

Informing the Design of Mobile Wayfinding Software
for Users with Acquired Brain Injury

by

Nathanael Kuipers
B.Sc., University of Victoria, 2003

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

MASTER OF SCIENCE

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ABSTRACT

Wayfinding is the process of determining and following a route. Survivors of acquired brain injury (ABI) may evince impaired wayfinding skills. Mobile technology offers a promising avenue for wayfinding support, but software is seldom designed for users with cognitive impairments. This research was intended to inform the design of mobile wayfinding software for survivors of ABI. Two qualitative studies were conducted to investigate wayfinding by survivors of ABI, and solicit views on a prospective mobile wayfinding aide. Data were used to generate a substantive theory of wayfinding in ABI. Participants were generally enthused by the prospect of a mobile wayfinding aide. They felt that it would be useful and bolster confidence, leading to improved community access. In conjunction with the theory and its implications, their remarks on usage and design indicate that mobile wayfinding software should: provide a simple interface; be context aware; afford an interactive user experience; integrate with calendar software; deliver [audio] notifications; and emphasize landmarks while affording map access.

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I would like to thank:

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my supervisory committee, for their guidance, encouragement, and patience.

my research participants, for sharing their time and insight.

*The Road goes ever on and on
Down from the door where it began.*
J.R.R Tolkien, The Fellowship of the Ring

DEDICATION

This thesis is dedicated to all those recouping from acquired brain injury.
It is dedicated also to my wife, who exemplifies hard work and success.

Chapter 1

Introduction

This thesis addresses the problem of designing mobile wayfinding software for survivors of acquired brain injury (ABI). It presents a substantive theory of wayfinding in ABI grounded in the views and experiences of research participants. The theory unites spatial orientation and personal *composure*. Composure refers to feeling relaxed and ideally confident about travelling, and in conjunction with orientation defines the concept of *control*. Wayfinding consists of establishing, maintaining, occasionally losing, and then regaining control of a discrete, immediate journey.

In addition to providing a novel and cohesive view of wayfinding in ABI, this theory is important because of its implications for software design. There are *two* broad, complementary targets for providing wayfinding software support: facilitating orientation, and managing anxiety. There are three broad, actionable contexts for doing so, corresponding to establishing, maintaining, and regaining control of a journey. Unfamiliar journeys are more likely to mandate [intensive] wayfinding support than familiar journeys. Users in an early stage of recovery are more likely to require [intensive] wayfinding support than those in a later stage.

Consequently, and in conjunction with participant views on adoption, usage, and design of a hypothetical mobile wayfinding aide, this thesis makes six recommendations. Mobile wayfinding software should: provide a simple user interface; accommodate the whole user and wayfinding context; afford an interactive user experience; integrate with calendar software; deliver [audio] notifications; and emphasize landmarks while affording map access. These recommendations and the findings from which they are drawn will help software developers design effective wayfinding aides for users with ABI, thereby bolstering user confidence and improving community access.

This thesis proceeds as follows:

Chapter 2 provides the necessary theoretic background on wayfinding. It then motivates the research, and concludes by listing the five research questions.

Chapter 3 begins with a methodological overview of two studies. It then describes the methods of recruitment, data collection, and data reduction/analysis for each study, and concludes with an evaluation of the trustworthiness of this research.

Chapter 4 presents a substantive theory of wayfinding in ABI, followed by three additional considerations outside the theory proper. It concludes with participant views on adoption, usage, and design of a hypothetical mobile wayfinding aide.

Chapter 5 discusses the significance and implications of the substantive theory. It then presents six recommendations for the design of mobile wayfinding software for users with ABI, and concludes with a review of some related work.

Chapter 6 summarizes the research.

Chapter 2

The Problem to be Solved

Traversing the environment is essential for accomplishing our objectives. During a typical day we might go jogging, go to work, run errands, meet friends at a coffee shop, and retrieve an item from the attic for use in the workshop. In doing so, we engage in a process called *wayfinding*. A more thorough description follows.

2.1 Background

The term ‘wayfinding’ was originally coined in 1960 by Lynch, in his seminal book on spatial cognition and municipal planning [36]. It is frequently conflated with *navigation*. Navigation is formally defined as the piloting of ships and aircraft over long distances [24], but has also been described as subsuming human locomotion and wayfinding [40]. This thesis is concerned with wayfinding proper. What, exactly, is wayfinding?

2.1.1 Wayfinding

Wayfinding is defined by Golledge [24] as,

“...the process of determining and following a path or route between an origin and a destination. It is a purposive, directed, and motivated activity. It may be observed as a trace of sensorimotor actions through an environment.”

This is a good working definition. It clearly identifies an origin, a destination, and the route connecting them. It highlights the relationship between cognitive processing

and corresponding sensorimotor actions. Finally, it implies that since wayfinding is purposive and may be observed as a trace, it can be represented accordingly using external artefacts. Propositional languages and analogical spatial representations such as maps are well suited to this task [22]. However, wayfinding success is greatly facilitated by the so-called *cognitive map*.

2.1.2 Cognitive Maps

A cognitive map is a mental representation of environmental spatial information. It has been described as a collection of loosely related maps in the head; a network of distorted paths and intersections; and a catalogue of independent procedures for getting from one place to another [30]. Consistent with the observation that spatial information is often distorted in the mind and therefore not cartographic *per se*, the metaphors *cognitive collage* and *spatial mental model* have also been proposed [55]. Constructing and referencing internal representations of spatial knowledge are considered to be the major processes in environmental cognition [20].

The cognitive map was proposed by Tolman in 1948 [54] and further addressed by Lynch [36]. To account for the observation that with repetition, rats run a maze with successively fewer errors and in less time, Tolman conjectured that,

“...incoming impulses are usually worked over and elaborated...into a tentative, cognitive-like map of the environment...indicating routes and paths and environmental relationships.”

He hypothesized that the cognitive map ranges from a simple strip-map-like¹ structure to something much more complex, and that its construction and complexity are largely dependent on actively attending to the environment. Later, Lynch posited an *image* of the environment, or, “... the generalized mental picture of the exterior physical world that is held by an individual.” The image serves as a broad frame of reference for organizing activity, belief and knowledge. It is also a prominent source of emotional security and well-being. Because it is extensible, it is the foundation for individual growth. Furthermore, it provides a great deal of the common ground that underlies group communication.

¹A strip map is a linear rendering of environmental features, in the order in which they are encountered. See [37] for a thorough discussion on the characteristics, history, and applications of strip maps.

Like Tolman, Lynch recognized that actively attending to the environment is critical for constructing a cognitive map, which he viewed as a two-way process:

“The environment suggests distinctions and relations, and the observer. . . selects, organizes, and endows with meaning what he sees.”

He defined the *legibility* of an environment as the ease with which its elements can be parsed and organized into a coherent image. Through extensive interviews with city dwellers, he identified five elements of the image of the city: paths, edges, districts, nodes, and landmarks. *Paths* are channels for movement. *Edges* are disruptions in continuity, such as shores and walls. *Districts* are medium-to-large sections of the city with a common or otherwise salient character. *Nodes* are strategic travel points, such as junctions. *Landmarks* are external reference points, usually consisting of simple physical objects like mountains, buildings, or signs. These elements are identified and endowed with meaning based on personal significance and/or prototypical suggestion. As a composite of sensory data obtained from experience and imbued with memory and meaning, each image is unique.

Notably absent from Lynch’s work is a discussion of the physio-cognitive underpinnings of constructing the image. As part of a computational model of the human cognitive map called PLAN (Prototypes, Location, and Associative Networks), Chown, Kaplan, and Kortenkamp [14] provided a novel, lightweight synthesis of findings from several domains of cognitive science that is very useful in this regard. PLAN emphasized the so-called “what” and “where” visual subsystems, in conjunction with a structure in the brain called the hippocampus. The “what” subsystem, or ventral occipitotemporal pathway, is responsible for object identification and the “where” subsystem, or dorsal occipitoparietal pathway, is responsible for object location [15]. The hippocampus is thought to store and index visual scenes according to the physical location of the observer and the orientation of the head and body [1]. It may also serve as an interface between spatial memory and current spatial perception [52]. PLAN also integrated several theories on the development of cognitive maps in children, which is comparable to adults in new environments [48].

A cognitive map based primarily on either the “what” or “where” subsystems results in different wayfinding strategies. The “what” strategy is characterized by repeatedly moving to a landmark and looking for the next landmark. The “where” strategy is characterized by continually updating the current position relative to some goal, and is commonly referred to as having a good sense of direction. Either strategy

is sufficient, but see [35] for a discussion on the insufficiency, due to error accumulation, of a process similar to the “where” strategy called path integration. Cognitive map development is influenced by both strategies.

The cognitive map develops as both a topological representation of landmarks and a set of directional encodings for their relative spatial positions. This provides two-fold redundancy in case either system is compromised. Development begins with the object or *landmark stage*, when salient objects are distinguished and identified. It proceeds to the *route map stage*, when the individual relates objects to self and then objects to objects. At this stage, the cognitive map consists of *route knowledge*. Each route is represented independently from all the others from an egocentric frame of reference. It is at this stage that the dual topological and directional nature of the cognitive map begins to be realized. The last stage is the *survey map stage*, which is characterized by development of an objective or allocentric frame of reference, and the determination of spatial relationships between objects and routes that are not visually proximal. At this stage, the cognitive map consists of *survey knowledge*. Travelled routes are integrated into a representation of the encompassing environment. In short, fully developed cognitive maps are synonymous with survey knowledge, which is built up from route knowledge, which comes from travelling a route.

Note that the Euclidean geometry and metric distances stored in the cognitive map are typically inaccurate. Supposing that accuracy is proportional to the cognitive cost of constructing and referencing the cognitive map, and that economical information storage confers an evolutionary advantage in terms of processing time, PLAN has two practical implications [14]. First, cognitive maps are “heads-up” or scene-based. Second, their imprecision is what makes them usable in a dynamic world with many wayfinding tasks.

2.1.3 Wayfinding Tasks

There is no universally agreed upon taxonomy of wayfinding tasks. Freksa characterized wayfinding “situations” as simple or complex searches that are time-critical, space-critical, or not critical, and are executed by searchers who are well- or uninformed, and “smart” or “helpless” [22]. Allen’s popular task-means schema [2] fits well with the everyday examples given at the start of this chapter. Tasks consist of travel to a familiar destination, exploratory travel with the goal of returning to a familiar origin, and travel to a novel destination. Means include oriented search,

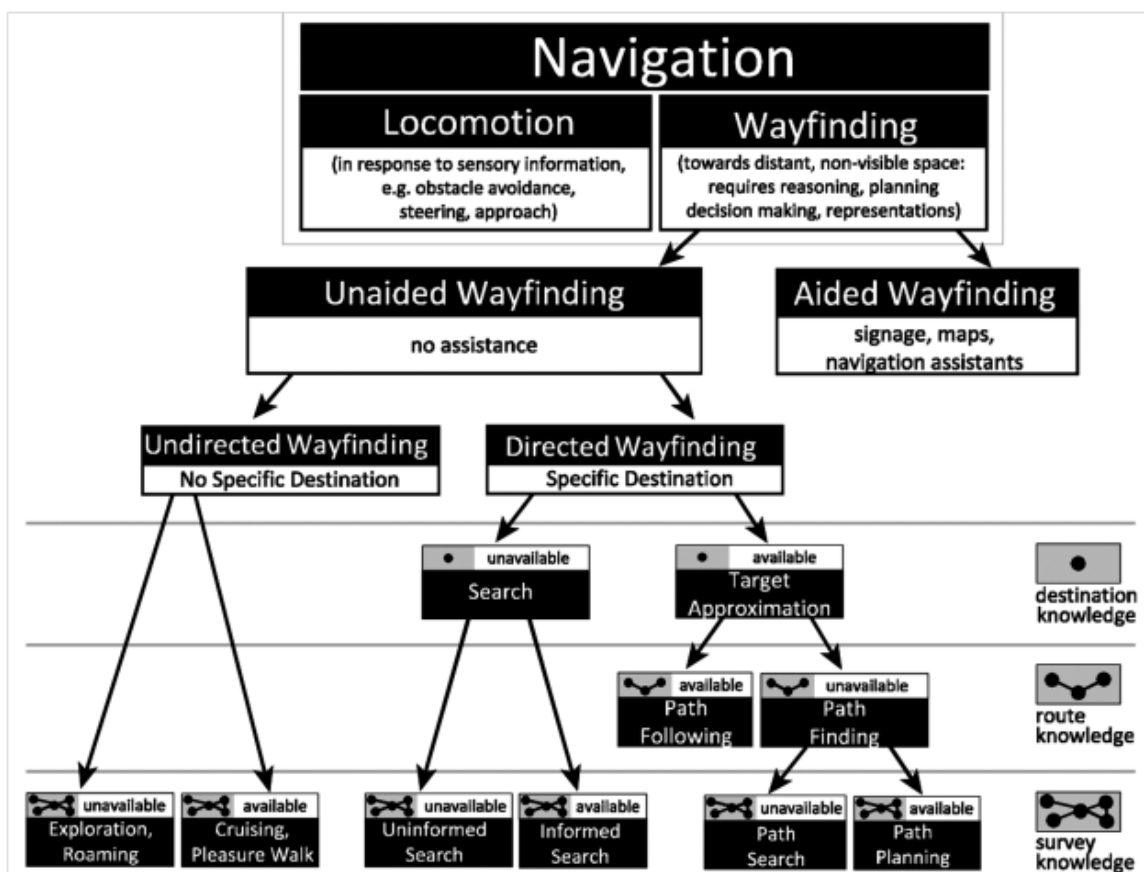


Figure 2.1: A knowledge-based taxonomy of unaided wayfinding tasks, reproduced from [56] with the permission of the authors. Note that the root is *Navigation* as defined by [40]. Different tasks may be executed according to the availability of destination, route, and survey knowledge. A fully developed cognitive map is synonymous with survey knowledge.

trail following, piloting between landmarks, habitual locomotion, path integration, and referencing the cognitive map. The same means may be invoked during different tasks, and a single task may invoke multiple means. Wiener, Büchner, and Hölscher extended Allen’s task-means schema with a “knowledge-based” taxonomy [56]. It divides Unaided Wayfinding into Directed Wayfinding to a specific destination, and Undirected Wayfinding for exploration or pleasure (Figure 2.1). Directed Wayfinding is further divided into Search and Target Approximation tasks, which are themselves sub-divided based on the availability of destination, route, and survey knowledge. Though less granular, Allen’s schema is useful because of its simplicity, intuitiveness, and explicit enumeration of wayfinding means and how they map to tasks. Both taxonomies recognize the critical importance of the cognitive map.

2.2 Motivation and Research Questions

This thesis is concerned with wayfinding by survivors of *acquired brain injury* (ABI), hereafter referred to as *survivors*. *Acquired* denotes injury that is neither congenital, nor degenerative. Rather, it is caused by discrete phenomena including surgical anoxia, stroke, and traumatic brain injury (TBI) due to external physical trauma. TBI subsumes *closed head injury* in which the cranium and dura mater remain intact. Recovery from TBI proceeds through three stages: acute, sub-acute or rehabilitative, and chronic. In the acute stage, medical personnel attempt to stabilize the patient and prevent further complications. The sub-acute stage begins once a patient is stable and conscious, and may include physical, mental, and emotional rehabilitation. Many patients show great progress in the first six months after which progression slows down, signalling the beginning of the chronic stage which may last for several years [10]. However, patients may continue to improve significantly over a period of two years post-injury, and then gradually over ten years or more [46]. It has been estimated that one Canadian sustains a TBI every three minutes, and that nearly 4% of Canadians live with an ABI [38].

The neural damage resulting from ABI is typically associated with cognitive impairment, which often impacts wayfinding. In their assessment of 127 participants with stable, focal lesions distributed throughout the brain, Barrash et al. found that complex route-learning was impaired in 87% of participants with damage to the medial occipital and posterior para-hippocampal cortices in the left or right hemispheres, the right hippocampus, and the right infero-temporal region; and 31% of participants with damage to other areas [5]. Spikman et al. found that survivors in the chronic stage of moderate to severe frontal closed head injury were distinguishable from control participants on a series of executive function tasks only by their relatively poor performance of an Executive Route Finding task [51]. Given deliberately misleading written directions through an unfamiliar neighbourhood, Lemoncello et al. found that survivors demonstrated greater error and hesitation and requested assistance more frequently than control participants, who were more likely to develop alternatives based on spatial reasoning and anticipation of errors [31].

