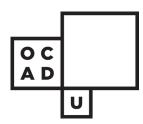
Embedded perspectives:

Considerations for the design of a multi-centre research registry

John Harvey

A thesis presented to OCAD University in partial fulfillment of the requirements for the degree of Master of Design, through the Digital Futures Initiative in Toronto, Ontario, Canada on May 09, 2014



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Abstract

The denial of decision support and research tools using real-time communication between medical centres is an ongoing problem in Ontario. Through fieldwork, a relationship was established with a neuroradiologist at a local area research hospital, and permission was obtained to create a website based on study data of patients suffering cerebral aneurysms as a step toward resolving this problem. One hundred case files from 2012-2013 were assembled, anonymized and exported from the hospital's patient records. Post-processing of patient's images was performed to secure a level of interactivity commensurate with users' experience through their workplace software. Paper prototypes of interface designs were created for both desktop and mobile platforms. These prototypes were presented to 'lay' users and then to representative end users neuroradiologists at two local area research hospitals. Interaction with the prototype and the ensuing discussions led to the creation of a second prototype, which in turn was presented at each hospital. Observations and findings from these sessions provided a set of design considerations. These considerations led to the formation of a design model which can serve as a basis for ensuring user contribution and reward for participating in an online medical research registry.

Acknowledgments

This project would not have been possible without the instigation, guidance and support of Dr. Sean Symons at Sunnybrook Health Sciences Centre, Toronto (SHSC). Dr. Aditya Bharatha at St. Michael's Hospital, Toronto (SMH) also provided valuable critique and a high level of access to his time and his colleagues. The following medical experts were also instrumental in contributing their time and advice: Drs. Peter Howard (SHSC), Robert Yeung (SHSC) and Julian Spears (SMH).

Interpretation of findings as well as of experts' interactions and comments would have overwhelmed the project were it not for the profound insight and calm guidance of Professor Bill Leeming. Professor Peter Coppin supervised the project, providing invaluable mentorship, conceptual overview and academic perspective.

The following professors must be also be acknowledged for their support and insights: Martha Ladly, Nick Puckett and Tom Barker.

Dedication

I dedicate this work to my fellow classmates in the Digital Futures Initiative second cohort, for their inspiration, friendship and support.

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Acronyms

- 3DVR Three-Dimensional Volume Render
- ANG Angiogram
- CT Computed Tomography
- CTA Computed Tomography Angiogram
- EMR Electronic Medical Record
- HIS Hospital Information System
- LHSC London Health Sciences Centre
- MRA Magnetic Resonance Angiogram
- MUMC McMaster University Medical Centre
- PACS Picture Archiving and Communication System
- PKD Polycystic Kidney Disease
- QTVR QuickTime Virtual Reality
- RIS Radiology Information System
- SHSC Sunnybrook Health Sciences Centre
- SMH St. Michael's Hospital
- THC Trillium Health Centre
- TOC The Ottawa Hospital
- TWH Toronto Western Hospital
- UID Unique Identifier
- WFNS World Federation of Neurologic Surgeons
- WRH Windsor Regional Hospital

1. Introduction

1.1 Background

This project began as an observation of radiologists' reference to patients' images as a conception of treatment decisions. Admission to the neuroradiology department at Sunnybrook Health Sciences Centre (SHSC) began as part of this study, as well as indirectly through a prior professional relationship with Dr. Sean Symons, a staff neuroradiologist at SHSC.

This investigation was modeled after Alac and Hutchins (2004) in their study of communication between scientists, specifically their use of gesture, language and drawing with mutual repeated reference to fMRI images to ensure knowledge transfer of brain area boundaries. Similarly, during our investigation, it was observed that decision support between neuroradiologists can involve particularly pointed, mutual reference to a patient's films. In one instance, Dr. Symons was asked to consult on a patient who was being prepared for intervention (a non-urgent case). He happened to be in the angiography suite control room as our guide. In response, he manipulated a three-dimensional render (3DVR) of the patient's cerebral vasculature—on display at a workstation—before forming an opinion. An example of the model being referred to is shown in Figure 1. His opinion differed from that of his colleague, and during the ensuing discussion the physicians took turns rotating the 3DVR to verify their position. The discussion ended when Dr. Symons suggested that a call another interventionist on staff (senior to the colleague) would be appropriate for confirmation. Later, Dr. Symons mused that he would like to know how a similar aneurysm would be treated at SHSC's partner hospital, St. Michael's (SMH), but that he had no way of discovering that information short of calling a friend. We learned that decision support from colleagues outside hospital boundaries with direct reference to patient films is not possible for SHSC, despite cooperative agreements SMH. This situation is common throughout Ontario (Canada Health Infoway 2012, King 2013, personal communication).



