Bad [Presentation March 15, 2013]. Greenville, NC: Joyner Library (East Carolina University). Last Accessed 20 May, 2019:  
<http://web.lib.ecu.edu/ncserialsconference/2013/files/presentations/Resource%20Description%20and%20Access.pptx>
- Hendler J (2003). Science and the semantic web. *Science*, 299: 520–521
- Israel BA, Schulz AJ, Parker EA, & Becker, AB (1998). Review of community-based research: assessing partnership approaches to improve public health. *Annual review of public health*, 19(1): 173–202
- Israel B, Schurman S, Hugentobler MK (1992). Conducting action research: Relationships between organization members and communities. *J Applied Behavioral Science*, 28: 74–101
- Kamel Boulos MN, Roudsari AV (2002). HealthCyberMap: a semantic visual browser of medical Internet resources based on clinical codes and the human body metaphor. *Health Information & Libraries Journal*, 19(4): 189–200

Kamel Boulos MN, Roudsari AV & Carson ER (2002a). Towards a semantic medical Web: HealthCyberMap's tool for building an RDF metadata base of health information resources based on the Qualified Dublin Core Metadata Set. *Medical Science Monitor*, 8(7): MT124–136

Kamel Boulos MN, Roudsari AV & Carson ER (2002b). A dynamic problem to knowledge linking Semantic Web service based on clinical codes. *Informatics for Health & Social Care*, 27(3): 127–137

Khan SA, Ancker JS, Li J, Kaufman D, Hutchinson C, Cohall A & Kukafka R (2009). GetHealthyHarlem.org: developing a web platform for health promotion and wellness driven by and for the Harlem community. *Proceedings of the AMIA Symposium*. AMIA Symposium, 2009: 317–321

Kickbusch IS (2001). Health literacy: addressing the health and education divide. *Health promotion international*, 16(3): 289–297

Kindon SL, Pain R & Kesby M (eds.) (2007). *Participatory Action Research Approaches and Methods: Connecting People, Participation and Places*. Routledge UK. ISBN 978-0415599764

Knightbridge S, King R, Rolfe T (2006). Using participatory action research in a community-based initiative addressing complex mental health needs. *The Australian and New Zealand Journal of Psychiatry*, 40(4): 325–332

Kurtuldu, M (2012). Web 3.0: HTML5 & Semantic Web. *Design Today*. Last Accessed April 19, 2018: <http://www.designtoday.info/web-3-0-html5-and-the-semantic-web/>

Langford LK (2010). Surf's up: Harnessing Information Overload. *Engineering Management Review*, IEEE 38(1): 164–165

Lee M (2016). An Overview of HTML5 Semantics. *Code Pen*. Last Accessed 19 April, 2018: <https://codepen.io/mi-lee/post/an-overview-of-html5-semantics>

Lewin K (1946). Action research and minority problems, *J Soc. Issues* 2(4): 34–46

Lorence DP & Spink A (2004). Semantics and the medical web: a review of barriers and breakthroughs in effective healthcare query. *Health Information & Libraries Journal*, 21(2): 109–116

Mahrer-Imhof R, Hediger H, Naef R & Bruylands M (2014). [Development of a nurse-led family counseling program for families of the elderly: the first cycle of a Community-Based Action Research Project (CBPR)]. *Pflege*: 27(4), 231–241

Marable L (2003). False Oracles: Consumer Reaction to Learning the Truth About How Search Engines Work. *Consumer WebWatch*, 30 June 2003. Last Retrieved 17 April 2018: <https://consumersunion.org/wp-content/uploads/2013/05/false-oracles.pdf>

Metzger MJ (2007). Making sense of credibility on the Web: Models for evaluating online information and recommendations for future research. *Journal of the American Society for Information Science and Technology*, 58(13): 2078–2091

Meyers EM, Fisher KE & Marcouz E (2009). Making Sense of an Information World: The Everyday-Life Information Behavior of Preteens. *The Library* 79(3)

Minore B, Boone M, Katt M, Kinch P, Birch S (2004). Addressing the realities of health care in northern aboriginal communities through participatory action research. *Journal of Inter-Professional Care*, 18(4): 360–368

Muramatsu J & Pratt W (2001). Transparent Queries: investigation users' mental models of search engines. *SIGIR 01: Proceedings of the international ACM SIGIR conference on Research and development in information retrieval*, 24<sup>th</sup> Annual (2001): 217–224

Nutbeam D (2000). Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health promotion international*, 15(3): 259–267

Ochocka J, Janzen R, Nelson G (2002). Sharing power and knowledge: professional and mental health consumer/survivor researchers working together in a participatory action research project. *Psychiatric Rehabilitation*, 25(4): 379–387

Oliver C (2010). *Introducing RDA: a guide to the basics*. ALA Editions p. 128

Rains JW, & Ray DW (1995). Participatory action research for community health promotion. *Public Health Nursing*, 12(4): 256–261

Robu I & Thirion B (2001, 2004a). Why and How to Use the Dublin Core Metadata for Health Resources on the Internet: An Introduction. *Proceedings of the European Conference of Medical and Health Libraries*, 9<sup>th</sup> Annual (2004)

Robu I & Thirion B (2004b). The Semantic Web Vision: An Introduction for Medical Librarians. *Proceedings of the European Conference of Medical and Health Libraries*, 9<sup>th</sup> Annual

Robson A & Robinson W (2013). Building on models of information behaviour: linking information seeking and communication. *Journal of Documentation*, 69(2): 169–193

Robu I, Robu V & Thirion B (2006). An introduction to the Semantic Web for Health Sciences Librarians. *Journal of the Medical Library Association*, 94(2): 198–205

- Singer G, Norbistrath U, Lewandowski D (2012). Ordinary Search Engine Users Carrying Out Complex Search Tasks. *Journal of Information Science* [Candidate Paper]: <http://arxiv.org/abs/1206.1492>
- Savolainen R (1995). Everyday life information seeking: Approaching information seeking in the context of “way of life”. *Library and Information Science Research*, 17: 259–294
- Savolainen R & Kari J (2004a). Conceptions of the Internet in everyday life information seeking. *Journal of Information Science*, 30(3): 219–226
- Savolainen R & Kari J (2004b). Placing the Internet in information source horizons. A study of information seeking by Internet users in the context of self-development. *Library & Information Science Research*, 26(4): 415–433
- Schulz A, Parker EA, Israel BA, Becker AB, Maciak BJ, Hollis R (1998). Conducting a participatory community-based survey for a community health intervention on Detroit's East Side. *J Public Health Manage Practice* 4: 10–24
- Shepperd S, Charnock D & Gann B (1999). Helping patients’ access high quality health information. *British Medical Journal*, 319(7212): 764
- Spina Bifida & Hydrocephalus Association of British Columbia (2016). ABOUT US. SBHABC. Last Retrieved 17 April 2018: [http://www.sbhabc.org/about\\_us/](http://www.sbhabc.org/about_us/)
- Spina Bifida & Hydrocephalus Association of Canada (2018). About Us. SBHAC. Last Retrieved 17 April 2018: <http://sbhac.ca/about-us/>
- Thornewill J, Dowling AF, Cox BA & Esterhay, RJ (2011). Information infrastructure for consumer health: a health information exchange stakeholder study. *American Journal of Preventive Medicine*, 40(5 S2): S123-S133
- UVIC Technology Integrated Learning (2017a). Categories and Tags. University of Victoria, Victoria BC. Last Retrieved 17 April 2018: <https://www.uvic.ca/til/services/oac/support/posts-and-pages/categories-tags/index.php>
- UVIC Technology Integrated Learning (2017b). Comments. University of Victoria, Victoria BC. Last Retrieved 17 April 2018: <https://www.uvic.ca/til/services/oac/support/posts-and-pages/share-like-comments/index.php>
- UVIC Technology Integrated Learning (2017c). What is the OAC? University of Victoria, Victoria BC. Last Retrieved 17 April 2018: <https://www.uvic.ca/til/services/oac/support/getting-started/what/index.php>