Mobile devices like tablet computers and smartphones are now ubiquitous, and offer a promising avenue for providing wayfinding support. These devices combine telephony with a personal digital assistant and multiple sensors, and are usually equipped with a camera and Global Positioning System (GPS) receiver. Sophisticated

wayfinding services are also available. For example, Google Maps² is a zooming street map and geographic information system (GIS) with schematic and satellite views, and layers including traffic flow and user-generated photos. Given an origin and destination, Google Maps generates a graphical route trace and corresponding directions for several modes of transportation (Figure 2.2). If GPS is enabled, then the location of the receiving device is also shown and updated in real time, and can even be shared with authorized persons using Google Latitude³. Google Street View⁴ shows street-level photographic imagery that is accessible from Google Maps. A user can toggle between the allocentric view of Maps and the egocentric view of Street View (Figure 2.3). These services are free of charge and largely platform independent, requiring only a Web browser. They also expose application programmer interfaces for developing native, or platform-specific, applications. Mainstream mobile platforms include iOS⁵, Android⁶, and Blackberry⁷.

Survivors and their care providers have strongly endorsed the notion of a mobile wayfinding aide [50]. Unfortunately, cognitive impairments are often not addressed by software designers. Keates et al. suggested that this is because cognitive impairments are largely invisible, difficult to diagnose, not universally defined, and not easy to accommodate [26]. They proposed five categories of cognitive capability: attention, memory, organizational skills, language skills, and social skills. Similarly, in recognition of the fact that software developers are not clinicians, Bohman and Anderson distinguished between clinical and functional cognitive disabilities [8]. Functional cognitive disabilities de-emphasize aetiological factors in favour of so-called limiting characteristics: attention, memory, problem-solving, reading and linguistic comprehension, mathematical comprehension, and visual comprehension. Although multiple limitations may exist within the same individual, many individuals fit primarily into one category. Compounding these considerations is the incredible diversity within a given population of cognitively impaired users, and even within a single individual whose abilities may change. Consequently, users with cognitive impairments require wayfinding supports that are highly customized, customizable, and/or self-adapting [11, 57]. By carefully considering their views and experiences with respect to wayfind-

²<http://maps.google.com/>

³www.google.com/latitude

⁴<http://maps.google.com/streetview>

⁵<http://www.apple.com/ios/>

⁶<http://www.android.com/>

⁷<http://www.blackberry.com/>

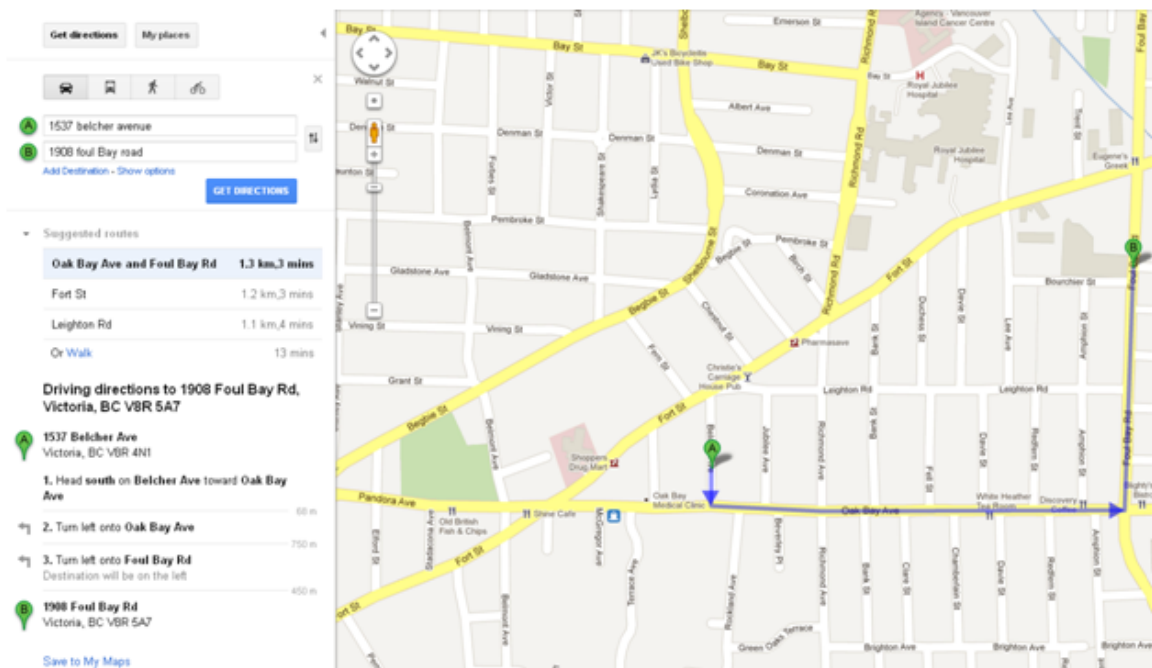


Figure 2.2: A route trace and directions generated by Google Maps. Directions consist of text, turn-arrows, and annotations. Above them is a push-button menu for toggling different travel modes. Dragging the yellow “Peg man” at the top left corner of the map (just above the zoom slider) to a location on the map launches Street View.

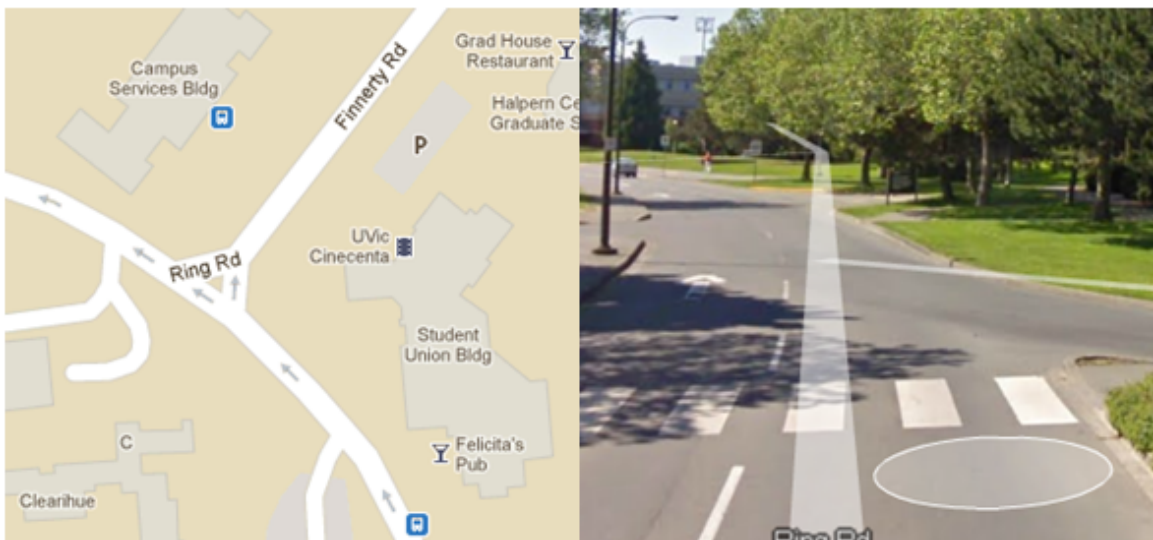


Figure 2.3: A side-by-side comparison of standard and Street View views of Google Maps. On the left is a zoomed-in portion of the University of Victoria campus, shown in the standard view of Google Maps. Prominent buildings and points of interest including restaurants and bus stops are labelled. Traffic flow around Ring Road is also shown. On the right is the Street View imagery of the triangular junction labelled “Ring Rd” in the map.

ing challenges and strategies, we can enhance our understanding in support of this requirement.

This thesis therefore investigates the following research questions:

1. How do survivors plan their excursions?
2. How do survivors stay on course?
3. Why do survivors lose their way?
4. How do survivors recover from losing their way?
5. How might survivors receive, use, and design the ideal mobile wayfinding aide?

Chapter 3

Investigative Approach

Two qualitative studies were conducted to address the research questions, in accordance with ethics approval provided by the University of Victoria Human Research Ethics Office. The first study targeted individuals with cognitive impairments, and their care providers. Its purpose was to gain a broad overview of wayfinding by cognitively impaired travellers, and to pilot questions for subsequent refinement. The second study, which was based on the first, targeted survivors. Its purpose was to generate a substantive theory of wayfinding in ABI. A substantive theory is an abstract analytic schema of a process, and is closely concerned with a particular phenomenon and/or population [16]. It may help explain practice and/or provide a framework for future research.

3.1 Methodology

The substantive theory was generated by applying the grounded theory approach to inquiry [16], which aims to generate or discover a theory that is “grounded” in the views and experiences of individuals [23]. These data are typically gathered through conversations with or among participants, and are then transcribed into text. The approach is inductive, rather than deductive, because it does not start with a theory from which hypotheses are formulated for testing. Inductive inquiries tend to be broad, allowing participants to provide relevant details of their own volition.

In grounded theory, data collection and analysis are interleaved. Analysis begins with coding the data. A *code* is a textual label that explains the significance of a fragment of data. Similar codes are reduced and abstracted into theoretical ideas

called *concepts*. Related concepts are further abstracted into high-level *categories* of information, whose *properties* they define. New data are compared to tentatively elucidated categories, thus affirming or enriching these categories, or indicating new ones. This is called *constant comparative analysis*. The emerging theory is elaborated by *theoretical sampling*, whereby participants are selected based on their projected ability to contribute new insights. The cycle of data collection and analysis continues until categories are *theoretically saturated*, meaning that new data do not alter or indicate categories. Analytic insights are recorded throughout by writing *memos*.

Constant comparative analysis, theoretical sampling, theoretical saturation, and memo writing have been the pillars of grounded theory since it was introduced in 1967 [23]. There are two popular modern variations of grounded theory: systematic [53] and constructivist [13]. Systematic grounded theory emphasizes *axial coding*, whereby a *core category* is identified that accounts for the remaining *peripheral categories*. Four kinds of peripheral categories are prescribed. *Causal conditions* are factors responsible for the core category. *Strategies* are actions taken in response to conditions. *Intervening conditions* are situational factors that influence strategies. *Consequences* are the outcomes of using strategies. Constructivist grounded theory makes no such prescription, nor does it stipulate that the theory must be built around one core category, as this may stifle the data. Instead, it emphasizes “. . . diverse local worlds, multiple realities, and the complexities of particular worlds, views, and actions” [16]. Given the incredible diversity among survivors, whose injuries may be quite different and may impact them quite differently, a constructivist grounded theory approach was therefore deemed to be especially appropriate.

In addition, constructivist grounded theory advocates analytic flexibility and reflexivity throughout the processes of *initial* and *focused coding*. Initial coding entails a close reading of the data, such that initial codes summarize, describe, and account for the data. Through *focused coding*, the researcher decides which initial codes should be reduced and abstracted to so-called focused codes. Initial and focused coding utilize *active codes* to capture actions and processes rather than neutral topics. Coding with gerunds¹ is recommended. By continuously writing memos, the researcher achieves a sense of which initial codes comprise a focused code, and which focused codes comprise a category.

¹A gerund is when a verb in its '-ing' form is used as a noun, such as “*Writing* aids memory.”

3.2 Methods: Study 1

3.2.1 Sampling

Recruitment was performed by four organizations serving clients with cognitive impairments in Greater Victoria: Community Living Victoria², the Garth Homer Society³, the Victoria Brain Injury Society⁴ (VBIS), and the Cridge Centre for the Family⁵. VBIS provided independent ethics approval before agreeing to perform recruitment. The organizations e-mailed a letter of information for implied consent (Appendix A.1) to qualifying clients. These were comprised of cognitively impaired adults who have difficulty wayfinding, and caregivers. The letter assured candidates that their participation was completely voluntary; that it would not affect their relationships with recruiting organizations; and that they could withdraw at any time. Interested candidates were invited to contact the researcher to review the letter and discuss any questions or concerns.

Six people responded, but one lived too far away and two withdrew for medical reasons prior to data collection. Coded names are used for the three participants (Table 3.1). Jennifer is 46 years old and sustained a traumatic brain injury (TBI) seven years ago. Samantha is 34 years old and sustained a brain injury very soon after birth. Note that although her injury is neither congenital nor degenerative, and is therefore aetiologically traumatic, it may effectively be considered a developmental injury because it occurred while her brain was still developing. Sharon is Samantha's adoptive mother. Sharon corresponded for herself and on Samantha's behalf.

3.2.2 Data Collection

The study was conducted at CanAssist⁶ headquarters at the University of Victoria. It consisted of a questionnaire followed by a focus group discussion. The questionnaire was administered immediately on participant arrival. The focus group discussion was moderated by the researcher, and audio-video recorded. The setting was casual: in a spacious room, several couches were arranged around a coffee table next to a bay window. There were two 10-minute breaks, during which refreshments were provided.

²<http://communitylivingvictoria.ca/>

³<http://www.garthhomer.com/>

⁴<http://vbis.ca/>

⁵<http://cridge.org/>

⁶<http://www.canassist.ca/>

The first break took place after the questionnaire. It was at this time that participants introduced themselves to each other. The second break took place approximately two thirds of the way through the focus group discussion. The session itinerary was listed in large black text on a whiteboard, and each item was check-marked in green by the researcher upon completion. The session took 1.5 hours. Afterwards, each participant was thanked, and received a small monetary gift.

The atmosphere throughout was easygoing, yet energetic. Participants quickly struck up a positive group dynamic. Jennifer later e-mailed the researcher, saying that she thinks often of the other women in the team, and what a pleasure it was to participate.

Questionnaire

The questionnaire was used to collect basic information, and prime participants for discussion. There were two versions. The version for participants with cognitive impairments assessed wayfinding patterns and logistics including excursion frequency and modes of transportation (Appendix A.2). It was piloted by two CanAssist staff including a volunteer with a brain injury, as well as two graduate students from the Computer Human Interaction Software Engineering Laboratory⁷. The version for caregivers assessed mobile device ownership, and asked whether a mobile wayfinding aide for users with cognitive impairments would be helpful (Appendix A.3). Questionnaires were completed in blue ink. Sharon completed Samantha's questionnaire in consultation with her. Amendments could be made after the focus group discussion

⁷<http://www.thechiselgroup.org/>

Table 3.1: Summary of Study 1 participants. Jennifer and Samantha have an ABI, while Sharon is Samantha's adoptive mother.

	Jennifer	Samantha	Sharon
Gender	F	F	F
Age (years)	46	34	
Time Since Injury (years)	7	33	N/A
Type of Injury	TBI	TBI	N/A
Physical Impairment(s)	N/A	cortically blind	N/A
Employment	N/A	volunteer	retired
Living Situation	with partner	with Sharon	

in red ink. Jennifer and Sharon both took advantage of this opportunity to clarify and supplement their initial responses.

Focus Group Discussion

The focus-group discussion began with a review of ground rules concerning respect and confidentiality (Appendix A.4). Participants were then asked several questions about their wayfinding challenges and strategies (Appendix A.5). A hypothetical scenario was provided to help contextualize and start discussion: “Meeting a friend at a coffee shop downtown, at 3:00 in the afternoon.” Finally, participants brainstormed the design of an ideal mobile wayfinding aide. The researcher displayed a smartphone and described several possible features to help contextualize and start the discussion, such as “It should remind me where I’m going” and “It must have big buttons.”

3.2.3 Data Reduction and Analysis

The researcher transcribed audio data into Microsoft Word, *verbatim*. Where speech was indistinguishable, “⟨could not make out⟩” was inserted. Samantha in particular tended to interrupt or speak simultaneously with others in her excitement.