Fig.1 Sample frames from an angiography-generated 3D QTVR

A discussion arose regarding the potential usefulness of a website reflecting relevant content from multiple treatment centres: would it not be a step toward resolving the problem of denied off-premise support? And were not cerebral aneurysms an ideal subject for such a site? And ideal for various reasons: a) a relatively short timeline for course treatment; b) the limited and distinct range of treatment options; c) uncomplicated outcomes; and d) the limited number of interventionists on whom to rely for feedback and participation (Symons 2013, Bharatha 2013, personal communication). Despite the selective bias that a small database would represent, it was felt that the recency, relevance and careful curation of cases would create a valuable contribution toward retrospective research in the field. We then obtained permission to acquire 100 of the most recent aneurysm case studies from the SHSC archives.

Online and software decision support tools for biomedicine have been developed and studied. In support of a data warehouse for dementia care, Khalid et al. (2010) stress the need for repositories to enhance quality of care. Lopes et al. (2010) describe their epidemiological data repository as beneficial for forecasting and community building. Karpov and Yudin (2010) developed their Doctor's Partner application as "an expert system that helps to direct one's attention to complicated situations in the conditions of ambiguous classification with [an] incomplete set of signs" (Karpov and Yudin 2010, p. 85). However, assessments of physicians' use of online support systems indicate that acceptance is contingent on a set of concerns that is often not part of a repository or application's call to action. Horan et al. (2006) describe a number of factors influencing intent to interact, including whether or not the physician would be directly inputting information. Croll (2010) and Janols et al. (2010) observe that perception of benefits, especially with regard to time usage, is the most important factor to physicians' adoption of an electronic support system. Nonetheless, mobile applications for radiology consultation are being developed and tested (Hite 2014, Mahmood et al., Tewes et al., Yarmenitis et al. RSNA 2013 Proceedings). Results are 'successful' in trial runs, but mass implementation is always contingent on approval from senior staff in hospital IT departments, which is very rarely granted. Note that use and development of such tools in Ontario is restricted due to privacy concerns, and slow due to institutional legacy (Canada Health Infoway 2012, Cavoukian 2008, Garcea, personal communication, Goonaratne, personal communication). Web-accessible, presentation-ready radiology cases, covering a wide variety of pathologies, are freely available via the Radiological Society of North America's Medical Imaging Resource Center (MIRC). However, contribution and use rates for MIRC remain low, perhaps due to the Virtual Private Network behaviour of the repository (Juluru and Weadock RSNA 2013 Proceedings).

This is not to suggest that online radiology repositories do not already bridge gaps in communication. *Radiopædia.org*, *AJNR.org* and *AuntMinnie.com* all provide portals to radiological content for widespread dissemination. My observations of residents in hospital, discussions with experts, online testimonials and commercial growth (in the case of AuntMinnie.com) all attest to the popularity of these resources. While reflecting only a fraction of potential user input, contribution to these sites is steady. The difference between these generalist sites and the proposed specialist site is that the knowledge link being sought is not global and educational but jurisdictional and supportive. This distinction is largely due to patients' privacy protection, paramount in the provision of online medical data (McClanahan 2008, Beiles et al. 2012). An Ontarian patient's data cannot be uploaded to a cloud-based network since the server must be located within Ontario's borders. Tellingly, Canada is not party to the UBM Medica network which supports Radiopædia.org. Canadian physicians are not permitted to post patients' files onto a public forum with any identifiers other than basic demographics and pathology, including the provider's identity, site of origin or date of study/treatment: Canadian

contributions are not found on the aforementioned websites. However, should an online site be limited to a sub-specialty whose content is known to be restricted within a particular region (such a southern and eastern Ontario), information such as contributor's identity or the site of treatment could be assumed (in confidence) by the expert user. It was this rationale which prompted Dr. Symons to observe that a website devoted to aneurysm treatment would be a useful and legally achievable resource.