- Wallerstein N (1999). Power dynamics between evaluator and community: research relationships within New Mexico's Healthier Communities. *Soc Sci Med*, 49: 39–53
- Wallerstein N & Bernstein E (1988). Empowerment Education: Freire's Ideas Adapted to Health Education. *Health Education Behavior*, 15: 379–394
- Wallerstein N & Duran B (2010). Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *American journal of public health*, 100(S1): S40–S46
- White R & Roth R (2009). Exploratory Search: Beyond the Query-Response Paradigm. *Synthesis Lectures on Information Concepts, Retrieval, and Services*, 1(1): 1–98
- Wilson TD (1997). Information behaviour: an interdisciplinary perspective. *Information Processing and Management*, 33(4): 551–572
- Wilson TD (1999). Models in information behaviour research. *Journal of Documentation*, 55(3): 249–270
- Wilson TD (2000). Human information behavior. *Informing Science*, 3(2): 49–55
- Wilson TD (2005). Evolution in information behaviour modeling: Wilson's model. In Fisher K, Erdelez S, & McKechnie L. (eds.) *Theories of information behavior* (pp. 31–39). Medford, NJ: Information Today
- W3C: World Wide Web Consortium (2018). HTML5 Semantic Elements. W3Schools.com. Last Retrieved April 19, 2018:  
[https://www.w3schools.com/html/html5\\_semantic\\_elements.asp](https://www.w3schools.com/html/html5_semantic_elements.asp)
- Wright KB & Bell SB (2003). Health-related Support Groups on the Internet: Linking Empirical Findings to Social Support and Computer-mediated Communication Theory. *J Health Psychology*, 8(1): 39–54

## Appendices

### *Letters to the Associations seeking Participation*

Figure 10: Personal Letter to Spina Bifida & Hydrocephalus Association of Canada

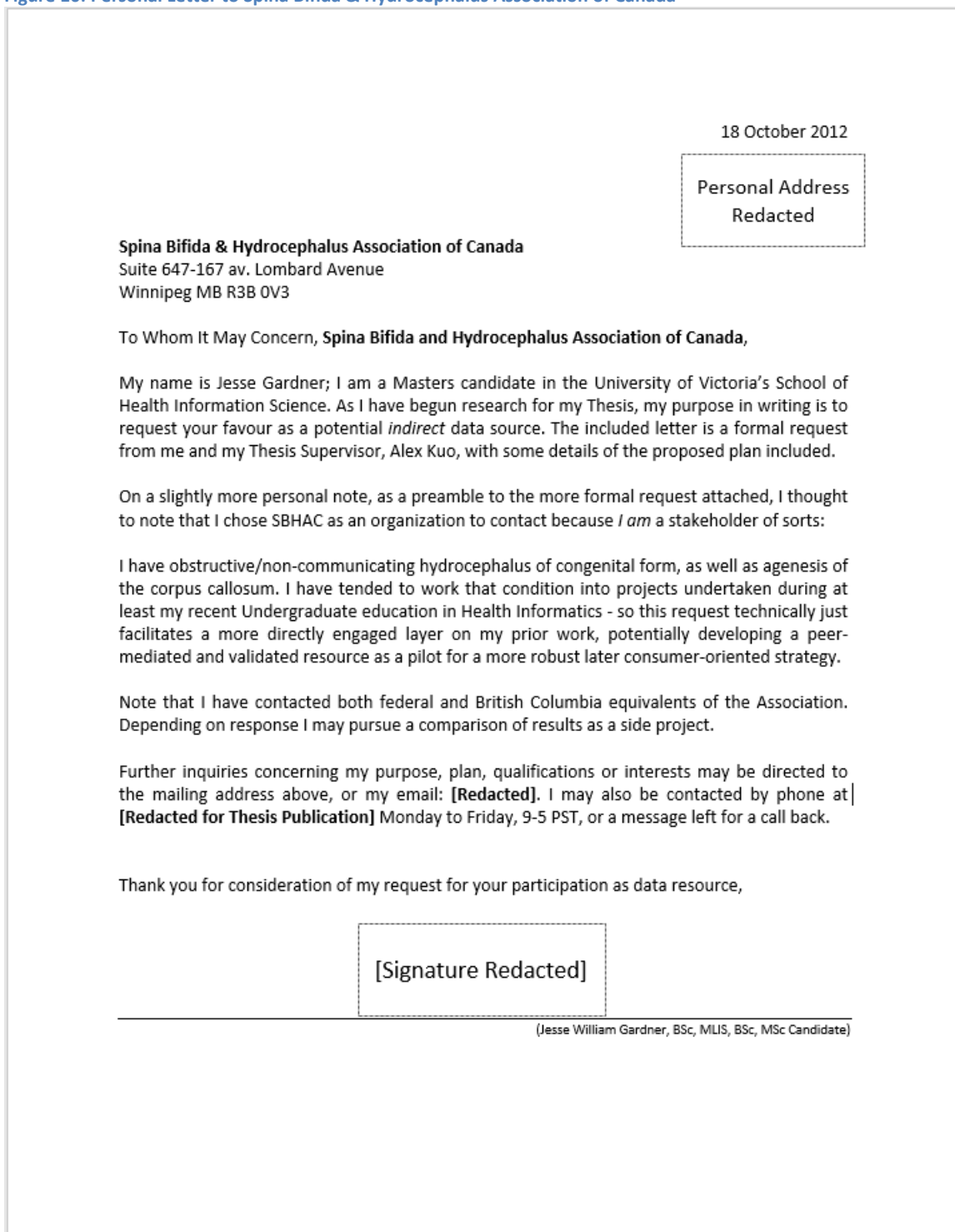


Figure 11: Letter for Approval to Spina Bifida &amp; Hydrocephalus Association of Canada

30 October 2012

**Spina Bifida & Hydrocephalus Association of Canada**  
Suite 647-167 av. Lombard Avenue  
Winnipeg MB R3B 0V3

To Whom It May Concern, **Spina Bifida & Hydrocephalus Association of Canada,**

My name is Jesse Gardner. I am a Masters candidate in the University of Victoria's School of Health Information Science. My area of interest in Health Informatics is at the intersection of the discipline and traditional 'library sciences'; for instance, managing and making appropriate decisions concerning the proliferation of consumer-oriented health information on the internet (and linked non-web resources). As I have begun research for my Thesis, my purpose in writing is to request your favour as a potential data source. Some background follows:

Given that a significant portion of both daily searches and URL 'hits' on the internet represent *just health* information seeking (a recent Pew survey cited a figure up to 80% of all activity) and given that health information is itself vastly nuanced, there is justification for a project making use of 'middleware' to enhance the presentation of search results – and thereby their authority, utility, and usefulness. To wit, understanding information needs and information seeking behaviours of users allows for better utilization of existing search results.