The researcher performed initial coding of the transcript using comments in Microsoft Word. Memos were recorded beneath the codes. The goal while coding was to concisely describe a given line, sentence, or utterance. Some passages were initially assigned multiple, tentative codes. As the researcher became more comfortable with coding and more familiar with the data, multi-codes were reduced to a single code that the researcher felt best accounted for the associated passage. Some passages were used as codes. These *in vivo* codes were eventually replaced by abstract versions per the recommendation in [13]. For example, the *in vivo* code, “Changing horses, midstream” became “Coping with unexpected change.”

Categories and subcategories were abstracted from recurring, similar, or otherwise related codes, as well as codes that were particularly striking. The researcher constructed a graphical framework of the findings using Microsoft PowerPoint (Appendix B.1). A point-form summary of the framework (Appendix B.2) was emailed to participants, who were asked to assess whether, “. . . anything seems wrong or is missing.” Jennifer and Sharon responded. They felt that the summary was accurate.

3.3 Methods: Study 2

3.3.1 Sampling

Prior to recruitment, the researcher met with administrators at the Victoria Brain Injury Society (VBIS) and Cridge Centre for the Family to discuss the research in depth. They were delighted with the research and affirmed its importance. They once again agreed to perform recruitment. They also identified several aspects of the design of Study 1 that could have discouraged candidates from participating, and suggested corresponding changes.

The most obvious oversight was that candidates may have little to no e-mail access, making “e-blast” impractical. The language of the letter of information for implied consent was too complicated, and the document itself was too long. Data were collected at an unfamiliar location. Having to write answers to a questionnaire and then discuss in a group may also have been prohibitive. Administrators recommended creating a flyer, which they would post and distribute on-site. They also recommended using simpler language, and limiting the letter to one page, double-sided. Finally, they recommended that data collection consist of personal interviews on-site. An ethics modification form reflecting these changes was approved by the University of Victoria Human Research Ethics Office prior to recruitment. Interested candidates were invited to contact the researcher to review the consent form (Appendix C.1) and discuss any questions or concerns.

Six men and three women responded. Each is a survivor of acquired brain injury (Table 3.2). Participant age ranged from 33 to 64 years (mean 52.6, median 55). Time since injury ranged from less than 1.5 to 39 years (mean 14.2, median 11.5, mode 4.5). All participants reported some degree of impaired short term memory (Table 3.3). The short term memory of Participant 6 (or, P6) is especially poor: he often forgets what he is saying and must be reminded. P9 reported that she misplaces objects in the open because she cannot recognize them, and that she has little to no concept of how her current location relates to the rest of a route. At the time of data collection, participants were nominally independent in that they regulated their own comings and goings. None were gainfully employed (Appendix D, Table D.1).

Table 3.2: Summary of Study 2 participants. TSI designates time since injury. ABI and TBI designate acquired and traumatic brain injury, respectively. Information on injury site was provided by each participant to the best of his or her knowledge. P2 listed the parietal, occipital, and left frontal lobes, the pons, the peduncle, the medulla, the hippocampus, the right hemisphere, and the optic nerve.

P#	Gender	Age (years)	TSI (years)	Type	Site(s)
1	M	37	14	TBI	back of head
2	M	49	4.5	ABI	various
3	M	58	39	TBI	cerebellum
4	M	62	9	TBI	frontal lobe
5	M	51	1.5	ABI	left hemisphere
6	M	33	21	ABI	left cerebrum
7	F	65	20	TBI	front, back of head
8	F	55	1.5	ABI	unknown
9	F	63	4.5	TBI	frontal, temporal lobes

Table 3.3: Cognitive and physical impairments of Study 2 participants. STM designates short term memory. Interpretation refers to hearing other people incorrectly – in effect putting words in their mouths – despite the fact that the sense of hearing itself is not impaired.

P#	Cognitive Impairment(s)	Physical Impairment(s)
1	STM, organization, interpretation	N/A
2	STM	legally blind, motor control
3	STM, concentration, organization	N/A
4	STM, concentration, decision-making, articulation	dim vision, motor control
5	STM	N/A
6	STM, articulation	right-side motor control
7	STM, motivation, organization, interpretation	vision, fine motor control
8	STM, concentration, organization	motor control
9	STM, organization, spatial cognition	N/A

3.3.2 Data Collection

The researcher conducted an intensive, structured interview with each participant over the course of three months. Every effort was made to accommodate participant schedules, and comfort zones. Interviews took place in a quiet room and were audio-recorded. Note-taking was kept to a minimum during the interviews to maximize researcher responsiveness. Responsiveness was very important, as participants occasionally forgot or were unable to articulate their thoughts, and/or had a tendency to ramble. When this happened, the researcher re-stated the question, or paraphrased the response to clarify and affirm the intended meaning: “Did you mean...?” Participants were encouraged to take breaks as needed. Snacks were made available throughout, and greatly appreciated. Each interview took 1.5 hours. Afterwards, each participant was thanked and received a small monetary gift. Several participants remarked on how glad they were to help other survivors by participating.

Interview Schedule

The interview schedule (Appendix C.2) was based on the questionnaire and revised focus group questions from Study 1.

Part 1 was used to collect personal information related to brain injury, and prime participants for discussion. It was intended to foster a deep understanding of participant perspectives, but also to provide a check for subsequent responses, as well as a basis for prompting the participant in the event of confusion: “Earlier you said that...” It included several questions adapted from the Self Assessment of Disabilities Interview (SADI) [21]. For example, participants were asked how having a brain injury impacts daily life, and if-and-how this might be expected to change in the next six months. Responses were not scored.

Part 2 investigated wayfinding patterns and logistics, challenges, and strategies. Participants were presented with the same hypothetical wayfinding scenario as in Study 1. They were also asked to describe, if possible, at least one incident in which they became lost or disoriented, and what they did to resolve the situation.

Part 3 assessed ownership of and familiarity with computers and mobile devices. For example, participants were asked whether they had ever used a smartphone. The researcher displayed a smartphone and a tablet computer running Google Maps to help contextualize and start the discussion. Participants were also invited to consider a hypothetical mobile wayfinding aide which was referred to as a Personal Travel

Guide (PTG). They were instructed to assume that the PTG had been perfectly designed and customized. They were then asked what they thought about this idea, in what contexts it would be most useful, and what kind of functionality and features it should include.

3.3.3 Data Reduction and Analysis

The researcher transcribed audio data from each interview into Microsoft Word, *verbatim*. Where speech was indistinguishable, “⟨could not make out⟩” was inserted.

The researcher performed initial and focused coding per the constructivist grounded theory procedure outlined in [13]. Codes employed gerunds to emphasize actions and processes, such as, “Worrying about getting lost” and, “Piloting heads-down.” The language of each code was carefully chosen to reflect analytic insights: “shunning” instead of “avoiding”; “balking” instead of “staying home.” At the same time, close attention was paid to ensuring that initial codes preserved context, as in, “Feeling paralysed by confusion on boarding.”

Transcripts were coded in the order in which the corresponding interviews were conducted. Passages were compared within and between transcripts, per constant comparative analysis. This promoted code modification and/or re-use. Each line of the first six transcripts was assigned an initial code to achieve a deep understanding of participants, and remain open to all analytic directions. This resulted in over 1000 strictly unique codes; far too many to work with. In the interests of time and analytic coherence, codes and passages deemed to be unrelated to wayfinding *per se*, such as, “Salvaging paternal role” or, “Pursuing opportunities *ad hoc*” were therefore removed from further consideration. The researcher then re-coded the relevant passages, compared the resulting codes to the first pass, and resolved the few discrepancies. Initial coding of the last three transcripts was more fluid. A phrase, line or story was coded if the researcher deemed it to be related to wayfinding. The code-recode procedure [29] was not applied.

Recurring or similar initial codes were reduced and abstracted as focused codes. For example, the three initial codes, “Marking destination, bus stop on Maps hard-copy”, “Highlighting a route on a map” and, “Writing warnings on a map” became the focused code, “Annotating a map.” Similar or otherwise related focused codes, as well as some that were singularly striking such as, “Travelling on automatic pilot” were in turn reduced and abstracted as categories. For example, “Annotating a map”

became a property of the category, “Establishing control of a journey” while, “Travelling on automatic pilot” became a property of the category, “Maintaining control of a journey.” Writing informal memos was critical to making these analytic decisions, and elaborating on focused codes and categories as they coalesced.

3.4 Trustworthiness of this Research

Trustworthiness refers to the validity of qualitative research. Guba’s model of trustworthiness [25][32] appears to have inspired a degree of consensus among qualitative researchers [29][47][42]. The model posits four aspects of trustworthiness: truth value, applicability, consistency, and neutrality. These aspects roughly correspond to internal and external validity, reliability, and objectivity in quantitative research, respectively.

Truth value, or *credibility*, is considered to be the most important aspect. Credible findings resonate strongly with members of the studied population. Member checking consists of [continuously] revealing data, categories, and other analytic products with participants to ensure that their experiences have been accurately represented. It is particularly important towards the end of a study [32]. It is also more difficult then, because the data have been analytically abstracted and require higher conceptual analysis from participants [29]. Moreover, revealing data may have ethical implications if those data cause distress, and/or may bias subsequent feedback. Employing additional strategies for establishing credibility, such as peer examination and thick descriptions of the data, is therefore important.

Applicability, or *transferability*, is the degree to which findings can be generalized. Because qualitative research tends to focus on a relatively small sample of individuals with specific traits, it has been suggested that providing sufficiently descriptive data to enable comparisons satisfies applicability [32]. By the same reasoning, consistency, or *dependability*, implies that although replication should not be expected to yield highly similar results, variability should be attributed to explainable sources and/or identified as atypical. Finally, neutrality is the degree to which findings arise solely from participant input. Whereas the quantitative criterion for neutrality is researcher objectivity, the qualitative criterion is data *confirmability*, due to the emphasis in qualitative research on decreasing the distance between researcher and participants. Confirmability follows from establishing truth value and applicability [32].

3.4.1 Threats to Trustworthiness

The practice of paraphrasing the participants conflicts with the criterion of neutrality. To paraphrase is to supply an *interpretation*; else it is not paraphrasing, but repeating. Paraphrasing therefore implicitly injects interviewer bias. However, it was necessary and mutually helpful as previously discussed, and should be considered an inherent limitation of performing qualitative research with survivors of ABI, whose short term memories are frequently impaired.

Likewise, grounded theory itself conflicts, to a point, with neutrality. Creswell states that, "...a grounded theory procedure does not minimize the role of the researcher... The researcher makes decisions about the categories throughout the process, brings questions to the data, and advances personal values, experiences, and priorities" [16]. Charmaz asserts that some researcher bias is unavoidable, but necessary if a theory and not a mere summary of the data is to be achieved [13]. Consequently, she recommends that initial coding should entail a close reading of the data; that coding should minimize extant phrases/concepts; and that the researcher should put aside extant theory and literature while drafting the grounded theory. Her recommendations were duly applied in this research.

Study 2 was based on Study 1, but within Study 2 there was no theoretical sampling. This was largely due to difficulties with recruitment, as well as time constraints. Several participants referred by name to injured peers who they felt should participate. The researcher invited these participants to inform their peers of the study, but felt ethically prohibited from pursuing the matter further. Regardless, the lack of theoretical sampling violates one of the principle demands of grounded theory. The inherent incompleteness and inconclusiveness of constructivist grounded theory [16] notwithstanding, there is no assurance of theoretical saturation without theoretical sampling. For example, it might have been instructive to recruit participants who are employed, or who require significant intervention from a care provider. Care providers, too, might well have offered additional, cogent insight. This is a tacit threat to both credibility and transferability. However, participant characteristics were recorded in as much detail as was feasible. Participants comprised a diverse sample including men and women of various ages and time since injury. They described or evinced various cognitive and physical impairments, primary mode(s) of transportation, and so on. The resulting theory must nonetheless be treated as highly substantive.

Six months elapsed from the time that the first data were collected for Study 2,

and the grounded theory was drafted. During that time, no member checking was performed. P8 recorded the interview on her own device and listened to the recording the next day. She later contacted the researcher and was very upset because her responses erroneously conflated times, and places. The researcher had already formed serious reservations about the integrity of her data because of several discrepancies. Her follow-up reinforced the decision to excise data that were not absolutely clear, and congruent with the rest of her data.

Continuous member checking was not performed for several reasons. Accommodating participants proved to be quite challenging in some cases, so that a single meeting per participant was optimal. Not all participants had email access for subsequent correspondence. Transcription and analysis were unexpectedly time-consuming, and the researcher simply did not know to check anything short of the end product of analysis. As time went on, the researcher deemed it less and less likely that participants would remember what they said because of their impaired short term memories.

The lack of member checking in Study 2 is a serious threat to credibility. Upon drafting the theory, a point-form summary was sent to participants with e-mail addresses. They were reminded of their participation in the research. They were *not* asked to verify the summary, but were invited to peruse it for the sake of interest, and to contact the researcher if they had any questions or comments. None responded. In addition:

- Hypothetical scenarios were employed to gather rich data.
- The researcher requested clarifications and paraphrased responses for confirmation during interviews.
- Analytic techniques prescribed in constructivist grounded theory were more rigorously applied than in Study 1.
- A code-recode procedure was performed for the first six transcripts.
- Member checking was performed at the conclusion of Study 1. Study 2 was based on Study 1, and mirrored several of its findings.
- Findings and discussion frequently included direct quotes, and exceptional circumstances were described in detail.
- *Post hoc* peer review was provided by a committee member who is expert in brain injury.

Conducting this research was highly instructive for the researcher, not only with respect to wayfinding in ABI, but to qualitative research and its unexpected challenges. Qualitative researchers working with survivors are urged to take seriously the software development mantra of *release early, release often*⁸. It is especially important to strive for rapid, light-weight analytic products that may be checked with participants, whose memories may be impaired.

⁸http://en.wikipedia.org/wiki/Release_early_and_release_often

Chapter 4

Findings

4.1 Substantive Theory of Wayfinding in Acquired Brain Injury

A substantive theory of wayfinding in acquired brain injury was generated according to the methods of the previous chapter. It states that wayfinding in acquired brain injury fundamentally consists of four phenomena: *establishing*, *maintaining*, occasionally *losing* and then *regaining control* of a discrete, immediate journey. Control is an abstraction that subsumes spatial orientation and personal *composure*. Composure refers to feeling relaxed and ideally confident about travelling. The remainder of this section describes wayfinding and its constituent phenomena in greater detail. The phenomena correspond to and address the first four research questions, and are presented accordingly.

4.1.1 How Survivors Plan their Excursions: Establishing Control

Establishing control of a journey means resolving to undertake the journey, and then constructing a travel plan. It begins when the journey is first considered, and depends largely on the degree of familiarity with the destination.

In the best case, the destination is very familiar, and is associated with an equally familiar route. Little or no deliberation or planning is typically required, and control is implicitly established. In the worst case, the destination and route are unfamiliar. P5 explained that assessing familiarity hinges on his ability to mentally visualize the

destination, or some nearby landmark. Failing to do so means that the destination is insufficiently familiar. The proposed journey is therefore fraught with fear and uncertainty *vis-à-vis* becoming lost or unable to return home. At minimum, “If it’s a place that I hadn’t been before, then I think I’d be worrying before I even left...” This trepidation – perhaps enhanced by traumatic memories of previous ventures – may be enough to deter survivors from undertaking the journey unless it is mandatory, such as a medical appointment.

In addition to insufficient familiarity, social factors may deter a survivor from undertaking a journey. P1 alluded to the psychological trauma associated with a memory of walking to the beach and becoming involved in an altercation. His attempts to circumvent the route by travelling along parallel streets have been unsuccessful. By virtue of their proximity and common destination, they too recall the damaging incident. As a result, that route is no longer tenable, and is shunned. Conversely, if a survivor resolves to undertake the journey, then control can be at least nominally established by constructing a travel plan.

Consulting Wayfinding Artefacts

Constructing a travel plan typically involves consulting one or more external cognitive aids for wayfinding, or *wayfinding artefacts*, such as transit schedules and street maps. Several participants reported using Google Street View before embarking, to prime recognition of the destination *en route*. P1 was the only participant who evidently does not consult wayfinding artefacts at all. His excursions consist mostly of daily walks through nearby neighbourhoods with which he is extremely familiar (Table E.1). Wayfinding artefacts are therefore unnecessary. Among the other participants, consulting a map is especially prevalent¹.

