

Participatory map-making after brain injury: a case-based feasibility study

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Summary: This paper outlines a participatory map-making collaboration with members of a charity supporting people experiencing difficulties following brain injury. The map-making involved members describing their experience of everyday life after brain injury. The study sought to assess how map-making may provide modes of individual, group web-based expression after brain injury.

KEYWORDS: Map-making, brain injury, web-sharing, community participation, advocacy

1. Introduction

Headway is a charity that supports people after brain injury. The project sought to assess whether map-making is a tractable and accessible way for members to describe their experiences, and whether a web-sharing platform could help produce a community map. Map-making compliments Headway's engagement and advocacy agendas¹. Standard searches² have revealed no similar examples of participatory GIS relating to neurological impairment in a community setting. The study outlined in the present paper is a 'public' collaboration (PPGIS) as we sought to achieve a shared understanding of the participants' knowledge (c.f. Jankowski, 2011:349).

Ten maps were produced during a five-month period. Seven were produced individually and three in a group. The participants (see *Table 1*) represent a representative sample of the day-centre community in terms of sex and age. Each had suffered a brain injury and continue to experience related impairments, including to memory, attention and communication, as well as difficulties such as fatigue, confusion and low self-esteem. Suitable participants were pre-selected Headway's by psychologist. The investigator imposed no formal schema on participants' modes of expression.

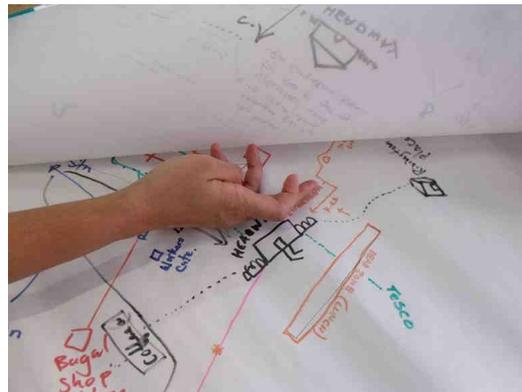
The initial map-making sessions were led by the investigator and Headway psychologist, after which two Headway members led individual and group sessions. Participants were requested to draw and annotate a map of their routine life. Map-making involved drawing on A3 sheets with coloured marker pens and ball-point pens. A similar map-making exercise was undertaken with a group of members. The pen-and-paper map-making was developed to support the production of a digital map of Headway members' experiences using a web-based image sharing platform. *Figure 1* provides an illustration of the map-making sessions³.

¹ Details are provided via <http://www.headwayeastlondon.org/services/discovery-programme/> [accessed February 2012]

² Including Google Scholar, Microsoft Academic Search, institutional library search

³ The investigator is not able to provide full illustrations due to participant privacy

Figure 1 An illustration of the Headway map-making sessions



1.2 Individual map-making

TR's map is complex and detailed, representing a network of routes and places weighted around his neighbourhood. There are two layers to the map: one 'written large layer' (the main routes and places) and the 'commentary layer' (thoughts, feelings and stories). Written large on Map One are places of interest: football stadia, retails areas and leisure destinations. Drawn around a tight cluster of activities is a ring labelled 'confident area safe zone'. His maps describe how his injury impacted negatively on his activities. For example, under a football stadium is written 'used to be an [Club A] fan but now difficult to get to the stadium so has switched to [Club B]; next to clothes shop (and intensified with 'fright' marks and capital letters) 'lost 18 months ago scared; [...] confused about which side of road shop was on. Walked up and down for 45 minutes'.

Table 1. Breakdown of participants

Name	gender	Age	yrs since injury	Cause	Impairments
TR	M	mid-20s	7	traffic accident	memory, vision
OH	M	male mid-40s	8	traffic accident	fatigue
PD	M	male mid-40s	5	trauma	memory, fatigue, navigation
Anon.*	M				
MM	M	male mid-40s	3	trauma	memory, hearing
FC	F	mid-20s	2	asthma	memory, fatigue, navigation
TR	M	late-20s	7	traffic accident	memory, fatigue, navigation

*no details collected as this map-making session was member-led

OH's map shows a major cluster of routes and places, featuring 'Home' at its centre. The routes and places are arranged by salience. Hence, the cluster that represents his everyday activities within a five-mile radius is disproportionate in size to a 40-mile journey he undertakes once a week. Routes are colour-coded and reveal his chief mode of transit to be his bicycle. OH has annotated his map according to activity rather than experience (eg 'shopping', 'seeing friend'). The phrase 'pass through' is written under every place not associated with everyday life, including a place demarcated as, 'repairing friend's bike pass through', meaning that this place bears personal and social salience but is no longer visited.