A project in that full scope, though, is a massive undertaking. The focus of my Thesis, instead, is a pilot project which investigates information seeking behaviour of a **single** set of stakeholders of a **single** medical condition (or at least a small self-contained spectrum), to develop a pilot tool for use by the participating organization. If proven successful this could also provide a model for the broader activity. This is where the assistance of an organization such as yours is so important: it provides a sample population from which to generate an appropriate portrait of the information needs of users at the narrow scope, without direct interference.

Privacy will be respected. I do not request access to any member lists nor direct contact with members. Rather, I intend to develop a data collection tool (such as an open ended survey) to gather the information that I need to develop the aforementioned middleware. At most I would want to know whether the respondent is a person diagnosed, a caregiver thereof, or merely an interested party. How this tool would be hosted and how responses would be directed to me would be discussed, and (given my timeline up to and including Ethical Approval by UVic) would not likely be implemented until mid-February.

Thank you for consideration of my request for your participation as data resource,

[Both Signatures Redacted]

(Jesse William Gardner, BSc, MLIS, BSc, MSc Candidate)                      (Alex Mu-Hsing Kuo, Supervising Professor)

Figure 12: Personal Letter to Spina Bifida &amp; Hydrocephalus Association of B.C.

18 October 2012

Personal Address  
Redacted

**Spina Bifida & Hydrocephalus Association of Canada**  
Suite 647-167 av. Lombard Avenue  
Winnipeg MB R3B 0V3

To Whom It May Concern, **Spina Bifida and Hydrocephalus Association of Canada,**

My name is Jesse Gardner; I am a Masters candidate in the University of Victoria's School of Health Information Science. As I have begun research for my Thesis, my purpose in writing is to request your favour as a potential *indirect* data source. The included letter is a formal request from me and my Thesis Supervisor, Alex Kuo, with some details of the proposed plan included.

On a slightly more personal note, as a preamble to the more formal request attached, I thought to note that I chose SBHAC as an organization to contact because *I am* a stakeholder of sorts:

I have obstructive/non-communicating hydrocephalus of congenital form, as well as agenesis of the corpus callosum. I have tended to work that condition into projects undertaken during at least my recent Undergraduate education in Health Informatics - so this request technically just facilitates a more directly engaged layer on my prior work, potentially developing a peer-mediated and validated resource as a pilot for a more robust later consumer-oriented strategy.

Note that I have contacted both federal and British Columbia equivalents of the Association. Depending on response I may pursue a comparison of results as a side project.

Further inquiries concerning my purpose, plan, qualifications or interests may be directed to the mailing address above, or my email: **[Redacted]**. I may also be contacted by phone at **[Redacted for Thesis Publication]** Monday to Friday, 9-5 PST, or a message left for a call back.

Thank you for consideration of my request for your participation as data resource,

[Signature Redacted]

---

(Jesse William Gardner, BSc, MLIS, BSc, MSc Candidate)

Figure 13: Letter for Approval to Spina Bifida &amp; Hydrocephalus Association of B.C.

30 October 2012

**Spina Bifida & Hydrocephalus Association of BC**  
 4480 Oak Street  
 Vancouver BC V6H 3V4

To Whom It May Concern, **Spina Bifida & Hydrocephalus Association of BC,**

My name is Jesse Gardner. I am a Masters candidate in the University of Victoria's School of Health Information Science. My area of interest in Health Informatics is at the intersection of the discipline and traditional 'library sciences'; for instance, managing and making appropriate decisions concerning the proliferation of consumer-oriented health information on the internet (and linked non-web resources). As I have begun research for my Thesis, my purpose in writing is to request your favour as a potential data source. Some background follows:

Given that a significant portion of both daily searches and URL 'hits' on the internet represent *just health* information seeking (a recent Pew survey cited a figure up to 80% of all activity) and given that health information is itself vastly nuanced, there is justification for a project making use of 'middleware' to enhance the presentation of search results – and thereby their authority, utility, and usefulness. To wit, understanding information needs and information seeking behaviours of users allows for better utilization of existing search results.

A project in that full scope, though, is a massive undertaking. The focus of my Thesis, instead, is a pilot project which investigates information seeking behaviour of a **single** set of stakeholders of a **single** medical condition (or at least a small self-contained spectrum), to develop a pilot tool for use by the participating organization. If proven successful this could also provide a model for the broader activity. This is where the assistance of an organization such as yours is so important: it provides a sample population from which to generate an appropriate portrait of the information needs of users at the narrow scope, without direct interference.

Privacy will be respected. I do not request access to any member lists nor direct contact with members. Rather, I intend to develop a data collection tool (such as an open ended survey) to gather the information that I need to develop the aforementioned middleware. At most I would want to know whether the respondent is a person diagnosed, a caregiver thereof, or merely an interested party. How this tool would be hosted and how responses would be directed to me would be discussed, and (given my timeline up to and including Ethical Approval by UVic) would not likely be implemented until mid-February.

Thank you for consideration of my request for your participation as data resource,

[Both Signatures Redacted]

(Jesse William Gardner, BSc, MLIS, BSc, MSc Candidate) (Alex Mu-Hsing Kuo, Supervising Professor)

## Responses from Associations Confirming Participation

Figure 14: Response from Spina Bifida & Hydrocephalus Association of Canada

**Subject:** Thesis data source  
**From:** "Bonnie" <bonnie.hidlebaugh@sbhac.ca>  
**Date:** Wed, November 14, 2012 1:28 pm  
**To:** jgardner@uvic.ca  
**Priority:** Normal  
**Options:** [View Full Header](#) | [View Printable Version](#) | [Download this as a file](#)  
[Report as Spam](#) | [View as plain text](#)

Hi Jesse

I would be happy to supply you with any information or as you refer in your letter to be a potential indirect data source. Please let me know what you might need from SBHAC to move forward with your proposed plan.

Regards,

**Bonnie Hidlebaugh**  
 Spina Bifida & Hydrocephalus Association of Canada  
 National Manager, Communication & Development Coordinator  
 647-167 Lombard Ave.  
 Winnipeg, MB R3B 0V3  
 Tel. 204 925-3650 Fax. 204 925-3654  
 Toll Free 1-800-565-9488

Figure 15: Responses from Spina Bifida & Hydrocephalus Association of B.C.

[Search Results](#) | [Unread](#) | [Delete](#) [Forward](#) | [Forward as Attachment](#) | [Reply](#) | [Reply All](#)

**Subject:** Follow Up to Letter dated October 18, 2012  
**From:** "Spina Bifida and Hydrocephalus Assoc of BC" <sbhac@shaw.ca>  
**Date:** Wed, February 13, 2013 10:36 am  
**To:** jgardner@uvic.ca  
**Priority:** Normal  
**Options:** [View Full Header](#) | [View Printable Version](#) | [Download this as a file](#)  
[Report as Spam](#)

Dear Jesse,  
 Thank you for contacting us regarding your Pilot Project/ Thesis Research. Our advisory committee has reviewed your letter and once you have received Ethical Approval from Uvic they would be interested in reviewing your proposal .Information can be forwarded to this address and I will disbure to the committee members.  
 Sincerely,  
 Pauline Doolley  
 Office Manager  
 Spina Bifida & Hydrocephalus Association of BC

Here is confirmation that the Survey would be posted in March 2013 to members of the B.C. Association subject to UVIC's Human Research Ethics Board approval:

**Subject:** Re: Follow Up to Letter dated October 18, 2012  
**From:** "Spina Bifida and Hydrocephalus Assoc of BC" <sbhac@shaw.ca>  
**Date:** Wed, March 13, 2013 11:32 am  
**To:** jgardner@uvic.ca  
**Priority:** Normal  
**Options:** [View Full Header](#) | [View Printable Version](#) | [Download this as a file](#)  
[Report as Spam](#)

Thank you Jesse for your email. I will wait until you have approval before proceeding. Good Luck !  
 Pauline  
 ----- Original Message -----  
**From:** jgardner@uvic.ca  
**To:** "Spina Bifida and Hydrocephalus Assoc of BC" <sbhac@shaw.ca>  
**Sent:** Monday, March 11, 2013 11:43:36 PM  
**Subject:** Re: Follow Up to Letter dated October 18, 2012

Hello Pauline,

My apologies for the delay in my response. My Human Research Ethics Board application package was submitted through my department, mid-last week, following a delay due to revisions. It currently has to go through three remaining stages.