Eight participants reported occasionally consulting a map in order to plan a route or refresh route memory, including four who successfully use Google Maps (P2, P4, P5, P6). Locating the destination was uniformly reported as the first step in constructing a travel plan with a map, as well as its primary usage, “Just to get a, a *bearing* of where, where this is, you know... so I know what bus and where to get off, or when to ask when to get off...” In this respect, Google Maps is evidently remarkable for its clarity. P2 commented on the effectiveness of the, “...two-dimensional information, it’s very informative...” while P4 remarked, “...it absolutely shows you where it is,

¹Two participants spoke of a ‘map book.’ Whether they meant a book of maps proper or a transit schedule with its accompanying maps is unclear.

like I mean there's no question as to where that place is..."

Planning Collaboratively

Some survivors, especially those who maintain close relationships with family, occasionally employ collaborative travel planning in addition to wayfinding artefacts. For example, P7 had driven to her daughter's home for a family dinner, and afterwards they discussed her route home. P7 proposed a travel plan that was based on turns: "...I did three rights and a left so then it has to be the opposite..." Constructing the opposite route is not always feasible, especially for motorists, because of one-way paths; but in this case her plan stood up to scrutiny. Collaboration is useful not only for confirming a travel plan, but also for constructing and understanding it.

Collaborative walkthrough is a synchronous review of route instructions involving the survivor, and a trusted peer who acts as a guide. Synchronous means that the guide waits for the survivor to understand one step before moving to the next. The survivor and guide may be co-located or distributed. They typically examine one or more wayfinding artefacts that are common to their workspaces, if not actually shared, as in each referring to a copy of the bus schedule. For example, P5 recalled struggling to understand route instructions on the transit company website. He phoned his sister and asked her to examine the offending page. She too was perturbed by its inordinate complexity, so,

"... what we did is I opened up, I think my map book and I brought up a map... and she just sort of walked me through it, you know, this is where you do it and then you gotta [*sic*] walk to here and catch this bus and that's on page whatever, ok... I take a highlighter and I'm like ok, and that's the one I want."

Collaborative walkthrough is an important strategy for establishing control of a journey beforehand, and for regaining control *en route*. As such, the guide may be a family member or a transit operator, for example.

Annotating Wayfinding Artefacts

In addition to highlighting information about the route, P5 said that he may write reminders to himself on the map or schedule, such as, "Don't stray off the path!" Several other participants reported similar practices. For example, P4 said, "...I'll

print up a copy of the [Google] map and then draw on the map an arrow where I'm supposed to go, in red, you know... and I'll mark X where the bus stop is and so on..." His annotations are more symbolic than P5's. This may reflect personal preference or ability, but also different usage.

P5's annotations are intended for personal use only. P4 also shows his to other people in the event that he gets lost, "... instead of having to explain to them..." He was afflicted with a, "... terrible speech impediment when I first had brain injury..." and still feels more or less communicative – and more or less able to communicate – on a given day. Having something to show to others therefore confers a significant advantage, allowing P4 to embark with a greater sense of assurance and safety.

4.1.2 How Survivors Stay on Course: Maintaining Control

Once control of a journey has been established, it must be maintained *en route*. Doing so is a complex cognitive endeavour that requires the survivor to reconcile the travel plan with the surroundings. This implies recalling the travel plan and assessing the surroundings. The degree of familiarity with the route plays a critical role in how these tasks are accomplished.

Recalling the Travel Plan

In the best case, the route is so familiar that the survivor proceeds on *automatic pilot*, that is, with little to no conscious thought as to location and heading at any given moment. If the route is insufficiently familiar to make automatic pilot possible, but is still reasonably familiar, having been traversed in the past, then the survivor may instead rely on consciously invoking residual route memory. For some survivors, like P1, even one traversal may instil the requisite familiarity, underscoring the effectiveness of learning a route by travelling it. Otherwise, the survivor must commit the travel plan to memory for retrieval, and/or refer to a wayfinding artefact *en route*.

The circumstances surrounding the former are exceptional. For example, P3 applies his extensive knowledge of the Greater Victoria street network – the result of decades of driving for pleasure, and in various jobs including pizza delivery – to support the tasks of planning and remembering an unfamiliar route through an otherwise familiar locale. He is therefore not wholly at the mercy of his short term memory but can also apply spatial reasoning, hinting strongly at a well developed cognitive map. Conversely, remembering the travel plan may be the only option. Due to his severely

impaired vision, referring to a typical visual artefact *en route* is at best cumbersome for P2, who, "...can just barely read my own writing right now...I have to, I'm really counting on my memory is what I'm doing..."

Striving to remember the travel plan may be ineffective or even detrimental. P9 remarked, "...any time I try to use my brain, it doesn't work" while P5 finds that, "...forcing myself to try and remember something...I tend to get more and more frustrating...[sic]" Supplementing memory with a wayfinding artefact is more feasible. The wayfinding artefact may be a map or schedule, or a series of hand-written travel notes. Somewhat surprisingly, given that all participants reported impaired short term memory, only two participants reported writing travel notes (P5, P6). P5 said, "I'm trying to progress past that." Writing travel notes was predominantly associated with constructing a new travel plan *en route*, rather than before embarking, by recording solicited verbal directions. Verbal directions may be difficult to parse and remember without writing them down.

Searching for Salient Landmarks

Assessing the surroundings can be an extraordinarily intense activity. For example, P5 said,

"I'll get to a corner and then I'll, if I'm already planning in my head when I get to a corner I have to turn right, I may get there and stand on the corner for thirty seconds and turn right and *look*, and then try and just sort of run a check in my head, you know, 'Is this right?'"

What do survivors look for? The consensus appears to be familiar or otherwise salient landmarks, if they are available, and possibly street signs as well.

Regarding landmarks, participants referred almost exclusively to urban structures, reflective of the environment through which they typically travel. The most important criteria for effective landmarks are distinctiveness and immutability. Distinctiveness may be satisfied by relative size or proximity to surrounding structures, or some other feature such as a vendor logo. Landmarks included small structures like restaurants, larger structures like churches, and grand civic structures like hospitals, bridges, stadiums, and legislative buildings. Immutability is especially critical, else landmarks may not be recognized, "And that's what I'm always worried about, you know, somebody changed something!" Jennifer, from Study 1, humorously compared mutable

landmarks to floundering in the breakfast section of the supermarket because the cereal packaging has changed.

However, the particular ease with which landmarks are noticed and remembered is not always beneficial. P9 said that landmarks encountered while lost may persist in memory, causing confusion, “. . . so the next time you come back here and you see them, ‘Oh is this. . . the right way, or is this the way that I’m recognizing, the lost way?’” Fortunately, the real power of landmarks with respect to maintaining control of a journey lies in chaining them together.

While riding the bus to the brain injury society, P4 invokes a learned progression of cues:

“I know when it’s turning that corner on um, Bay Street, and I’m just about two stops from my bus stop, I counted them. There’s Dairy Queen. . . and then the next stop is the one I get off at. . . It’s all, it’s sort of like predestined. I have to have those landmarks then I know that I’m, where I’m going, right? Yeah.’

The significance of the concept of landmarks is poignantly illustrated by the fact that even street corners and bus stops, which do not satisfy the criteria for effective landmarks particularly well, are part of ‘those landmarks.’ It is their place in a progression of cues that makes them so. The central cue is Dairy Queen, which indicates the point where P4 must prepare to disembark. Identifying Bay Street is the primer for the central cue. Counting bus stops provides additional contextual glue, so to speak. As each cue is encountered, the travel plan is further affirmed, and confidence is further reinforced.

4.1.3 Why Survivors Lose their Way: Losing Control

Losing control of a journey may be thought of as ‘getting lost.’ It refers chiefly to a loss of bearings *en route*, due to a breakdown in recalling the travel plan and/or assessing the surroundings. However, a purely spatial understanding of ‘getting lost’ is inadequate, particularly when time constraints are involved. P5 described a typical scenario in this regard:

“I’ll be at a bus stop and I’ll be going, ‘That bus should be here by now’ and then I start thinking, ‘Oh God, what if I missed that bus?’ Start checking the schedule, ‘Oh God, the next one’s not until here!’ You know I gotta get to my doctor’s or something like that.”

For some survivors, ‘getting lost’ extends beyond spatial disorientation *per se*, to feeling overwrought of circumstances – spatial, temporal, or otherwise – that [threaten to] compromise adhering to the travel plan. Deviating from the travel plan, either unwittingly by making an error in judgement or because of extraneous circumstances, is thus an important aspect of losing control of a journey.

Forgetting the Travel Plan

Three participants (P7, P8, P9) described a cognitive lapse that is here referred to as *spontaneous acute disorientation* (SAD). Spontaneous means without apparent cause, and acute means sudden-onset. Participants could not account for why they experienced SAD, nor did their stories yield telling contextual clues such as distraction or poor visibility. It has been suggested to P7 by a support worker that anxiety may lead to SAD, “...but I don’t know.” Given the critical impact of familiarity in establishing and maintaining control of a journey, it is striking that the likelihood, severity, and emotional impact of experiencing SAD do not appear to be mitigated by a high degree of familiarity with the route. All of the reported incidents took place while driving in settings that were highly familiar. Indeed, a significant aspect of P9’s distress over one incident was the stunned disbelief that, “I had my office there for fifteen years... I’m on the streets I lived on, the street I drove on every day and I’m lost...”

The severity and emotional impact of SAD was most dramatically illustrated by P9’s account of driving from a ferry toll booth to the boarding lane, a distance of about two car-lengths. Between booth and lane, “I didn’t know where I was! I looked around as if I was on the moon, and I just sat there and cried. I had no idea where I was.” Similarly, P7 was driving to the brain injury society when, “...it’s like I lost my way! I couldn’t figure out where I was supposed to be... and even if it said the address... I know when I’m in that state of mind I would say, ‘Where in the hell is that?’” Phrases like ‘on the moon’ and ‘that state of mind’ indicate the totality of cognitive disarray. Victims of SAD feel unhinged and agitated, to the extent that spatial information loses its meaning. Corroborating P7’s reflection on the uselessness of an address, P9 said that in the aftermath of SAD, “There’s no point getting a map out. I’m just lost.”

Failing to Assess the Surroundings

SAD is a singularly mysterious and compelling cause of losing control of a journey. Others are more mundane, such as being situated in an illegible environment. For example, several participants recalled becoming disoriented at night because darkness obscures visual cues. Travelling at night is especially problematic for survivors with impaired vision because the artificial lighting further distorts the visual tableau. P2 remarked that,

“...seeing things from a different angle, so um, and the lights, you know, changes the perspective of everything too, so, and the shadows and the reflections and stuff so being vision impaired really uh, it’s, it’s, it’s a challenge...”

At minimum, further cognitive resources must be invested to parse the distorted cues and remain oriented.

Some environments are illegible regardless of ambient lighting or visual impairment. P4 and P6 described a network of paths that were difficult to distinguish from each other, like a maze. There are indoor and outdoor mazes. For example, P4 became trapped inside a store because he, “...kept going up and down the same aisles and I couldn’t get out...” He attributed this primarily to experiencing a lapse in concentration from feeling self-conscious of his brain injury. However, he conceded that his lack of familiarity with the store was also a factor, and further remarked, “...big places like that are really bad for me...” because their interiors are poorly defined. Similarly, P6 often has difficulty trying to locate his car in large parking lots. These are ill-defined, especially when full. P6 also described several incidents where he became lost while hiking along, “...trails that all interweave and stuff like that...” By comparison to the uniformly forested surroundings, “...the different buildings and the placement of them...” in urban settings are, “...a lot clearer in my mind than trails.” Without salient objects to reference, survivors may end up going in circles.

Interestingly, observing public transit etiquette may also cause a breakdown in assessing the surroundings. If a survivor is intently looking out of the window to spot landmarks, and is compelled to move because of priority seating or the imperative to move back, then important cues may be missed. In addition, the survivor may not be afforded a similarly useful vantage point afterwards, resulting in frustration and anxiety.

Deviating from the Travel Plan

Adhering to the travel plan is important. For example, survivors may ignore buses that are not prescribed by the travel plan, including those that they know are faster or more convenient. Increased route efficiency is not worth the confusion that may ensue. Nevertheless, survivors occasionally deviate from the travel plan for various reasons.

Deviating from the travel plan may follow a loss of bearings. In one account, P2 walked away from his destination as a result of losing his bearings while travelling at night. However, several instances described by participants were the result of simple human error. All else being equal, pedestrians walked in the wrong direction, thinking it correct; transit users boarded the wrong bus because they mistook its number for a similar one; motorists took the wrong highway exit because they misconstrued ambiguous signs. In these cases, disorientation *ensued* when, sooner or later, the surroundings no longer matched expectations. Even a slight deviation can cause things to, “. . . look a little scrambled. . .” and alert survivors that something is wrong.

Perhaps the most pernicious reason for deviating from the travel plan is being compelled by unforeseen circumstances to do so. This was described by Jennifer, from Study 1, as, “. . . changing horses, midstream.” Although it is difficult and stressful to change the travel plan before embarking, her ability to do so has improved over time. Changing the travel plan on the fly is still a significant obstacle however, and “. . . if the, the bus changes a route for an accident or something, I’m just like, ‘Okay, now where am I?’” Conversely, changing circumstances may elicit a subtler chain of mishaps. For example, P2 had arranged to get a ride with a friend from an appointment. When the appointment took longer than expected, he had to take the bus instead. To negotiate some rough terrain while walking to the bus stop, he was watching the path very carefully. As a result, he walked past the bus stop and kept going.

4.1.4 How Survivors Recover from Losing their Way: Regaining Control

Participants described several strategies for recovering from losing control of a journey *en route*, including trying to regroup, searching for familiar or otherwise salient visual cues, and requesting assistance. The most prevalent were searching for visual cues and requesting assistance. Some participants reported one or the other. Others re-

ported both. Which strategies are used is evidently a matter of competing constraints. Several participants who did not report requesting assistance are profoundly apprehensive of socializing with strangers, for example. Among those who reported both strategies, the governing constraints were less clear. Suffice to say that if a survivor is sufficiently disoriented and/or overwrought, and/or there is a compelling reason to expedite the process of regaining control – such as getting to an appointment on time – then requesting assistance is likely.

Trying to Regroup

Having lost control of a journey, several participants mentioned first making a conscious effort to regroup, or “. . . try and sort of get calm and figure it out.” This usually entailed halting, but P9 mentioned drinking a Coke to calm down, and conversing with herself helped P7 to keep driving after experiencing SAD. However, regrouping is not always feasible. When he realized that he had boarded the wrong bus, for example, P5 was alarmed and felt compelled to act immediately. Interestingly, in the same situation, P2 decided to sit and enjoy the ride until the bus was nearly empty. This may reflect a preference for an unobstructed aisle to accommodate his impaired vision and mobility, as well as greater self-confidence owing to his experience and a longer recovery period.

In addition to the perceived urgency of the situation, feeling overwhelmed by sensory stimuli exacerbates agitation and impedes regrouping. All three participants from Study 1 agreed that the confusion and/or anxiety that accompany losing control of a journey make filtering out sensory stimuli much more difficult. Similarly, after disembarking from the wrong bus as soon as he could, P5 was unable to cope with, “. . . all this traffic zipping around and I was just like oh no, I can’t stay here. . .” P7 fell victim to information overload when, “. . . I went and I looked at the bus stop and they have, you know, all this scheduling information so it was like aw no, get me away from this, this is terrible. . .” Both incidents occurred soon after injury and caused the survivors to recoil in dismay. P5 explained that, “A lot of things like that were just so overwhelming.”

Searching for Salient Visual Cues

Searching for salient visual cues was strongly associated with becoming disoriented in surroundings that a survivor knows or supposes are familiar. For example, P5 said

that he has gotten lost walking home on several occasions, “. . . but I’ve lived a large portion of my life here. . .” and so, “. . . going up to street corners and staring up at the sign. . .” is a natural and effective strategy. Similarly, on becoming unsure of how to proceed to an unfamiliar university building, P2’s previous visits to campus nevertheless ensured that, “. . . I’m not threatened by it.” He saw an ‘Open’ sign and reasoned that it signified a place where he could ask for directions, and so make it to his appointment on time. Making sense of something in the environment anchors a survivor both spatially and emotionally, and is critical for determining where to go, much like maintaining control of a journey.