PD's map includes a circle drawn around the region comprising home, pub, nearby shops, nearby family, football and Headway. PD's map shows his interest in football and how disabilities have affected his engagement in the sport: 'really misses football'. PD notes that he watches football in the nearby pub, but has had to leave the venue due to the noise and crowds. PD reveals that he is able to travel to Headway twice weekly during the morning's rush hour, but habitually picks up a newspaper and 'puts his head in it and tries to ignore other people'.

Anon.'s map is unique among the materials in that it shows only places, not routes. Some but not all London's markets are depicted, and only one football stadium is shown; more places in north-west London are shown than places elsewhere in the city. The map also shows London's major airports, plus a major music venue. Hence, landmarks are simply geographic but also salient. Anon.'s sole annotation on the map is a single asterisk that appends a football stadium.

MM's map shows places and routes in London's west end, encircled and annotated with 'anxiety zone ... crowds!'. Shops are situated in a 'very disorientating' underground complex, and the major transport interchange was 'horrible, being noisy and difficult to navigate'. MM symbolised this by a sketch of an ear surrounded by alarm marks.

FC's map reveals that she travelled widely and regularly by bus before her injury, but now avoids this for several reasons: they are too busy, 'awkward to stand on', the drivers are 'mad', 'park too far from the kerb', 'the passengers use the same doors to entry and exit'.

1.2 Group map-making

Group maps were produced using several sheets of paper in various formats, taped together asymmetrically and rendered in a variety of vividly coloured felt-tip pens. Each map shows a region surrounding the Headway day centre. While the focus of interest was on the surrounding streets and resources, one map included some locations on the south coast of England.

The group-work maps combine different viewpoints and perspectives and bear conflicting scales of description, for example a pet cat is rendered the same size as a supermarket. The marks of several participants are evident, revealing differing modes and capabilities of expression.

1.3 Web-sharing

Participant OH led a map-making session using a popular web-based, image sharing platform with participant MM. OH shadowed MM on a regular trip, and used an iPhone to take pictures of him *en route*. The images were geo-tagged, uploaded to the web-sharing platform and annotated with additional prompts. The intention was for MM to log in to the site on his mobile phone, and use the sequence as an aid to memory. The author has requested MM to use this platform as he sees fit for a period of months, and assess the potential use of web-sharing platforms.

2. Discussion

The study demonstrated that map-making is a tractable and accessible mode of expression following brain injury. More critically, the participatory map-making was shown to involve *ideational* activities, meaning that everyday experiences were brought to presence as a *thinking-space* (c.f. Rosenberg in Garner, 2007: 110). Hence, the maps may be viewed as creative and authored surfaces. Developments in web science currently afford to the map-maker a broader modal and dimensional scope, including platforms for rapid authorship. Hence, ‘semantic web’ knowledge-modelling tools may also allow the participant to ‘think on the web’⁴.

Expanding on these technical themes, we may consider John Urry’s critique of current descriptions of social arrangements as networks of people, places, materials and mobilities; also observing how web platforms may represent such rapidly evolving landscapes (Urry, 2004). These social networks bear a kind of conceptual proximity – for example of ‘friendliness’ or ‘strangeness’ – which were instantiated in the map-making sessions, for example in the delineations of ‘safe zones’.

For those experiencing impairments as a result of brain injury, everyday life may involve deliberately managed activities. Their maps of everyday life (including social arrangements and phenomenal encounters) must be reconfigured rapidly and constantly, with minimal cognitive load. The task ahead is to explore how semantic web tools may provide agile support for map-making as a *thinking-space* activity.

References

Garner, S. (2007) *Writing on Drawing: Essays on Drawing Research and Practice*. Bristol: Intellect Books.

Jankowski, P. (2011) Designing Public Participation Geographic Information Systems. In: Nyerges, T., Couclelis, H., and McMaster, R. *The Sage Handbook of GIS and Society*. London: Sage Publications Ltd.

Urry, J (2004) Small Worlds and the New “Social Physics”. *Global Networks* 4 (2):109-130

⁴ c.f. Alesso et al (2009) *Thinking on the Web*, London: Wiley Publishing.