- First, my department's approval, of which only the Department Chair's signature is outstanding. I expect this by mid-week.
- Second, Research Ethics will assess whether it qualifies as 'minimal risk' or 'above minimal risk'. This should take only one further day.
- Third:

Note: the remainder of the email above is redacted from the screen capture due to the 'third' condition containing information about the HREB's process for granting Ethics Approval, with specific respect to my Thesis; which I felt was unnecessary exposition to prove that Approval was granted.

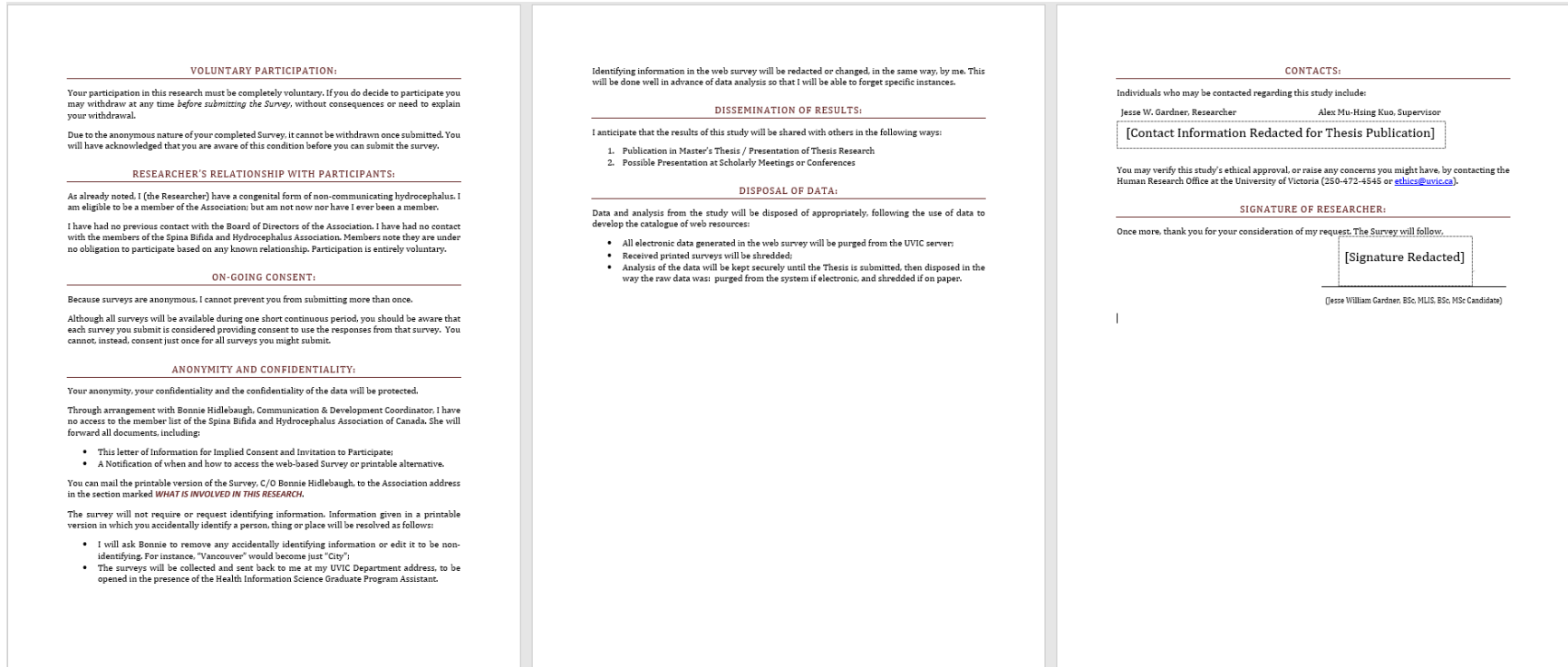
However, all files are available on request to confirm their full, unredacted, content. Email addresses have been left unredacted following approval the Associations' respective Office Managers, as of the dates shown; and because they are already publicly available on the Internet on the respective websites for the Associations.

## Letters of Information for Implied Consent

Figure 16: Implied Consent, Spina Bifida & Hydrocephalus Association of Canada

This represents the version of the Letter of Information for Implied Consent that was (a) approved by UVIC's Human Research Ethics Board, (b) sent to the Spina Bifida Association of Canada, and (c) posted so that users of the Web Version of the Survey would see it before being directed to the Survey Questions page.