In both processes, orientation and confidence are reinforced with each cue, which is typically a landmark or street sign. For example, P7’s efforts to reorient after experiencing SAD *en route* to the brain injury society revolved around crossing a bridge. Bridges evidently partition a city into simple yet meaningful areas, so that crossing the bridge enabled P7 to recall that the destination was, “. . . on this part of town.” This coarse sense of location was the basis for trying to recall pertinent landmarks. She eventually noticed a stadium, which sparked the recollection that her destination was near a stadium. Adjusting her course, she continued to become progressively more oriented as her route memory solidified. Her story resonates strongly with P4’s earlier explanation of how turning a corner primes subsequent cues.

The fundamental difference between searching to maintain, and searching to regain control of a journey is that rather than searching for a discrete thing that is more or less expected, the survivor casts about for *anything* that is familiar, or at least meaningful, and affords a sense of location or heading. Landmarks are especially valuable when a survivor is flummoxed. For example, after fretfully disembarking from the wrong bus, P5, “. . . could see the hospital so I . . . walked back to the hospital, because I could see it so I thought, ‘Hey if I get there I’ll be okay.’”

Requesting Assistance

Most participants described one or more instances in which they requested assistance after losing control of a journey. The particular circumstances surrounding the resolution to do so varied, but uniting almost all of them was a sense of urgency, frustration, or distress. P4 said, “If I’m halfway in the middle of nowhere I ask for directions, try to talk to people.” Similarly, after getting lost in a desolate area at night, P7 thought, “. . . you gotta [*sic*] get out of the car now and ask this other driver. There

might not be another car for like an hour, you know, or maybe never!” She spoke with the other motorist and then followed her into town. Her account exemplifies appealing for rescue.

Rescue is when a survivor is soothed in, and/or extricated from an untenable situation by someone else. Stories of appealing for rescue encompassed a variety of behaviours. These included reflexively grabbing the elbow of a trusted peer who then functioned as a guide; calling a loved one using a pre-programmed number on a mobile phone; and breaking into tears in front of a transit operator, who then contacted a transit manager, who drove the survivor home. Appealing for rescue is tantamount to relinquishing responsibility for regaining control of the journey to someone else, at least temporarily. Some survivors may forgo appealing for rescue if the wayfinding task is perceived to be *ideally trivial*. An ideally trivial task is one that used to be trivial, pre-injury, and ‘should’ be trivial, post-injury, as well. For example, one of the reasons why P5 decided not to call his family to pick him up after boarding the wrong bus was his, “. . . fear of failure for something as trivial as being able to get back home again. . . .”

Of the seven accounts of appealing for rescue, five came from three women. Of the three participants who alluded to ideally trivial wayfinding tasks, two were men. These data suggest that men may be more prone to struggling with pride over their injuries [with respect to wayfinding] than women. It follows that requesting assistance may be more personally challenging for men. P2 is, “. . . learning the biggest obstacle is my pride and ego I guess, basically to be able to ask a complete stranger to help me walk across the road. . . .” while P4 remarked,

“. . . us guys, you know, we had, always had this problem: we don’t take directions. We’re gonna find it ourself. . . I remember when I was driving, it was driving, ‘Keep driving, I’ll find it. But that’s not the reality. . . the reality is try to find it as quickly. . . and you know, as efficiently as possible. . . cuz you have those obstacles.’” (*sic*).

For P4 and other participants who use public transit, transit operators (TOs) are an important resource in this regard. TOs were commended for their situational awareness, reliability, patience, approachability, and overall trustworthiness. P2 identified an element of reciprocity that is involved with requesting assistance from a TO. Referring to a TO who not only provided directions on request, but also contacted and stayed the appropriate bus, P2 said that, “. . . it makes them feel good that they’re

helping, you know, someone else, so, and they made my day too...” This unique insight may reflect his previous employment as a TO.

Requesting assistance from a stranger raises the issue of disclosing brain injury. For example, P4 carries a card issued by the brain injury society, which he humorously called a ‘crazy card.’ It states, “. . . that you have a brain injury, right, and the type of brain injury you have and what that person can do for you, like they’ll say, ‘Phone help’ or, ‘Phone the police’ or, ‘The police know this’...” Like his annotated copy of Google Maps, it replaces a verbal explanation, and provides a measure of assurance and safety. It is reserved for dire emergencies:

“Not that everybody I see I pull out my card; I would never do that, right, because I’d be ostracised. . . [people] start talking louder to you, which is the usual thing: ‘Hi, how are you?!’ I’m not deaf I’m just confused.”

Disclosing injury in this way may provoke social aversion or judgement, which is especially harrowing for P4 because he is profoundly self-conscious of his brain injury.

Some survivors opt instead for what might be called *bounded disclosure*. P7 recalled approaching someone on the street not long after her injury, and saying, “Look I’m experiencing some disorientation because I’ve been in a car accident and I just can’t remember how to get home!” Although she communicated the cause of her predicament, she did not explicitly identify her brain injury. P8 described an even more implicit approach. Based on her experience with having impaired mobility as a result of brain injury, she hypothesized that having a cane softens the demeanour of those she approaches. They can see at a glance that she may require especial assistance, but know only that she is mobility impaired.

4.2 Additional Findings

Wayfinding in acquired brain injury (ABI) has been characterized by the phenomena of establishing, maintaining, occasionally losing and then regaining control of a journey. The substantive theory cohesively expresses the bulk of participant feedback *vis-à-vis* wayfinding. However, participants identified three additional factors that may impact wayfinding, and are indeed broader life realities that should be taken into account by developers. They are presented below, for completeness.

4.2.1 Having Financial Concerns

Living with a brain injury is expensive. Compounding the cost of therapeutic measures, survivors may not be able to secure or maintain gainful employment. Subsidization is sometimes available, but filling out paperwork may be prohibitive. Finances are therefore a pressing concern for some survivors, who may in extreme cases transition from, "... a good investment portfolio and RRSPs and everything else, to huge debt..." This may limit travel options. For example, P5 said that he never takes a taxi because it costs too much.

4.2.2 Keeping Track of Life

Almost every participant reported relying on a calendar or day-planner, despite the fact that calendars were not explicitly addressed in the interview schedule. Indeed, P3 remarked that, "... I didn't used to carry a calendar and now I do, and that's my crutch as I say..." The Victoria Brain Injury Society gives a day-planner to all of its clients, and urges them to use it.

However, using calendars is not without pitfalls. Forgetting to do so is one, because, "... it don't talk to you, means you actually gotta look at it. I mean and then you might forget to look at it..." (*sic*). In addition, a day-planner is easily misplaced. Consequently, P9 said that she tends to copy entries on loose paper, as a backup. This is a vicious cycle: there is no guarantee that the papers will not be misplaced, which mandates creating multiple copies. The result is a chaotic assortment of reminders which may be forgotten anyway, and/or cause her to experience bewildered distress when she goes to find something.

4.2.3 Accounting for Physical Status

Recall from Chapter 2 that although Lynch asserted that constructing the image is best accomplished by actively experiencing the corresponding environment, he had little to say about human factors influencing that process. He was mainly preoccupied with the structure of the environment itself. In addition to composure and other psychological factors outlined in the substantive theory – consider P4's self-consciousness versus P2's acceptance of injury and subsequent self-assurance – as well the more practical issues outlined above, the current research indicates that wayfinding in ABI may also be influenced by physical constraints. These constraints

include physiological ailments, physical impairments, and for lack of a better term uniting hunger and fatigue, energy level. Together, they comprise the *physical status* of a traveller.

Hunger, as it relates to energy level, was the most unexpected constraint to surface, and yet P4 remarked that, "...eating is a big difference between people with brain injury." He said that people with brain injury are liable to forget to eat because,

"We're stupid! We're stupid in a way; we, we don't do things, like, we won't eat breakfast, cuz you forget about it, you just wanna go, get on, so that affects you physically, mentally, throughout the day" (*sic*)

Two other participants reported a tendency to neglect to eat, each for a different reason. P7 has no appetite as a result of her injury. P9 struggles so much with the task of preparing food that she forgoes eating, "...and maybe by the third or fourth day [after purchasing groceries] you'll eat something. It's *too hard*. It's *too hard*." None of these participants reported that neglecting to eat stymied wayfinding *per se*. However, P4, who is diabetic, referred to a hypothetical journey of forty-five minutes, in which case it is important to ask, "...are you gonna [*sic*] be hungry when you come back or should you eat something before you go?"

Similarly, two participants reported planning their excursions in accordance with a fatigue threshold. P1 relies on walking as his primary mode of transportation. He can only walk for approximately one hour before feeling prohibitively fatigued and sore. Returning home prior to reaching that state is a pressing concern, and further to his preference for walking explains why he is confined to a relatively localized area. P8 struggles with progressively worsening mobility and is acutely aware that, "...there are only so many meters in my system per day..."

For survivors with impaired mobility in particular, avoiding physical obstacles is important. This includes preferring accessible buses. Obstacles may include rough terrain, stairs, and other people. Rough terrain requires additional concentration to negotiate, tantamount to piloting heads-down and possibly missing vital wayfinding cues. Stairs are particularly daunting. P4 safeguards his back by taking stairs cautiously because, "...climbing up and down stairs is really an issue for me." Even ramps may be prohibitive. P8 explained that some are too steep, too long and thus fatiguing, or lack [useful] handrails. Finally, pedestrians who are composing text messages on their phones are often oblivious to their surroundings, and may therefore become obstacles. Experience has shown P2 that the best solution is to stand still

rather than try to hurry out of the way, but, “. . . sometimes they run right into me, you know, and. . . they go flying back!”

4.3 Participant Views on the Ideal Mobile Wayfinding Aide

The findings presented thus far are concerned with the practice of wayfinding, in accordance with the first four research questions which were explored in the second, central part of the interview. The remaining research question pertains to perspectives on a hypothetical wayfinding tool – the Personal Travel Guide (PTG) – and was explored in the third part of the interview. As such, participants were invited to put aside *what* and *how* in favour of *what if* and *how about*. The opportunity to reflect on tool adoption, usage, and design was a refreshing change of pace for both the researcher and the participants. Though relatively brief, it elicited some very thoughtful and passionate feedback.

Response to Concept

Participant response to the concept of a perfectly designed and customised PTG was overwhelmingly positive. Six participants were quite enthused, and felt that it would be very useful. P5 remarked on the convenience factor, while P1, who is deeply uncomfortable with computers and technology, said, “I would use it. I *would* get over my fear of machines and technology because it would be profitable to my life. . . I’d be more happy.”

However, P4 said that financial concerns prohibit owning a smartphone. This is unfortunate because, “. . . the kind of help it would give would be great. . .” P6 affirmed that, “. . . the pocket thing, like the price. . . the price is big.” He and several others commented on the risk and commensurate anxiety regarding device loss or damage. P2 also expressed concern over becoming a target of device theft.

In addition, P3 and P8 were indifferent as far as personal use was concerned. P3 dismissed the PTG as unnecessary, although he conceded that it might be useful, “. . . if there was <pause> somewhere new to go, nice to have that.” P8 arranges most of her excursions via taxi or the provincial transportation service for persons with disabilities² (Table E.1). Despite their personal indifference, both felt that the notion

²HandyDART (<http://www.translink.ca/en/Rider-Info/Accessible-Transit/HandyDART.aspx>)

had merit.

Use Cases

Four participants, including P3, said that a PTG would be most useful for visiting new destinations. P1 remarked that a PTG would bolster his confidence by providing, “Freedom with no fear, knowing that I have a back-up. . . I’d be able to see more, to know more of Victoria, with my eyes. . .” P2 stipulated that avoiding bad neighbourhoods when visiting new cities should be taken into consideration. Conversely, two participants said that they would never travel without a PTG. P4 said that it would be, “. . . nice to know where you are, and nice to know where you’re going. . .” at any given moment, while P5 felt that a PTG could prevent him from walking in the wrong direction. Additional use cases included staying oriented in the mall and then locating the car afterwards (P6); checking bus trip duration while planning an excursion, as well as the estimated time until arrival at any given moment *en route* (P4); procuring a real-time estimate of bus arrival time while waiting at a stop, for reassurance (P5); locating the nearest bus stop in the event that taking the bus becomes mandatory after a change in plans (P2); and succinctly informing a taxi service of the current location over the phone, at the touch of a button (P2).

Functionality and Design

Participants from both studies, including all three from Study 1 and five of nine from Study 2, emphasized audio output. The taxi-location example resonates strongly with a use case from Study 1, that is, ‘speaking’ the current location to a care provider over the phone when in distress. P9 suggested providing pre-emptive voice prompts while driving. Prompts should include the distance in blocks until the next turn, and the name of the next intersection. She also stressed the importance of a voice that sounds natural and calm. P7 emphatically suggested an application that delivers notifications using her own voice. However, although P5 conceded that talking waypoints would be very useful for several of his peers, he imagined audio output for himself as an alarm that notifies him when he walks the wrong way.

Participants also commented on some of the visual aspects of a prospective user interface. For example, the screen might need to be enlarged and its contents presented in high contrast to accommodate visually impaired users (P2) and promote map comprehension (P7). P1, P6, and P7 felt that enriching a street map with landmarks,

either via photo-realistic or other pictorial representations would be very useful. P6 and P9 advocated displaying a map route trace. For walking, P6 was less interested in seeing a trace of the recommended route than of the route that he had taken to that point, reflecting a desire to retrace his route where possible. For driving, P9 was especially concerned with being able to toggle between a whole-route trace that provides context – especially before embarking – and the immediately pertinent segment of the route. In addition to map-based visualizations, several participants endorsed dynamic directional indicators with respect to facing direction, as in a compass (P2, P5), and recommended direction, as in a signpost (P5, P6).

Aside from particular visualizations and features, several participants remarked on the need for interface simplicity in general. For example, voice programming was preferred over typing in a destination (P2, P5, P7), which is complicated and error prone, echoing sentiments from Study 1. P8 provided a concrete definition of simplicity: three interactions are the limit, and promoting repetition is best. P9 evinced an even starker understanding of simplicity when she said, “. . . we want something that’s really, really simple and as obvious as possible, like ‘Off’ and ‘On’ . . .” Similarly, P5 felt that a user should be able to, “. . . just like pull it out and ‘Okay.’”

4.4 Summary

The substantive theory of wayfinding in acquired brain injury states that wayfinding fundamentally consists of four phenomena: *establishing*, *maintaining*, occasionally *losing* and then *regaining control* of a discrete, immediate journey. Control is an abstraction that subsumes spatial orientation and personal *composure*. Composure refers to feeling relaxed and ideally confident about travelling. Consequently, control is influenced by the familiarity of a journey and the degree of recovery from brain injury. Recovery tends to progress over time, thereby decreasing the tendency to lose composure and increasing the ability to regain it. Controlling a journey is essential for completing it without experiencing undue apprehension, which may proscribe future journeys.

Establishing control of a journey begins when the journey is first considered, and depends largely on the degree of familiarity. Social trepidation may also be a factor. If a destination is very familiar, then control is implicitly established. Otherwise, establishing control entails explicitly constructing a travel plan, unless the survivor balks outright. Constructing a travel plan typically involves consulting one or more

wayfinding artefacts, including maps. Some participants also engage in collaborative travel planning. Collaborative walkthrough is a synchronous review of route instructions involving a survivor and a guide, as well as one or more common wayfinding artefacts. Annotating a wayfinding artefact is an effective way to foster assurance. The annotated wayfinding artefact may be intended for personal use, and as a visual aid for requesting assistance from others *en route*.

Maintaining control of a journey means reconciling the travel plan with the surroundings. Recalling the travel plan and assessing the surroundings are necessary. The means for recalling the travel plan depend on the degree of familiarity with the route. They include automatic pilot, consciously invoking residual route memory, or committing the travel plan to memory for retrieval, with or without the aid of an artefact such as maps and hand-written notes. Notes are mostly associated with recording solicited verbal directions *en route*. Assessing the surroundings primarily involves searching for salient landmarks, which are ideally distinctive and immutable. Chaining landmarks together into a sequence of cues is a powerful strategy for reinforcing route memory and confidence.

Losing control of a journey entails a breakdown in recalling the travel plan or assessing the surroundings, and/or deviating from the travel plan. Some survivors are prone to spontaneous acute disorientation, a severe cognitive lapse which typically evokes distress and whose proximal triggers are unclear, though stress is a likely candidate. Assessing an environment effectively depends, in part, on its legibility. Legibility is reduced at night time. Poor legibility is exacerbated by visual impairments. Environments comprised of visually indistinct pathways are illegible mazes, and a survivor may end up going in circles. Survivors deviate from the travel plan because of disorientation and human error, or because they are compelled by unforeseen circumstances, such as detours, to do so.

Strategies for regaining control of a journey include trying to regroup, searching for familiar or otherwise salient visual cues, and requesting assistance. Regrouping may not be feasible depending on perceptions of urgency, and/or feeling overwhelmed by sensory stimuli. Searching for visual cues is most effective in familiar surroundings. Requesting assistance is typically associated with a pressing sense of urgency, frustration, or distress. Rescue is when a survivor relinquishes responsibility for regaining control to someone else. Appealing for rescue may conflict with the perception of an ideally trivial task. Transit operators are a valuable, trusted, and approachable source of wayfinding assistance. Requesting assistance from a stranger raises the issue

of disclosing brain injury, either through explicit or bounded means.

Several additional, broad life realities that may impact wayfinding were also identified. Having financial concerns limits travel options such as taking a taxi. Tracking events with a calendar was prevalent, but survivors may forget or misplace the calendar. Accounting for physical status may include remembering to eat, limiting travel to accommodate fatigue, and avoiding obstacles.

Most of the participants were enthused by the notion of a PTG, although several expressed concerns related to its cost and two were personally indifferent as to its utility. Audio and especially speech output was a prevalent feature request. Suggested visualizations included street maps enriched with landmarks and route traces, and dynamic directional indicators. The simplicity of the user interface was an overriding concern.

Chapter 5

Discussion

The purpose of this research was to inform the design of mobile wayfinding software for users with acquired brain injury (ABI). The findings presented in the previous chapter are the foundation for doing so. This chapter therefore begins with a discussion of the significance of the substantive theory and its implications for the design of mobile wayfinding software. It continues with a series of broad recommendations, and concludes with review of some related work.

5.1 Significance and Implications of the Substantive Theory

The substantive theory of wayfinding in ABI says that at the heart of each discrete, immediate journey is the notion of *control*. Control subsumes orientation and *composure*. Composure refers to feeling relaxed and ideally confident about travelling. The need for composure, both before and during a journey, was a singularly momentous insight provided by participants. Some of them cannot take composure for granted, because they do not cope well with uncertainty or change.

Extant theories of unaided wayfinding, including PLAN and the task-means and knowledge-based taxonomies presented in Chapter 2, focus on orientation as it relates to spatial knowledge and cognition. These theories echo throughout the findings of the current research. For example, chaining landmarks resonates with wayfinding based on the “what” visual subsystem, and depends on the “heads-up” formation of a rudimentary cognitive map. However, these theories do not account for composure, which is beyond their scope.

Several researchers have provided tantalizing snippets of insight in this regard. May, et al. observed that travel information is utilized *en route* to enable decision-making, but also to enhance confidence in between decision points [39]. Sohlberg, et al. found that survivors with severe cognitive impairments were prevented from venturing out by the fear of getting lost [50]. While field-testing a mobile wayfinding tool for pedestrians with cognitive disabilities, Chang, et al. noted that confidence along unaided control routes was consistent with success or failure for five out of six participants [12]. The substantive theory described in the present thesis is important because it provides a simple but cohesive framework uniting spatial orientation and personal composure throughout the entire process of wayfinding, and because of its implications for the design of effective mobile wayfinding software.

The first implication is that there are two broad, complementary targets for providing wayfinding support: facilitating orientation, and managing anxiety. The findings suggest that facilitating orientation – and re-orientation, as the case may be – will to a large extent prevent or curb anxiety while simultaneously bolstering confidence. Pursuant to the association between confidence and success noted by Chang et al., achieving wayfinding success and inspiring commensurate confidence is critical because success/failure and confidence/doubt feed forward. As P3 remarked, “Nothing succeeds like success,” echoing P2s assertion that generally speaking, “It’s much easier to stay positive when things are positive. . .” The best laid plans sometimes fall through *en route*, but mean nothing if a survivor is deterred from travelling to begin with.

The second implication is that there are three broad, actionable contexts for providing wayfinding support: establishing, maintaining, and regaining control of a journey. Moreover, participant strategies corresponding to a given context suggest promising avenues for implementation. For example, by annotating his map book in collaboration with his sister, P5 was essentially transitioning from *passively consuming* information to *actively producing* it. At minimum, supplying additional annotations promotes engaging with the material. It also seems reasonable to suggest that by concretely reminding himself to proceed with caution, P5 is more likely to assess a given decision *en route* than to take it for granted. While hesitation could conceivably have its own pitfalls, the immediately pertinent result of annotating a wayfinding artefact was an enhanced sense of control.

However, *caveat emptor*: the potential disadvantages of a strategy are just as revelatory. For example, during an instance of collaborative walkthrough with her

daughter over the phone, P7 was attempting to follow along with Google Street Maps, to which her daughter referred. She also had a paper street map open as a backup, but could not coordinate, “. . . what she’s saying, the street map with Google Map!” Simultaneously coordinating multiple sources of information levied a prohibitively heavy cognitive load such that, “I’m getting tired in my mind, you know. . . I’m using so much of my mental energy to do this. . .” Issues like these illustrate aspects to avoid or improve in terms of transferring participant wayfinding strategies to software.

The third implication is two-fold. First, journeys with which a user is unfamiliar are more likely to mandate [intensive] wayfinding support than those that are familiar. Second, survivors in an early stage of recovery are more likely to require [intensive] wayfinding support than those in a later stage. These claims are complementary: a user in early recovery who is faced with an unfamiliar journey is most likely to require [intensive] wayfinding support. These claims also come with an important caveat. The possibility of simple human error, experiencing a cognitive lapse such as SAD, or an otherwise unexpected change in the travel plan means that even highly familiar journeys – which might normally proceed by automatic pilot – may require [intensive] wayfinding support *en route*. Although the prospect of a detour or delayed appointment is not wildly infeasible, and a user may be prone to experiencing SAD, these eventualities are essentially unpredictable. Wayfinding software must nevertheless be prepared to handle them in a timely fashion.

5.2 Recommendations for the Design of Mobile Wayfinding Software

Given the findings and the implications of the substantive theory, this thesis makes six broad recommendations for the design of mobile wayfinding software for users with ABI. Providing a simple user interface and accommodating the whole user and wayfinding context are paramount. Other recommendations include affording an interactive user experience; integrating with calendar software; conveying information in real-time via notifications, as audio where feasible; and emphasizing landmark information while affording access to a street map. A more detailed description of each recommendation follows.

5.2.1 Provide a simple user interface

Participants made it clear that providing a simple user interface is critically important. This cannot be overstated; one participant recounted abandoning a new product because the packaging was too complex. Planning a route can be mentally draining, particularly when multiple sources of information are involved. Distress and/or cognitive disarray may render otherwise comprehensible wayfinding information useless. In addition, learning new technology is challenging. For example, P2 utilizes and appreciates Google Maps, but conceded that, “. . . learning how to use it I think is the thing, so I gotta [*sic*] just dive in and make mistakes. . .” He further asserted that the rapid pace of technological advancement exacerbates the learning problem for many survivors. For these reasons, and in accordance with participant recommendations, a simple user interface should:

- Promote repetition
- Minimize the number of *required* user interactions
- Take care not to overwhelm the user with information, and interface elements
- Provide prominent interface controls with clear roles and affordances
- Maintain user interface form and function from one software release to the next, to the extent feasible

Fastidiously implementing these criteria will result in software that is easy to learn, and use.

5.2.2 Accommodate whole user and wayfinding context

What is *overwhelming*? What is *prominent*? What is *clear*? In other words, what, exactly, is *simple*? These terms are highly subjective. For example, despite the clarity that it affords some participants, Google Maps is practically unusable by others. P7 struggles to manipulate the controls because of arthritis. The size and contrast of the text, especially on yellow roads, are not amenable to her impaired vision. Scrolling and zooming cause her to feel extremely disoriented. She associated a similar - albeit less disorienting - disruption in work flow with turning the pages in her map book. This is also a problem for P5, for whom the scrolling action of Google Maps is, in contrast, an improvement. Pedestrian navigation systems have been identified as

targets for “deep personalization” with respect to impaired spatial cognition [57]. As the above example illustrates, mobile wayfinding software must accommodate the whole user, accounting for physical and cognitive abilities, which in turn influence interface preferences. A comprehensive user profile is therefore required.

Building on that profile, mobile wayfinding software should address the current, actionable wayfinding context and commensurate cognitive and emotional state of the user. It must therefore be highly user- and context-aware. For example, planning when to eat should be part of establishing control of a journey for a diabetic user like P4. With respect to context awareness, device sensors measuring time, location, cardinal heading, and speed must be leveraged, at minimum. This will help foster the timely detection and handling of user error, as in going the wrong way. Subtler inferences are also possible by detecting lengthy pauses and/or turning excessively in place. These behaviours might indicate an episode of [spontaneous acute] disorientation, and should cue the software to “check in” with the user to ensure that everything is all right. Although distraction should be avoided in the interests of personal safety, minimizing cognitive load, and searching for salient visual cues, managing anxiety is also critical. “Checking in” should therefore proceed gently but insistently, so as not to cause [further] alarm.

5.2.3 Afford an interactive user experience

“Checking in” relies upon and reinforces the context awareness of wayfinding software, and reminds and *reassures* users that they are not without support. Similarly, software interactivity is expected to promote control of a journey. For example, annotating a wayfinding artefact and participating in collaborative walkthrough are compelling examples of real-life strategies for establishing control of a journey in an especially interactive way. These strategies lend themselves well to implementation in software. P7’s spontaneous reference to, “. . . some kind of diagram process for people, maps and things. . .” evokes the notion of emulating collaborative walkthrough by conducting an interactive, software-guided, synchronous review of route instructions. At each step of constructing and/or reviewing a travel plan, a user could be afforded the opportunity to provide annotations before affirming comprehension. Annotations could entail underlining or colouring items, composing brief notes or voice recordings, or doodling directly on a map. In short, interactivity promotes control. Wayfinding software should therefore engage the user, especially in the context of establishing

control of a journey.

5.2.4 Integrate with calendar software

The calendar or day-planner is a familiar and engaging paradigm, and an appropriate access point for wayfinding functionality. Relying on day-planners to stay organized and support memory appears to be prevalent among survivors. Moreover, day-planner entries provide a top-level view of where to go next, and in the foreseeable future. Consulting a day-planner affords an opportunity to review the travel plan for getting to an event, however briefly. Finally, algorithmically analysing a calendar is a promising strategy for ascertaining whether an impending journey is likely to be very familiar, somewhat familiar, or unfamiliar, without requiring explicit clarification from the user. It therefore reinforces context awareness without compromising interface simplicity. Integrating wayfinding software with calendar software is therefore highly recommended, although wayfinding support should also be made available in a stand-alone application.

5.2.5 Deliver [audio] notifications

Given the tendency of some participants to forget “what’s happening” – including forgetting to check their day-planners – delivering notifications is a critical design consideration, and one that fits well with context awareness. For example, several participants said that a hypothetical personal travel guide should provide just-in-time notifications of up-to-date travel information *en route*. Although the content of these notifications varied with use case and mode of transportation, they were uniformly associated with audio, which naturally promotes “heads-up” piloting. Notwithstanding impaired hearing, audio appears to be an ideal way to deliver notifications and other feedback, despite the propensity for some participants to become overwhelmed by sensory stimuli - especially after losing control of a journey - and/or to struggle with parsing and remembering verbal directions while regaining control of a journey. Jennifer, from Study 1, explained that ear buds facilitate a kind of selective attention. They filter out ambient noise while focusing her attention on relevant audio cues. With respect to processing verbal directions, the problem is receiving too many instructions, too quickly. Delivering brief audio notifications in a timely fashion is therefore recommended.

5.2.6 Emphasize landmarks, but afford map access

Maps represent survey knowledge, while landmarks are associated with route knowledge. The survey knowledge of some participants was quite impressive. Even so, landmarks tend to be the go-to entities for learning and following a route, and for attempting to reorient after losing control of a journey. Despite the potential drawback of becoming confused by the landmarks encountered after losing control of a previous journey, supplementing a travel plan with relevant landmark information should therefore be integral to wayfinding software for survivors. Existing models of landmark saliency are predicated on distinctiveness [45] [28]. The findings make it clear that although distinctiveness is crucial, it is not the sole attribute of an effective landmark. Measures of immutability should also be derived, and incorporated into the choice of landmark information.

However, street maps should not be forgotten. For some participants they are an important part of establishing control of a journey, where they provide a bearing on the destination relative to the origin, and a high-level preview of the route. Though distress and/or cognitive disarray may render them useless for reorientation, they can serve as a visual aid for explaining the situation to others. For these reasons, a street map should be readily available on demand while travelling.

Landmarks and street maps can be complementary, and previous research has demonstrated that route instructions enriched with local landmarks are easier to understand than those that are not [19]. The suggestion from several participants to enrich maps with landmarks is sound, and also fits very well with affording an interactive user experience. Transit users and especially pedestrians could be notified of imminent landmarks along an unfamiliar route, and asked if they would like to take a picture or record a short video supplementing the landmark information already provided. These media could be used as additional annotations, in effect sharing the responsibility for enriching the map with the user. To be clear, the chief benefit in such a scenario would be the increased interactivity, with the aim of stimulating the formation of route memory. The resulting media would be more or less useful after the fact.

5.3 Related Work

Chapter 2 laid a foundation for understanding wayfinding, ABI, and the challenge of designing software for users with cognitive impairments. Having presented the implications and recommendations of the current research, it is helpful to contextualize them further. The selection of related work that follows covers wayfinding strategies and support modalities, and general technology design guidelines for users with cognitive impairments. It also describes a number of experimental mobile wayfinding systems.

5.3.1 Technology Design Guidelines

Pigot et al. presented four guidelines for designing “advanced technology” for the cognitively impaired, including persons with Alzheimers disease, brain injury, and schizophrenia [44]. A support must be personalized. It must be easy to use: the right information must be presented at the right time in order to minimize user interactions. It must be context aware, to account for fluctuations in user abilities and detect problems. Finally, it must be well received: the user must understand its benefits and feel empowered, not stigmatized or supervised.

Dawe described four aspects of simplicity in assistive technology: portability, ease-of-learning, ease of configuration, and ease of replacement, which is related to cost and availability [17]. In addition, technology should become more complex as warranted by user learning and abilities. Exhaustive initial configuration should be avoided in favour of incremental configuration. Updates should be safe, that is, they should support backing-up, exporting, and restoring system and custom configurations.

Boisvert et al. presented six guidelines for designing mobile assistive technology (MAT) for people with cognitive impairments [9]. MAT should offer a customized user experience. This will reduce cognitive load by making decisions less time-consuming, and foster user appreciation. It should provide frequent feedback to promote the feeling of being in control of the MAT. Information should be delivered multi-modally to increase the chances of comprehension, yet clearly and concisely. Errors should be reduced by providing a consistent interface that is “deep” instead of “broad” and requires confirmation before executing critical actions. User input should be minimal and ideally automated. Finally, MAT should degrade gracefully in the absence of network or other resource connectivity. In light of the current research, frequent feedback could actually be detrimental to controlling a journey because of the “heads-

up” nature of wayfinding. Event-driven feedback that errs on the side of minimal is likely to be safer and more effective.