<p style="text-align: center;"><b>LETTER OF INFORMED CONSENT TO: MEMBERS OF SBHAC</b></p> <hr/> <p><b>RE:</b> Participation in Exploratory Study of Health Information Seeking and Information Retrieval  </p> <p>My name is Jesse Gardner. I am a Graduate Student in the School of Health Information Science at the University of Victoria. As a Graduate Student at the University, I am required to conduct thesis research as part of the requirements for my Master's degree in Health Information Science. This research is being conducted under the supervision of Alex Mu-Hsing Kuo, Assistant Professor.</p> <p>Our contact information is included at the end of this Letter. If you have further questions not addressed by this Letter of Information and Implied Consent you may contact me directly.</p> <p style="text-align: center;"><b>PURPOSE OF STUDY:</b></p> <p>My thesis is that understanding information needs and Internet information-seeking behaviours of users can lead to better design of Search Engines (for instance Google), and this is especially the case when the needs and interests of users are incorporated into the design process.</p> <p>I propose a pilot project which surveys past information seeking behaviour of a single set of stakeholders with a medical condition. Members of the Spina Bifida and Hydrocephalus Association have the kind of interest and experience of one such medical condition which I want to survey.</p> <p>The survey will inform the design of a catalogue of relevant search results which, I think, other internet searchers with a similar medical history would find useful and relevant to their needs. The proposed catalogue of search results would be organised and filled according to my findings from a survey of the kind and the depth of information which members of the Spina Bifida and Hydrocephalus Association have wanted during their experience of the condition.</p> <p>When completed the catalogue of resources could be hosted on the Spina Bifida and Hydrocephalus Association Website (<a href="http://www.sbhac.ca/">http://www.sbhac.ca/</a>).</p> <p style="text-align: center;"><b>IMPORTANCE OF THIS RESEARCH:</b></p> <p>I chose SBHAC because I have obstructive/non-communicating hydrocephalus of congenital form, as well as agenesis of the corpus callosum. In simpler terms: I have one of the conditions supported by the Spina Bifida and Hydrocephalus Association of Canada. I want to help people with a similar experience to my own, including caregivers or parents and guardians. This research is intended to help users access information considered relevant and useful by their peers and helpers.</p> <p>Choosing a survey method limits my own bias from being introduced: I have my own ideas about what information an individual with my condition might seek in terms of symptoms, diagnosis, treatment and therapies, or medication management, and so on. What I'm interested in is what makes this research important and unique: how your experience can be brought forth to help other members find information that can help them understand and manage their condition.</p>	<p style="text-align: center;"><b>PARTICIPANTS SELECTION:</b></p> <hr/> <p>This letter is addressed to all SBHAC members, to ask that you volunteer. There is no selection or exclusion process: each of you represents a valuable resource for investigating the information needs which could be of most use to other members of the Association.</p> <p style="text-align: center;"><b>WHAT IS INVOLVED IN THIS RESEARCH?</b></p> <hr/> <p>If you consent to voluntarily participate in this research you will be asked only to complete a Survey of your information needs. The Survey will be made available in a web-based form, hosted by the University of Victoria.</p> <p>Members have the option of a printable form, also downloaded from a UVIC web address.</p> <p>The print version may be mailed back to the Spina Bifida and Hydrocephalus Association:</p> <div style="border: 1px solid black; padding: 5px; margin: 5px 0;"> <p>Spina Bifida and Hydrocephalus Association of Canada        C/O: Bonnie Hildebaugh, National Manager - Communication &amp; Development Coordinator        Suite 647-167 av. Lombard Avenue        Winnipeg MB Canada R3B 0Y3        ATTENTION: Print Survey for Jesse Gardner's Web Resource Project</p> </div> <p>You may do the survey anywhere and at any time you feel most comfortable.</p> <p>You may ask for the assistance of trusted helpers such as caregivers, family members or guardians, clinical professionals or other familiar authorities. <i>Young Members are asked to strongly think about taking this advice. Someone that you trust may help you understand technical terms and large words, and help you give answers which you may find hard to put into your own words.</i></p> <p>You will be asked your membership type: similar to the Form you filled out to become a Member:</p> <ul style="list-style-type: none"> <li>• A person with a condition represented by SBHAC;</li> <li>• A caregiver, parent or guardian of a person with such a condition;</li> <li>• A clinical professional with responsibility to treat persons with the conditions;</li> <li>• A researcher or other member with an interest.</li> </ul> <p>You will be asked to name your condition, or that of the person in your care. You may choose not to disclose, but your response to this question will help the Researcher understand the context of your other responses.</p> <p>The survey asks for detailed and descriptive responses in order to create groups of search concepts. I will leave it to your comfort to determine the level of personal detail with which you chose to respond. You will <u>not</u> be asked to volunteer identifying or very personal information.</p> <p style="text-align: center;"><b>POTENTIAL INCONVENIENCES:</b></p> <hr/> <p>As a participant you, or a trusted helper, should be able to use simple web tools. For example, either:</p>	<ul style="list-style-type: none"> <li>• How to use, edit, and submit web surveys or forms;</li> <li>• How to download and edit a Word Document (if submitting a printable survey).</li> </ul> <p>The Web Survey system will not allow surveys to be paused and resumed at a later date, though participants should be able to take short breaks between answering questions.</p> <p>It is up to you, the participant, to decide when and for how long you work on answering the survey.</p> <p style="text-align: center;"><b>RISKS:</b></p> <hr/> <p>While completing the survey, you may feel anxious or uncomfortable with the personal details you are sharing. If you feel this is too personal, you may edit the survey:</p> <ul style="list-style-type: none"> <li>• The web survey will allow all answers to be edited up to (but not after) submission of the form. This final step will be clearly marked;</li> <li>• You may edit the print version more than once before sending it by mail to the Association.</li> </ul> <p style="text-align: center;"><b>BENEFITS:</b></p> <hr/> <p>There are several potential benefits to your participation in this Survey, if you complete a Survey you will have participated in a knowledge gathering exercise with a real, usable end product.</p> <p>The product will be a web-based resource patterned after tools which are familiar to web users, for instance internet search and library catalogues. Content will be generated by gathering your own experience of seeking relevant information:</p> <ul style="list-style-type: none"> <li>• What information you have looked for;</li> <li>• What answers you found;</li> <li>• Where and how you found them;</li> <li>• Your satisfaction with the resources that contained your answers;</li> <li>• Your satisfaction with the answers.</li> </ul> <p>This process will benefit you and other members of the Association:</p> <ul style="list-style-type: none"> <li>• Because content will be collected based on your own responses to the surveys, it should improve access to web-based information suited to your experience;</li> <li>• This experience may be shared partly or wholly by other members of the Association and by persons within society at large. Many people could benefit.</li> </ul> <p>The state of knowledge benefits in three ways:</p> <ol style="list-style-type: none"> <li>1. Your participation adds new perspective from each answer;</li> <li>2. The resource will be designed to provide the best results, judged by user satisfaction, instead of just access to results that include the answer. Other information providers can learn from this example;</li> <li>3. It describes a process for engaging health information and support providers (such as the Spina Bifida and Hydrocephalus Association) in the task of providing better access to authoritative and valid health information online.</li> </ol>
---	---	---



The Letter for Informed Consent that was sent to the Spina Bifida & Hydrocephalus Association of British Columbia is virtually identical, except being addressed to members of the Association of B.C. The original documents may be viewed at request.

## Surveys

Figure 17: Survey of the Spina Bifida & Hydrocephalus Association of Canada

This series of screen captures represents the Survey in its administrative Form Builder view, and doubles as demonstration of the process of building a Survey within the Survey Web-application Project. Users receive a clean anonymous survey which removes all the Editor prompts; however, it is only generated during the Survey period, so is no longer visible or archived in that format.

The screenshot displays the administrative interface for a survey. At the top, a navigation bar includes 'Surveys', 'Designer', 'Results', 'Campaigns', and 'Help', along with a 'Logout' button. Below this, the 'Page 1' editor shows various toolbars for editing questions and page structure. The main content area displays the survey preamble, which includes a title 'Survey for Exploratory Study' and a detailed consent statement.

**Page 1** Delete | Insert question | Insert line break | Enable random | Edit branching | Enable submit

↓ Edit question | Edit answers | Delete | Clone | Insert question | Insert page break | Insert line break | Skip logic

ID : PREAMBLE

Help Text:



## Survey for Exploratory Study

*Health Information Seeking and Information Retrieval*

---

*This preamble assumes you have read the preceding letter inviting you to participate in the Study, and have understood your rights and responsibilities as presented in the letter. Completing the survey will be considered consent for responses you provide to be used as data about your information needs. Completing the survey will not require information that could be used to identify you. It does not even request identifying information. Answers will be collected anonymously and combined with other similar results so that respondents cannot be singled out.*

*Geographical region (Province or Territory) and whether you live in an 'urban' or 'rural' place are only collected to compare the members' responses to responses from members of the Spina Bifida and Hydrocephalus Association of British Columbia. These other responses will come from a survey which will be mailed to that Association.*