Nandigam et al. investigated mobile phone user interface design for people with traumatic brain injury [41]. They interviewed four individuals with moderate to severe cognitive impairments due to traumatic brain injury. Despite the unique perspectives of each participant, common themes emerged with respect to managing both physical and cognitive impairments. The authors recommended that a mobile phone user interface should support soft finger and stylus manipulation. It should display large buttons, and icons with titles. Finally, it should avoid context menus in favour of a single level menu structure.

5.3.2 Wayfinding Strategies and Support Modalities

Antonakos conducted a case study of compensatory wayfinding behaviour in three individuals with topographic disorientation due to brain injury [3]. Topographic disorientation may be characterized by periodic, severe disorientation along previously familiar routes, and the inability to learn new routes. With the exception of impaired route learning, it bears a striking resemblance to what has been referred to in the current research as *spontaneous acute disorientation*. Likewise, all of Antonakos’s participants reported visually scanning the environs and recognizing landmarks to compensate. Two also reported memorizing sequences of landmarks, but the third was unable to do so.

Dawe investigated mobile phone usage and design requirements for young adults with cognitive disabilities and their parents [18]. Five families were interviewed. Several prevalent themes were identified, including the need for a navigation menu with fewer options, and the tendency for families to use mobile phones in the contexts of navigational error recovery when plans change, as in missing a bus, and checking in for safety assurance.

Sohlberg et al. evaluated the performance of twenty individuals with severe cognitive impairments due to brain injury, who were tasked with walking each of four equivalent routes using a different prompt mode [49]. Prompt modes included aerial image with directional arrow, point-of-view image with directional arrow, text, and auditory. Auditory was statistically more effective than either image mode. Auditory was most-preferred by twelve participants because it was straight-forward and afforded eyes-free walking. Image modes were least-preferred by nine participants

because they were difficult to relate to the surroundings. The authors concluded that although text check-lists are prevalent for task completion in cognitive rehabilitation, auditory prompts may be better suited to route following, corroborating recommendations from participants in the current research.

Liu et al. evaluated the efficacy of various guidance modalities of mobile indoor wayfinding software for users with cognitive impairments [34]. Modalities included text with audio, text with photos, and text with audio and photos. Different modalities were more or less effective for, and more or less preferred by, different participants. Photos were useful for disambiguating text and audio, but required additional cognitive resources. Text was easier to process, notwithstanding unfamiliar vocabulary. Audio prompts were problematic if ill-timed or delivered too rapidly. Positive confirmatory feedback was appreciated amidst uncertainty, else it was resented. The authors concluded that accounting for varying physical impairments, use cases, and preferences is important. Incorporating landmarks into maps, and fostering greater user interactivity were identified as areas of future research. The current research identifies several strategies related to the latter, including “checking in,” annotating a wayfinding artefact, planning collaboratively, and exposing wayfinding functionality through the familiar calendar paradigm.

Lemoncello et al. evaluated the efficacy of written directions for orienting individuals with acquired brain injury at the start of a route [31]. Directions were comprised of landmark, cardinal point, or left/right information. Participants with ABI were more error prone and hesitant using cardinal and left/right directions than controls, but performed equally well using landmarks. They were less confident regardless of direction type. Landmark directions were preferred by both groups.

5.3.3 Mobile Wayfinding Aids

Baus et al. designed and prototyped REAL, an augmented-reality, indoor-outdoor pedestrian navigation system [6]. Given a request and user model, REAL computed an optimal route. It then optimized route presentation according to the quality of sensor data - including on-board sensors and distributed infra-red beacons where available - and graphical constraints of the output device. The authors emphasized the importance of seamlessly switching between indoor and outdoor contexts, and adapting presentations according to “user context” including intentions, distraction, and stress.

Patterson et al. designed and implemented Opportunity Knocks, an automated routing system for users who cannot use public transportation effectively because of "...short-term confusion or memory lapses" [43]. Deployed on a cellular phone, it was named for the sound of a door knocking, played at critical junctures to get the attention of the user. A novel inference engine obviated the need for a user to specify a destination. Instead, the user was presented with photographs of up to four predicted destinations, based on previous journeys. Upon selection, the system provided text directions from the current location. It detected deviations from the travel plan by incorporating location and real-time transit information, and prompted users to take photos of frequented locations.

Kikiras et al. presented a user model and corresponding semantic Web ontology for navigation systems, which they used to develop an indoor navigation system called OntoNav [27]. Under the model, a User Profile subsumes general demographics, mental/cognitive characteristics, sensory abilities, mobility, navigational preferences with respect to optimal routes and obstacles to avoid, and interface preferences including device type and instruction modality. OntoNav provided a User Profile Creator which, in addition to creating a custom profile from scratch, allowed a user to select and [progressively] customize one or more predefined profiles. It also specified a Navigation-Aiding Module to detect deviations from the route, and attenuate the User Profile.

Beeharee and Steed developed a prototype pedestrian navigation system in which directions were presented as text and, in an alternate view, as a trace on a map [7]. The map incorporated location-specific photographs extracted from existing geophoto repositories. In an exploratory user study, most users relied on text instructions and scanning the surroundings to make decisions, but the map was useful for gaining an overview. Photographs were most often used to confirm a decision. However, some users found the photographs confusing because they were taken from a different point of view.

Chang et al. developed a mobile guidance system for pedestrians with cognitive disabilities [12]. It relied on QR-code tags to deliver prompts consisting of photos with directional arrows overlaid, as well as brief instructions. QR-code tags are two-dimensional bar codes. PDAs were furnished with scanning software. Being user-solicited, the prompts were therefore delivered just-in-time. In addition, the system employed a user time-out mechanism to detect possible problems based on expected trip duration. Preliminary field testing was successful. Four out of six cognitively im-

paired participants used the system to traverse each of five routes without getting lost. The remaining two participants became lost on one of the routes. In light of the current research, it is reasonable to speculate that the success of the QR-code approach was due, at least in part, to promoting targeted visual search and enforcing user interactivity. Encountering each QR-code bolstered confidence, much like chaining landmarks. However, whereas QR-codes were evidently effective for route following, they are unlikely to foster route learning. This is because they are indistinguishable from each other and totally context-free.

Liu et al. designed and implemented a mobile wayfinding prototype that included a landmark selection system and user model [33]. It provided customized directions by modelling the direction selection problem as a Markov decision process (MDP) consisting of states, options and associated transition probabilities, and costs and rewards related to cognitive load versus time required. Key customization factors identified in a user study included employing the preferred prompt modality; using familiar landmarks, where possible; adjusting the level of detail for each route instruction; accounting for relevant health conditions, including fatigue; detecting user-specific errors and intervening appropriately; and accounting for different levels of user safety awareness.

Barbeau et al. designed and implemented TAD, a Travel Assistant Device to help people with cognitive disabilities use public transit safely and independently [4]. TAD provided real-time, multi-modal prompts for when to [prepare to] signal the transit operator, and a prominent visualization reflecting GPS connectivity. Deviations from the planned route generated alerts to care providers, who could also track the progress and manage the trip itineraries of their charges through a Web site. Preliminary field testing yielded mixed results. Researcher-participants characterized 89% of prompts as delivered at the ideal time, compared to just 41% for cognitively impaired participants.

Chapter 6

Summary and Conclusions

The purpose of this research was to inform the design of mobile wayfinding software for users with acquired brain injury (ABI). Five research questions were posed:

1. How do survivors plan their excursions?
2. How do survivors stay on course?
3. Why do survivors lose their way?
4. How do survivors recover from losing their way?
5. How might survivors receive, use, and design the ideal mobile wayfinding aide?

To answer them, two qualitative studies were conducted. A novel, substantive theory of wayfinding in ABI was generated from the data using constructivist grounded theory. According to the theory, wayfinding fundamentally consists of four phenomena: establishing, maintaining, occasionally losing and then regaining control of a discrete, immediate journey. These phenomena address the first four research questions. Control is an abstraction that subsumes spatial orientation and personal composure. Composure refers to feeling relaxed and ideally confident about travelling. Consequently, control is influenced by the familiarity of a destination, route, and locale, and the degree of recovery.

This theory is important because it provides a simple but cohesive framework uniting spatial orientation and personal composure throughout the entire process of wayfinding. It also implies the following, with respect to the purpose of this research:

1. There are two broad, complementary targets for providing wayfinding support: facilitating orientation, and managing anxiety.

2. There are three broad, actionable contexts for providing wayfinding software support: establishing, maintaining, and regaining control of a journey.
3. Unfamiliar journeys are more likely to mandate [intensive] wayfinding support than those that are familiar.
4. Survivors in the early stage of recovery are more likely to require [intensive] wayfinding support than those in later stages.

In addition to the substantive theory proper, three additional considerations were identified. First, survivors may have pressing financial concerns. Second, survivors typically rely on day-planners. Finally, some survivors must account for physical status including physiological ailments, physical impairments, and energy level.

Notwithstanding some reservations as to cost and utility, most participants were quite taken with the notion of a perfectly designed and customized mobile wayfinding aide. They described a number of potential use cases, including visiting new places and staying on course. Using audio to provide feedback and notifications was a prevalent feature request. Several participants suggested enriching a street map with landmarks, and emphasized the importance of a simple user interface.

In conclusion, this research corroborates previous work demonstrating that variability within and between users prohibits a one-size-fits-all approach to wayfinding software design. It grounds the following software design recommendations:

- Provide a user interface that is simple: minimal, obvious, and seamless.
- Accommodate the whole user and current wayfinding context via user profiles, instrumentation, and “checking in.”
- Afford an interactive user experience to promote control.
- Integrate with calendar software.
- Deliver notifications, ideally as audio, to foster “heads-up” piloting.
- Emphasize landmarks that are distinctive and immutable, but afford map access too.

Several participants made it clear that an effective mobile wayfinding aide would bolster their confidence, and lead to increased and/or less traumatic community access. These recommendations will support software developers in their efforts to make this a reality.

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Appendix A

Study 1 Research Materials

A.1 Letter of Information for Implied Consent

You are invited to participate in a study called “Informing the design of navigational software for users with cognitive impairments” that is being carried out by Nathanael Kuipers. Nathanael is a graduate student in the Department of Computer Science at the University of Victoria. This research is supervised by Dr. Margaret-Anne Storey and Dr. Nigel Livingston.

Purpose and Objectives

The purpose of this study is to explore wayfinding challenges and solutions for pedestrians with cognitive impairments. Wayfinding is getting where you want to go without getting lost. The objectives are to learn how to increase independence and reduce anxiety while wayfinding, and enable more visits to new places. This information will guide the design of wayfinding software.

Importance of this Research

Research of this type is important because it increases our ability to design effective software for cognitively impaired people, which may improve their quality of life. No one can expect to design a good solution without understanding the problem first!

Participant Selection

You are being asked to share your thoughts about wayfinding, assuming that it is something you find challenging or that you know someone else who feels this way. If you are a care provider reading this on behalf of a client, then that person is the participant. If you are a care provider who wishes to take part directly, then *you* are the participant. Care providers may participate and help their clients participate, separately. Participants must be able to converse. This includes assisted speaking.

What is Involved

This study involves a questionnaire and a guided group discussion. All groups will meet at the headquarters of CanAssist, located at the University of Victoria. The questionnaire will come first. Then, in the discussion, you can share your thoughts about several questions related to wayfinding. The questionnaire and discussion together should not take more than one and a half hours.

Inconvenience

Participation in this study may cause some inconveniences to you. These include re-arranging your schedule (and that of any personal support, such as child care) to attend, and travelling to and from CanAssist.

Risks

There are potential risks to you by participating in this study:

- You may feel stressed during the discussion, especially if there are disagreements.
- You may know other participants in your group, which could be awkward or otherwise change how they think of you and behave around you.
- You may become tired or uncomfortable, especially if you have any medical needs.

You should bring anything you may need for your health and comfort. There will be a first aid kit for medical emergencies. There will be two ten-minute breaks, and you may of course use the restroom or take a break as needed. “Ground Rules” given

at the beginning will emphasize respect. A “moderator” will guide the discussion, remind everyone of the Ground Rules, and resolve problems as appropriate.

Benefits

There are potential benefits to you by participating in this study:

- You may feel good about helping to solve an important problem.
- Hopefully, participation will be fun, and you might make new friends, too.
- You or someone you know may end up using wayfinding software that you helped design by participating.

Compensation

As a way of compensating you for any inconvenience related to your participation, you will be given a gift of ten dollars (\$10) when you leave CanAssist. Care providers who are not participants and are assisting a participant are also eligible for this gift. Refreshments will be available. If you would not participate without this compensation, **then you should decline!**

Voluntary Participation

Your participation in this research is **completely up to you!** If you decide to participate you may stop **at any time** without worry. You will not be contacted after withdrawing unless you ask to be, but you are welcome to offer feedback. If you withdraw *before* the group discussion, your questionnaire will be destroyed and not used. If you withdraw from the study *during* or *after* the group discussion, your data will be used in a summary form with no identifying information. Compensation will not be affected.

Anonymity

Your anonymity cannot be fully protected during group discussion, especially if you happen to know someone in the group. Though first names are necessary to communicate with others, last names will not be displayed or used. However, the discussion will be recorded using a digital camcorder. If this is unacceptable to you, **then you should not participate!**

Your anonymity will be fully protected after the data has been collected. Video data will be transcribed into digital text, and the transcript will be coded. Fake names will be used for analysis and presentation of results. For example, “In group four, all the participants except P3 agreed that anonymity is important.” Video will *never* be shown with the results.

Confidentiality

Confidentiality cannot be guaranteed: participants may talk with their friends and family about what was said during the group discussion. We cannot and should not stop this totally, but confidentiality will be covered in the Ground Rules as part of respect.

Confidentiality of data files is guaranteed. Data will be stored on a secure server and two research computers. The only person allowed to access the files will be Nathanael. The only people allowed to view the un-coded data will be Nathanael and his supervisors Dr. Storey and Dr. Livingston. Coded transcripts may be shown to colleagues, and parts of coded transcripts may be included in results.

Distribution of Results

Results will be included in Nathanael’s thesis, and may be published in scholarly articles and presented to peers. Interested participants will receive a summary of results.

Disposal of Data

Questionnaires will be scanned and then shredded on the same day that they are collected. Computer files containing un-coded data will be deleted no later than January 1st, 2013. Computer files containing coded data will be encrypted and moved to a private portable storage device. These files will not be used in future research.

So... What Now??

If you are interested in participating in this study, please contact Nathanael as soon as possible. Include any questions or concerns you may have. If you are happy with the answers to your questions and concerns, you will be randomly assigned to a group after the deadline and contacted with the date and time of your group’s meeting at CanAssist.

IMPORTANT: You do not have to attend the meeting if you change your mind! Attending implies that *you or your legal guardian(s) are giving free and informed consent for your participation*. It means that you (they) understand conditions of participation, and have had the opportunity to have questions and concerns addressed.

Contacts

You may contact Nathanael by email (nkuipers@uvic.ca) or phone at (250)-721-7302. You may contact Dr. Storey by email (mstorey@uvic.ca) or phone at (250)-472-5713. You may contact Dr. Livingston by email (njl@uvic.ca) or phone at (250)-721-7121. To verify the ethical approval of this study, or raise any concerns, contact the Human Research Ethics Office at the University of Victoria by email (ethics@uvic.ca) or phone at (250)-472-4545.

Please retain a copy of this document for your reference.

A.2 Questionnaire for Cognitively Impaired Participants

Section A – Personal Profile

First name:

Last name or initial (optional):

Age:

Gender:

Area of residence (for example, Oak Bay):

1. Have you sustained a brain injury? Circle one: Yes No
2. If you answered “Yes”, please write when the injury happened. If you answered “No”, skip this question and go to question 3.
3. Describe any physical impairment you may have. For example, “difficulty walking”, “low vision”, or “cannot use hands well”.

Section B – Wayfinding Information

1. About how many times per week do you leave your home to go somewhere?
2. When you leave your home, where do you go? List your most common destinations. For example, “grocery store, the park” and so on.
3. For each of the following modes of transportation, circle the word or phrase that best describes how often you use it.