<p> Edit question  Edit answers  Delete  Clone  Insert question  Insert page break  Insert line break  Skip logic</p> <p>ID : PREAMBL2</p> <p>Help Text:</p> <p><i>The Spina Bifida and Hydrocephalus Association of Canada allowed me a question concerning a member's stake in the Association. It is <b>not</b> inappropriately identifying information. You will be asked if you are either a:</i></p> <ul style="list-style-type: none"><li><i>a) <b>Person with one of the conditions the Association represents;</b></i></li><li><i>b) <b>Family member or other caregiver of such a person;</b></i></li><li><i>c) <b>Medical professional with expertise in care for or treatment of persons with one or more of the conditions.</b></i></li></ul> <p><i>This piece of information will not be used to group results. Each member may have contributions which may be useful to other members. The request for your membership type is included in order to understand how each perspective may differ on the issues raised by your answers.</i></p> <p><i>The survey will allow lengthy responses. <b>Your responses may be about personal experience and they may be as long or as short as you feel necessary.</b> The amount of personal detail with which you choose to respond is up to your own comfort level. If at any point in the process you feel uncomfortable with any of your responses you may edit or change them. You have the right to withdraw your survey at any time before you submit it; but anonymous delivery makes it impossible to delete already-submitted surveys.</i></p> <p> Edit question  Edit answers  Delete  Clone  Insert question  Insert page break  Insert line break  Skip logic</p> <p>ID : PRE4Y</p> <p>Help Text:</p> <p><i>If you are a young Member of the association you are very welcome to respond to the survey, but you are strongly advised to discuss the survey with a parent, guardian, care provider, or other trusted person before submitting it. Getting someone to help you fill out the survey may also help you understand questions and help you put your thoughts into words.</i></p> <p style="text-align: right;"><i>Jesse W. Gardner, MSC Candidate (2013). University of Victoria</i></p>	^
---	---

ID : Q1	Help Text:
<b>What is your Province/Territory of Primary Residence?</b>	
<input type="text" value="[[Enter Province]]"/>	
<a href="#">↑</a> <a href="#">↓</a> <a href="#">Edit question</a>   <a href="#">Edit answers</a>   <a href="#">Delete</a>   <a href="#">Clone</a>   <a href="#">Insert question</a>   <a href="#">Insert page break</a>   <a href="#">Insert line break</a>   <a href="#">Skip logic</a>	
ID : Q1A	Help Text:
<b>If your Province has its own Association are you member of that as well?</b>	
<input type="radio"/> YES <input type="radio"/> NO	
<a href="#">↑</a> <a href="#">↓</a> <a href="#">Edit question</a>   <a href="#">Edit answers</a>   <a href="#">Delete</a>   <a href="#">Clone</a>   <a href="#">Insert question</a>   <a href="#">Insert page break</a>   <a href="#">Insert line break</a>   <a href="#">Skip logic</a>	
ID : Q1B	Help Text:
<b>Are you a member of other Provincial or Territorial Spina Bifida or Hydrocephalus Associations?</b>	
<input type="radio"/> YES <input type="radio"/> NO	
<a href="#">↑</a> <a href="#">↓</a> <a href="#">Edit question</a>   <a href="#">Edit answers</a>   <a href="#">Delete</a>   <a href="#">Clone</a>   <a href="#">Insert question</a>   <a href="#">Insert page break</a>   <a href="#">Insert line break</a>   <a href="#">Skip logic</a>	
ID : Q1C	Help Text:
<b>If you answered 'yes' to the previous question, please specify which others</b>	
<input type="text" value="[[Other Associations]]"/>	
<a href="#">↑</a> <a href="#">↓</a> <a href="#">Edit question</a>   <a href="#">Edit answers</a>   <a href="#">Delete</a>   <a href="#">Clone</a>   <a href="#">Insert question</a>   <a href="#">Insert page break</a>   <a href="#">Insert line break</a>   <a href="#">Skip logic</a>	
ID : Q2	Help Text:
<b>Do you reside in a Rural or Urban location?</b>	

Members of the Federal Association may be members of one or more Provincial Associations; since proof of residence is not required and memberships carry when Members move to different Provinces, unless they cancel on their own initiative.

RURAL	URBAN
<p> <a href="#">Edit question</a>   <a href="#">Edit answers</a>   <a href="#">Delete</a>   <a href="#">Clone</a>   <a href="#">Insert question</a>   <a href="#">Insert page break</a>   <a href="#">Insert line break</a>   <a href="#">Skip logic</a></p>	
ID :	
Help Text:	
<p><b>Group 2: Condition Represented by Survey Subject</b></p>	
<p> <a href="#">Edit question</a>   <a href="#">Edit answers</a>   <a href="#">Delete</a>   <a href="#">Clone</a>   <a href="#">Insert question</a>   <a href="#">Insert page break</a>   <a href="#">Insert line break</a>   <a href="#">Skip logic</a></p>	
ID : Q3	
Help Text:	
<p><b>Why are you a member of the Spina Bifida and Hydrocephalus Association of Canada?</b></p> <p><input type="radio"/> a. Person with Spina Bifida or Hydrocephalus</p> <p><input type="radio"/> b. Parent or guardian of a person with one such condition</p> <p><input type="radio"/> c. Expecting parent</p> <p><input type="radio"/> d. Other caregiver</p> <p><input type="radio"/> e. Medical professional with responsibility to treat/care for patients with condition</p> <p><input type="radio"/> f. Researcher with stake</p> <p><input type="text" value="Describe research"/></p> <p><input type="radio"/> g. Other relationship to patient</p> <p><input type="text" value="Describe relationship"/></p>	
<p> <a href="#">Edit question</a>   <a href="#">Edit answers</a>   <a href="#">Delete</a>   <a href="#">Clone</a>   <a href="#">Insert question</a>   <a href="#">Insert page break</a>   <a href="#">Insert line break</a>   <a href="#">Skip logic</a></p>	
ID : Q4	
Help Text:	
<p><b>What is the nature of your diagnosed condition(s) / the conditions of the individual(s) in your care?</b></p> <p><input type="checkbox"/> a. Spina Bifida Meninocele</p>	

<input type="checkbox"/> a. Spina Bifida Meningocele	^
<input type="checkbox"/> b. Spina Bifida Occulta	
<input type="checkbox"/> c. Spina Bifida Myelomeningocele / with Myeloschisis	
<input type="checkbox"/> d. Arnold-Chiari II malformation	
<input type="text" value="Type (I-IV)"/>	
<input type="checkbox"/> e. Agenesis or other Abnormal development of Corpus Callosum	
<input type="checkbox"/> f. Hydrocephalus	
<input type="text" value="Congenital or Acquired?"/>	
<input type="checkbox"/> g. Prenatally diagnosed neural tube disorder, consequence not yet known	
<input type="checkbox"/> h. Other	
<input type="text" value="Specify Other"/>	
<input type="checkbox"/> i. Prefer not to disclose	
<a href="#">↑</a> <a href="#">↓</a> <a href="#">Edit question</a>   <a href="#">Edit answers</a>   <a href="#">Delete</a>   <a href="#">Clone</a>   <a href="#">Insert question</a>   <a href="#">Insert page break</a>   <a href="#">Insert line break</a>   <a href="#">Skip logic</a>	
ID : Q5	
Help Text:	
<b>Explain your responses to the previous two questions. Please avoid identifying information (e.g. names, locations, specific healthcare providers)</b>	
<div style="border: 1px solid black; height: 100px; width: 100%;"></div>	
v	

**Group 3: Information Seeking BEFORE/AT Diagnosis (includes Perinatal)**

  [Edit question](#) | [Edit answers](#) | [Delete](#) | [Clone](#) | [Insert question](#) | [Insert page break](#) | [Insert line break](#) | [Skip logic](#)

ID : Q8

Help Text:

**Did you or someone who helps you seek any information about Spina Bifida or Hydrocephalus before you were (or the person in your care was) diagnosed with a specific form?**

 YES NO

  [Edit question](#) | [Edit answers](#) | [Delete](#) | [Clone](#) | [Insert question](#) | [Insert page break](#) | [Insert line break](#) | [Skip logic](#)

ID : Q7









Help Text:

*Note to Survey Participant: your responses to this Question will have a direct effect on the Catalogue of resources generated from this Survey's results.*

*The more new categories you can provide the more complete the collection of useful resources will be.*

**Please indicate what kind of information you sought.**

For example: background of the condition, causes, pathologies, locating resources, facilities or medical specialists, etc. Your answer need not limit to these suggestions.