Bicycle	Daily	Every few days	Weekly	Monthly	Very rarely	Never
Bus	Daily	Every few days	Weekly	Monthly	Very rarely	Never
HandyDART	Daily	Every few days	Weekly	Monthly	Very rarely	Never
Taxi	Daily	Every few days	Weekly	Monthly	Very rarely	Never
Family car	Daily	Every few days	Weekly	Monthly	Very rarely	Never
4. How often do you travel by yourself? Circle one of the following:
Daily Every few days Weekly Monthly Very rarely Never
5. Would you prefer to travel by yourself more often? Circle one: Yes No
6. If you answered “Yes”, where would you go? List some destinations. If you answered “No”, why not?

Section C – Mobile Devices

1. Which of the following devices, if any, do you own or use regularly? Circle all that apply:
 - Smart phone (for example, an iPhone, Android, or Blackberry)
 - iPad
 - Other GPS-enabled device

Section D – Follow-up

1. Would you like to receive a summary of findings from this study when they become available? Circle one: Yes No
2. If you answered “Yes”, please provide your preferred mailing or email address. This address will only be used to send the summary of findings, and will be kept strictly confidential. If you answered “No”, skip to Section E.

Section E – Comments

You are welcome to share any additional comments, ideas, or suggestions:

A.3 Questionnaire for Care Providers

Section A – Personal Profile

First name:

Last name or initial (optional):

1. For how long have you been a care provider for a cognitively impaired person?
2. Are you a professional care provider? Circle one: Yes No
3. If you answered “No”, circle the word which best describes the relationship with the cognitively impaired person under your care:

Partner Relative Friend

Section B – Mobile Devices

1. Which of the following devices, if any, do you own or use regularly? Circle all that apply:
 - Smart phone (for example, an iPhone, Android, or Blackberry)
 - iPad
 - Other GPS-enabled device
2. Do you think that cognitively impaired people could benefit from an appropriately navigational application on a mobile device? Circle one: Yes No

Section C – Follow-up

1. Would you like to receive a summary of findings from this study when they become available? Circle one: Yes No
2. If you answered “Yes”, please provide your preferred mailing or email address. This address will only be used to send the summary of findings, and will be kept strictly confidential. If you answered “No”, skip to Section E.

Section D – Comments

You are welcome to share any additional comments, ideas, or suggestions:

A.4 Focus Group Discussion Ground Rules

1. We want everyone to feel comfortable sharing their thoughts. Please respect the opinions of others!
 - Don't make fun.
 - Try not to shout.
 - DO think of everyone here as a team mate!
2. If you talk with your friends and family about the discussion, please do not refer to your team mates by name.

A.5 Focus Group Discussion Questions

1. We all need to go places. Let's say you are to meet a friend at a coffee shop down-town at 2:00 in the afternoon. What do you think would be difficult or stressful about getting to the coffee shop on time, especially if you were alone?
2. Do you use anything to help you travel? For example, perhaps you use the computer to look up an address, have directions written down on a piece of paper that you take with you, or ask people for help along the way.
3. Imagine a hand-held device with a program to help you travel by walking and using the bus, all by yourself. This program is tailored to YOU. What do you want from this program? For example, "I want it to remind me where I'm going" or, "It should speak directions to me" or, "It needs big buttons." Let's brainstorm!

Appendix B

Study 1 Findings

B.1 Graphical Framework

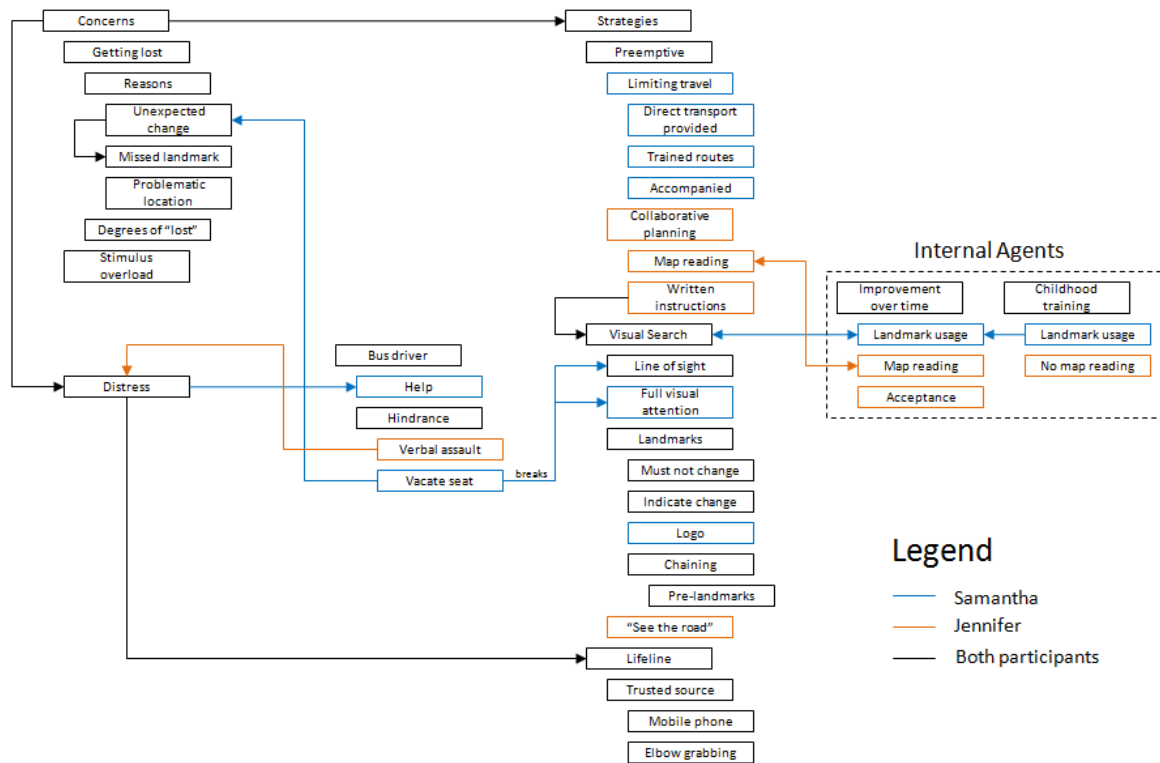


Figure B.1: A graphical framework of findings from Study 1, constructed for researcher edification and as a basis for subsequent member checking. Indentation indicates a “falls under” relationship. Colours indicate from which participant(s) a particular insight was drawn. Arrows between boxes indicate that one concept in some way drives the other.

B.2 Point-Form Summary for Member Checking

Reasons for getting lost:

- Missed landmark
- Unexpected change ("changing horses")
- Too much going on (overwhelming!)
- Some places are just tough to navigate (like the mall)

Travel strategies:

- Limiting travel
 - Getting a ride (handyDART, family, friends...)
 - Trained bus routes only
 - Don't often travel alone
- Planning with someone you trust, in advance
- Visual search
 - Using landmarks that must not change or move!
 - * Landmark-to-landmark travel; logos are good ("bud get")
 - * Pre-landmarks warn about an important landmark coming soon
 - Seeing street names, signs... "the road"
- Lifeline if things go wrong
 - mobile phone
 - elbow grabbing

Role of the bus driver:

- Provides assistance:
 - Remembers where you are going, cues you to get off
 - Provides directions

- Calls supervisor if there is a problem
 - Helps you across the street
- Causes anxiety:
 - Asks that you leave your seat
 - Yelling

Other:

- Childhood training and experience is important
- Wayfinding skills improve over time
- Crying is a response to distress, and a way of letting others know you are upset

Designing a device to help:

- “Show the route” like a camera flying along as you go
- Preview mode, to explore a route ahead of time from home
- Needs to know current location
- Gives audio cues
- Speech input (“I’m going to...”)
- Customizable

Appendix C

Study 2 Research Materials

C.1 Letter of Information for Implied Consent

You are invited to participate in a study that is being carried out by Nathanael Kuipers. Nathanael is a computer science graduate student at the University of Victoria.

Purpose

Wayfinding is choosing and following a route. This study aims to describe wayfinding by pedestrians with a traumatic brain injury, making it possible to design good wayfinding software for them to use. Community access may then be improved.

Participants

You may participate if:

- You are a survivor of traumatic brain injury.
- You go out into the community.
- You are able to talk about your experiences.

What is Involved

This study involves an interview at the Victoria Brain Injury Society or Cridge Centre for the Family. The interview should not take more than one and a half hours. It will be audio-recorded.

Risks

You may become stressed, tired or uncomfortable while participating. Bring anything you may need for your health and comfort. There will be a first aid kit. Please use the restroom or take a break as needed!

Benefits

You may feel good about helping in this research. You or someone you know may end up using software that you helped design by participating. Hopefully, participation will be fun, and interesting!

Compensation

To thank you for your help, you will be given ten dollars (\$10). If you would not participate without this gift, then you should not participate.

Voluntary Participation

Your participation in this research is completely up to you! You may stop at any time. If you decide to stop, your data will be destroyed and not used. You will still receive your \$10.

Anonymity

Anonymity cannot be guaranteed because you will be interviewed where people know you. However, once the interview is over your real name will not be used in the data or results.

Confidentiality

Researcher confidentiality is guaranteed. Data files will be stored securely. Only Nathanael and his supervisors will be allowed to access the files.

Distribution of Results

Results will be included in Nathanael's thesis, and may be published in articles or presented in talks. If you want, you will also receive a summary of results.

Disposal of Data

Data will be copied to a secure computer. Paper notes will be shredded. Computer files will be deleted by January 1st, 2013, and will not be used in other research.

What Now?

If you have any questions, ask Nathanael! Contact information is given below. If you are happy with the answers to your questions, arrangements can be made to meet for the interview.

Attending the interview implies that you are giving free and informed consent to participate.

You can change your mind about participating. You may stop participating at any time.

Contacts

Nathanael can be reached by email (nkuipers@uvic.ca) or phone: 778-679-4636.

To verify the ethical approval of this study, or raise any concerns, contact the Human Research Ethics Office at the University of Victoria by email (ethics@uvic.ca) or phone: (250)-472-4545.

Please retain a copy of this document for your reference.

C.2 Interview Schedule

Brain injury basic information and SADI primer/check

1. How long ago did your brain injury happen? How old were you?
2. What happened?
3. Which parts or areas of your brain were injured?
4. What were your living arrangements *before* the injury? What about now?
5. What formal education had you received *before* the injury? What about since?
6. How were you employed *before* the injury? How have you been employed since?

The following questions are based on the Self Awareness of Deficits Interview

1. What do you see as your problems, if any, resulting from your injury? What is the main thing you need to work on or that you would like to get better? (Supply prompts below, as necessary.)
 - Physical abilities (e.g. movement of arms and legs, balance, vision, endurance)?
 - Memory/confusion?
 - Concentration?
 - Problem-solving, decision-making?
 - Organizing and planning things?
 - Controlling behaviour?
 - Communication?
 - Getting along with other people?
 - Personality change?
 - Other?

2. Does your head injury have any effect on your everyday life? Can you explain?
 - Ability to live independently?
 - Manage finances?
 - Look after family/ home?
 - Driving?
 - Work/study?
 - Leisure/social life?
 - Knowing where you are now, and where to go next?
 - Using signs, maps, or other instructions?
 - Going to new places?
 - Other areas of life which you feel have changed/*may change*?

3. What do you hope to achieve in the next 6 months? Do you have any goals? What? Do you think your head injury will still be having an effect on your life?

Turning now to questions about community access and wayfinding. . .

1. How often do you go out into the community during a typical week?
2. Give as many examples as you can of where you go. *How* you get to those places?
 - Grocery store, bank, other errands?
 - Health-related?
 - Meeting family or friends?
 - Recreational activities?
3. Are there places you would like to go more often? If so, what are they, and what is stopping you?
4. How often do you go out into the community by *yourself*?
5. Are there circumstances in which you were, or are, uncomfortable travelling by yourself? Please explain.
6. *Wayfinding* is the process of planning and following a route to some destination. For example, imagine that you are to meet a friend at a coffee shop tomorrow at 2:00 PM.
 - What, if anything, might be difficult or stressful about getting there on time?
 - What steps would you take to plan your trip to the coffee shop?
 - On the way there, how would you keep track of where you are, and where to go next?
7. Generally speaking, when you are travelling to a *familiar* place. . .
 - Do you plan or check the route first? If so, how?
 - On the way there, how do you keep track of where you are and where to go next?
8. Generally speaking, when you are travelling to an *unfamiliar* place. . .

- Do you plan or check the route first? If so, how?
 - On the way there, how do you keep track of where you are and where to go next?
9. How often do you become lost or disoriented?
10. Can you recall one or more incidents of becoming lost or disoriented? If so:
- Where were you at the time?
 - Where were you going, and how were you getting there?
 - What time of day was it? What was the weather like?
 - Why did you become lost or disoriented?
 - What did you do to get “back on track”?
 - Can you think of anything that might have been helpful at the time? What?
 - If you were in the same situation again, what do you think you might do differently?

Wayfinding technology solutions awareness and use

1. Do you own your own computer? If yes, what kind?
2. Are you comfortable using computers? If not, can you explain why?
3. How often do you use a computer? What do you use it for?
4. Do you own a portable computing device like a smart phone or tablet? (Show examples.) If yes, what kind?
5. Are you comfortable using such devices? If not, can you explain why?
6. How often do you use a portable computing device? What do you use it for?
7. Have you ever used Internet wayfinding services, such as Google Maps and Street View, to help plan or follow a route?
 - If so:
 - Which service did you use, and why?

- Was it helpful? Why or why not?
 - What do you like about it? What could be improved?
 - If not: why not?
8. Imagine that you have a new smart phone. And imagine that your new smart phone comes with a program to help you find your way when you go out. It is a *personal travel guide* designed especially for *you*.
- What do you think about this idea?
 - Do you think you might use a personal travel guide on a small device?
 - If so:
 - * In what situations do you think it would be (or *should* be) most useful to you?
 - * What would be some useful or nifty features of *your* personal travel guide?
 - If not: why not?

That was my last question. Have I missed anything important? What? Do *you* have any questions, or closing thoughts to share? *Please* do so!

Appendix D

Study 2 Supplementary Participant Information

Table D.1: Socio-educational demographics of Study 2 participants. ILS designates independent living, with support. The participants to which it applies live alone in an apartment, and are periodically visited by a support worker. Community living means living semi-dependently with an unrelated family.

P#	Pre-Injury Edu.	Post-Injury Edu.	Employment	Living Situation
1	college diploma	Bachelor degree	N/A	ILS
2	some university	some university	N/A	ILS
3	some university	some university	volunteer	community living
4	high school	N/A	N/A	alone in apartment
5	some college	N/A	N/A	ILS
6	grade 7	college diploma	N/A	with parents
7	vocational cert.	vocational cert.	volunteer	alone in apartment
8	some university	N/A	N/A	alone with pet
9	some university	N/A	N/A	alone in house

Appendix E

Study 2 Supplementary Findings

Table E.1: Travel logistics of Study 2 participants. E/W designates the number of excursions per week. VBIS designates Victoria Brain Injury Society.

P#	E/W	Example Destinations	Modes of Transportation
1	4-5	grocery store, warehouse store, bank	walking, some bus, rides with family/friends
2	6-7	college, gym, medical offices, the park, cinema, cooking class	bus
3	7+	church, family/friends, woodworking studio, cinema, VBIS	bus, some driving
4	2-3	VBIS, warehouse store	bus
5	6-7	grocery store, retail outlet, family, hospital, medical offices, cooking class	bus
6	4	grocery store, the mall, warehouse store, karaoke, dojo, the park	driving, some bus
7	7-14	church, volunteering, grocery store, bank, family, medical offices, VBIS	driving, some bus
8	1-2	medical offices, VBIS	HandyDART, taxi
9	1-2	ferry terminal, grocery store, bank, pharmacy, cinema	driving

Table E.2: Computer/mobile device ownership of Study 2 participants. Mobile phone in this context means a mobile phone that is not a smart phone.

P#	Computer	Tablet	Mobile Phone	Smart Phone
1	no	no	no	no
2	yes	no	yes	no
3	no	no	no	no
4	yes	no	no	no
5	yes	no	yes	no
6	yes	no	yes	no
7	yes	no	no	no
8	yes	no	no	yes
9	yes	no	no	no