<p>ID : Q7a</p> <p>Help Text:</p> <p><b>What was your motivation for seeking information prior to a diagnosis?</b></p> <input type="text"/>	^
<p>  <a href="#">Edit question</a>   <a href="#">Edit answers</a>   <a href="#">Delete</a>   <a href="#">Clone</a>   <a href="#">Insert question</a>   <a href="#">Insert page break</a>   <a href="#">Insert line break</a>   <a href="#">Skip logic</a></p>	
<p>ID : Q7b</p> <p>Help Text:</p> <p><b>Did your search turn up results that were later reflected in the medical diagnosis?</b></p> <input type="text"/>	
<p>  <a href="#">Edit question</a>   <a href="#">Edit answers</a>   <a href="#">Delete</a>   <a href="#">Clone</a>   <a href="#">Insert question</a>   <a href="#">Insert page break</a>   <a href="#">Insert line break</a>   <a href="#">Skip logic</a></p>	
<p>ID : Q7c</p> <p>Help Text:</p> <p><b>What sort of PRINT information sources did you consult?</b></p> <input type="text" value="[For Example: Library Resources including Catalogues, Medical Reference Books, Journals]"/>	
<p>  <a href="#">Edit question</a>   <a href="#">Edit answers</a>   <a href="#">Delete</a>   <a href="#">Clone</a>   <a href="#">Insert question</a>   <a href="#">Insert page break</a>   <a href="#">Insert line break</a>   <a href="#">Skip logic</a></p>	
<p>ID : Q7d</p> <p>Help Text:</p> <p><b>What sort of ELECTRONIC information sources did you consult?</b></p> <input type="text" value="[For Example: Internet, or Journal Databases from your local Library]"/>	
<p>  <a href="#">Edit question</a>   <a href="#">Edit answers</a>   <a href="#">Delete</a>   <a href="#">Clone</a>   <a href="#">Insert question</a>   <a href="#">Insert page break</a>   <a href="#">Insert line break</a>   <a href="#">Skip logic</a></p>	
<p>ID : Q7e</p> <p>Help Text:</p>	v

ID : 7sat

Help Text:

**Regardless of whether or not search results matched your diagnosis: how satisfied were you with the results of your search(es)?**

I COULD FIND THE ANSWERS I NEEDED  I COULD TRUST THE ANSWERS I FOUND  OTHER COMMENTS

[↑](#) [↓](#) [Edit question](#) | [Edit answers](#) | [Delete](#) | [Clone](#) | [Insert question](#) | [Insert page break](#) | [Insert line break](#) | [Skip logic](#)

ID :

Help Text:

***Group 4: Information Seeking Immediately AFTER Diagnosis***

[↑](#) [↓](#) [Edit question](#) | [Edit answers](#) | [Delete](#) | [Clone](#) | [Insert question](#) | [Insert page break](#) | [Insert line break](#) | [Skip logic](#)

ID : Q8

Help Text:

**Directly following diagnosis of yourself or the person(s) in your care: what was your overall experience concerning looking for health information concerning the medical condition?**



11

ID : Q9

Help Text:

*Note to Survey Participant: providing a calendar year (and month if you recall) will help estimate the scope of resources which may have been available to you as an information-seeker. Consider, for instance, that internet-based resources have a date of publication before which they were unavailable.*



**When, and in what context did you first seek out information?**

  Edit question | Edit answers | Delete | Clone | Insert question | Insert page break | Insert line break | Skip logic

ID : Q10a

Help Text:



**What sort of PRINT information sources did you consult?**

  Edit question | Edit answers | Delete | Clone | Insert question | Insert page break | Insert line break | Skip logic

ID : Q10b

Help Text:

**What sort of ELECTRONIC information sources did you consult?**

  Edit question | Edit answers | Delete | Clone | Insert question | Insert page break | Insert line break | Skip logic

ID : Q10c

Help Text:



**What sort of HUMAN information sources did you consult?**

**How satisfied were you with the results of your search(es)?**

I COULD FIND THE ANSWERS I NEEDED

I COULD TRUST THE ANSWERS I FOUND

OTHER COMMENTS

  Edit question | Edit answers | Delete | Clone | Insert question | Insert page break | Insert line break | Skip logic

ID :

Help Text:

Note to Survey Participant: For the following question consider for instance any experience related to the condition. Queries could respond to any or all of the following, but are not limited to these choices:


- post-diagnosis treatment or management responsibilities
- treatment or management methods and protocols
- new complications from treatment and management
- newly experienced symptoms or signs, other experiences mistaken for symptoms or signs
- locating physically situated information resources (e.g. special collections, libraries)
- locating other support networks, care providers or clinical professionals
- anything else which you feel is relevant and would be useful for other information seekers

  [Edit question](#) | [Edit answers](#) | [Delete](#) | [Clone](#) | [Insert question](#) | [Insert page break](#) | [Insert line break](#) | [Skip logic](#)

ID : Q11

Help Text:

**What kind of information did you seek at this stage?**



### **Group 5: Information sought during subsequent living/coping with the Condition**

  [Edit question](#) | [Edit answers](#) | [Delete](#) | [Clone](#) | [Insert question](#) | [Insert page break](#) | [Insert line break](#) | [Skip logic](#)

ID : Q12

Help Text:

**During the period after initial diagnosis of yourself or the person(s) in your care: how had your process of looking for health information concerning the medical condition changed (if at all) compared to the scenario in the previous section?**

  [Edit question](#) | [Edit answers](#) | [Delete](#) | [Clone](#) | [Insert question](#) | [Insert page break](#) | [Insert line break](#) | [Skip logic](#)

ID : Q13

Help Text:

**How had your feelings about the process of finding information changed (if at all)?**

Note to Survey Participant: For the following question consider for instance any new experience related to the condition, so that you may include both queries that remain unchanged as well as entire new ones. New queries could respond to any or all of the following, but are not limited to these choices







- newly experienced symptoms or signs
- new complications from treatment and management
- having a changed prognosis or diagnosis
- a new interest in the latest treatment or management methods and protocols
- locating physically situated information resources (e.g. special collections, libraries)
- locating other support networks, care providers or clinical professionals
- anything else which you feel is relevant and would be useful for other information seekers- newly experienced symptoms or signs
- new complications from treatment and management
- having a changed prognosis or diagnosis
- a new interest in the latest treatment or management methods and protocols
- locating physically situated information resources (e.g. special collections, libraries)
- locating other support networks, care providers or clinical professionals
- anything else which you feel is relevant and would be useful for other information seekers

  Edit question | Edit answers | Delete | Clone | Insert question | Insert page break | Insert line break | Skip logic

ID : Q14

Help Text:

**Since diagnosis and through the course of management of your medical condition (or that of your charge if you are their caregiver or relative) what kinds of information did you subsequently seek?**

ID : Q15	^
Help Text:	
<b>Considering your previous information seeking experience(s), what sort of sources of new information did you consult in this period?</b>	
<b>(Note: these may be new <u>sources</u> in addition to similar sources of <u>new information</u>)</b>	
  <a href="#">Edit question</a>   <a href="#">Edit answers</a>   <a href="#">Delete</a>   <a href="#">Clone</a>   <a href="#">Insert question</a>   <a href="#">Insert page break</a>   <a href="#">Insert line break</a>   <a href="#">Skip logic</a>	
ID : Q15a	
Help Text:	
<b>What sort of PRINT information sources did you consult?</b>	
<input type="text" value="[For Example: Library Resources including Catalogues, Medical Reference Books, Journals]"/>	
  <a href="#">Edit question</a>   <a href="#">Edit answers</a>   <a href="#">Delete</a>   <a href="#">Clone</a>   <a href="#">Insert question</a>   <a href="#">Insert page break</a>   <a href="#">Insert line break</a>   <a href="#">Skip logic</a>	
ID : Q15b	
Help Text:	
<b>What sort of ELECTRONIC information sources did you consult?</b>	
<input type="text" value="[For Example: Internet, or Journal Databases from your local Library]"/>	
  <a href="#">Edit question</a>   <a href="#">Edit answers</a>   <a href="#">Delete</a>   <a href="#">Clone</a>   <a href="#">Insert question</a>   <a href="#">Insert page break</a>   <a href="#">Insert line break</a>   <a href="#">Skip logic</a>	
ID : Q15c	
Help Text:	
<b>What sort of HUMAN information sources did you consult?</b>	
<input type="text" value="[For Example: Community experts, family or other caregivers and other persons with the condition, or Medical Professionals]"/>	

ID : Q15sat

Help Text:

**How satisfied were you with the results of your search(es)?**

COULD FIND THE ANSWERS I NEEDED  COULD TRUST THE ANSWERS I FOUND  OTHER COMMENTS

[Describe]  [Describe]

[↑](#) [↓](#) [Edit question](#) | [Edit answers](#) | [Delete](#) | [Clone](#) | [Insert question](#) | [Insert page break](#) | [Insert line break](#) | [Skip logic](#)

ID : Q16

Help Text:

**Given experience from your prior information seeking, are the resources you will continue to make use of likely to change significantly from the responses given in the previous few questions?**

YES  NO

[↑](#) [↓](#) [Edit question](#) | [Edit answers](#) | [Delete](#) | [Clone](#) | [Insert question](#) | [Insert page break](#) | [Insert line break](#) | [Skip logic](#)

ID : Q17

Help Text:

**Do you expect to continue to seek information concerning your (or if you are a care provider, your charge's) medical condition in the future?**

YES  NO

[↑](#) [↓](#) [Edit question](#) | [Edit answers](#) | [Delete](#) | [Clone](#) | [Insert question](#) | [Insert page break](#) | [Insert line break](#) | [Skip logic](#)









ID : Q18

Help Text:

**Do you have any other Closing Comments that you feel would be useful to this Survey's Researcher, or to other clients of the Spina Bifida and Hydrocephalus Association of Canada?**

Figure 18: Survey of the Spina Bifida & Hydrocephalus Association of B.C.

The Survey sent to British Columbia Association members is exactly identical to the Canadian survey in all sections except this one, the Geographic Information group of questions; which is patterned after the Canadian one, so doesn't assume Membership in the Federal association unless specified:

Group 1: Non-Identifying Geographic Information	
  Edit question   Edit answers   Delete   Clone   Insert question   Insert page break   Insert line break   Skip logic	
ID : Q1	
Help Text:	
<b>Are you also a Member of the Spina Bifida and Hydrocephalus Association of Canada?</b>	
<input type="radio"/> YES	<input type="radio"/> NO
  Edit question   Edit answers   Delete   Clone   Insert question   Insert page break   Insert line break   Skip logic	
ID : Q1A	
Help Text:	
<b>Are you a member of other Provincial or Territorial Spina Bifida or Hydrocephalus Associations besides BC?</b>	
<input type="radio"/> YES	<input type="radio"/> NO
  Edit question   Edit answers   Delete   Clone   Insert question   Insert page break   Insert line break   Skip logic	
ID : Q1B	
Help Text:	
<b>If you answered 'yes' to the previous question, please specify which others</b>	
<input type="text" value="[Other Associations]"/>	
  Edit question   Edit answers   Delete   Clone   Insert question   Insert page break   Insert line break   Skip logic	
ID : Q2	
Help Text:	
<b>Do you reside in a Rural or Urban location?</b>	
<input type="radio"/> RURAL	<input type="radio"/> URBAN

## Ethical Approval Form

Figure 19: Ethical Approval Form

 <b>University of Victoria</b>	<b>Human Research Ethics Board</b> Office of Research Services Administrative Services Building PO Box 1700 STN CSC Victoria British Columbia V8W 2Y2 Canada Tel 250-472-4545, Fax 250-721-8960 ethics@uvic.ca www.research.uvic.ca	
	<h3>Certificate of Approval</h3>	
<b>PRINCIPAL INVESTIGATOR:</b> Jesse Gardner <b>UVic STATUS:</b> Master's Student <b>UVic DEPARTMENT:</b> HEIS <b>SUPERVISOR:</b> Dr. Alex Mu-Hsing Kuo	<b>ETHICS PROTOCOL NUMBER:</b> 13-098 Minimal Risk - Delegated <b>ORIGINAL APPROVAL DATE:</b> 08-Apr-13 <b>APPROVED ON:</b> 08-Apr-13 <b>APPROVAL EXPIRY DATE:</b> 07-Apr-14	
<b>PROJECT TITLE:</b> A Pilot Project Exploring the Effectiveness of Enlisting Health Information & Support Networks to Enhance the Experience of Consumer Health Information Seekers, Using Semantic Web Middleware <b>RESEARCH TEAM MEMBER:</b> None  <b>DECLARED PROJECT FUNDING:</b> None		
<b>CONDITIONS OF APPROVAL</b>		
<p>This Certificate of Approval is valid for the above term provided there is no change in the protocol.</p> <p><b>Modifications</b> To make any changes to the approved research procedures in your study, please submit a "Request for Modification" form. You must receive ethics approval before proceeding with your modified protocol.</p> <p><b>Renewals</b> Your ethics approval must be current for the period during which you are recruiting participants or collecting data. To renew your protocol, please submit a "Request for Renewal" form before the expiry date on your certificate. You will be sent an emailed reminder prompting you to renew your protocol about six weeks before your expiry date.</p> <p><b>Project Closures</b> When you have completed all data collection activities and will have no further contact with participants, please notify the Human Research Ethics Board by submitting a "Notice of Project Completion" form.</p>		
<b>Certification</b>		
<p>This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Participants.</p> <p style="text-align: center;">[Signature Redacted]</p> <p style="text-align: center;">Dr. Rachael Scarth Associate Vice-President, Research</p>		
Certificate Issued On: 08-Apr-13		

13-098 Gardner, Jesse