Note that the terms 'website', 'repository' and 'registry' differ in their connotations of accessibility and purpose for medical research. Part of the project's discovery, described below, was that it's design intent challenged these differences: I therefore use the terms 'website' and 'registry' interchangeably. The website's intended users are interventional neuroradiologists within Ontario – clinicians who share related research interests but whose practices differ in terms of type and number of procedures performed.

It had been noted that 3DVR (or 3D QTVR) is a particularly important reference tool for the registry's intended users. This interactive movie format was considered essential to user engagement, and the task of creating QTVR files became a major component of collecting data for the site. Besides QTVR files, numerous other files were required. Data collection was a lengthy process: it became a way to familiarize myself not only with the content but with a potential user's work environment. This environment includes dictation of diagnoses, discussions with residents, fellows and colleagues from other departments, and use of the department's image Viewer and post processing software. By understanding the environment, I would also come to determine 'appropriate' or 'effective' affordances with regard to the registry interface. Nonetheless, the place or role for a designer here remained elusive.

1.2 Research question

The question of the designer's role was reiterated in more pragmatic terms, "How do design methods meet the specific internal needs of stakeholders at various medical centres while addressing the development of an aneurysm registry?" If it could be determined that certain affordances foreign to online medical research—such as visual (versus semantic) organization, or personal (versus role-based) access channels—could succeed, then the

designer's role would be clear. However, finding the space for design would require qualifying or measuring users' concerns in some way.

1.3 Project goal

Such measurements could be obtained through video recordings of prototyping sessions. The multi-centre aspect of the project was essential to broadening our scope of observations, as would careful planning for the quality and granularity of feedback obtained. The project's goal was therefore to prototype the interface at each of two medical centres and determine how users' interactions and comments would influence the prototype's next iteration. These interactions and comments would be presented as design considerations for any subsequent iterations. My original objective in this study was to collect a sample of the most recent cases from SHSC (100 cases) and from SMH (150 cases) so that a live prototype of the website would indeed reflect the multicentre nature of its database and encourage contribution from other centres. Due to the time constraints of the program of study and delays associated with ethics board approval from SMH, only 100 cases from SHSC were collected. Due to the same time constraints, a browser-enabled wireframe of Prototype 1 could not be presented to the users: had it been, user interaction and comments would likely have produced additional findings.

2. Literature Review

"... we have seen design grow from a trade activity to a segmented profession to a field of technical research and to what now should be recognized as a new liberal art of technological culture" (Buchanan 1995, p.130). Buchanan writes at a time when graphic and industrial designers were apprehensive of the looming world of immateriality that digital technology represented: design theory had not yet evolved to accommodate digital design techniques. Yet his words still resonate, positioning the designer as a renaissance figure, a humanist capable of overseeing and negotiating the relationships that technology both enables and renders obsolete. His observations are all the more relevant to the designer who approaches the hospital as a site for fieldwork. It might be useful to consider Attila Bruni's description of the hospital as a 'technologically dense environment', "In case of modern medicine, technological density then does not simply imply an increase in diagnostic, therapeutic, and administrative technologies, but leads to manifold interdependencies between them" (2013, p. 68). As the designer is faced with such an environment, it is easy to imagine creative paralysis in face of it. In such a case, the designer's judgment is her guide. In order to define 'adequate design' and legitimize self-assigned limits, Nelson and Stolterman describe framing judgment as "marked by an altruistic and pragmatic judgment of whom to agree to serve—a judgment of who the clients, in the broadest sense, are or ought to be." (2012, p.148). Framing judgment is similar to Buchanan's principle of relevance (1995, p. 16) but more precise, not only in its empowerment of the designer but in its position within a series of design-related judgments made throughout a project's duration, each of which enable it to bear fruit.

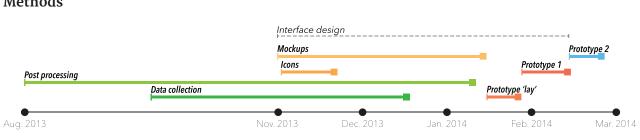
But framing judgment assumes a high degree of contextual immersion. Whereas standard assessment entails "'looking around' to see how things fit" (Nelson and Stolterman 2012, p. 79), immersion reveals the detail of a client's culture. "'Looking into' a system requires analysis. ... 'Looking out' of a system entails synthesis" (Nelson and Stolterman 2012, p. 79). In the spirit of 'looking out', and for the purpose of design research, I adopted the position of designer-as-participant observer. This position builds on a long-standing association of design and ethnography. While my research is not purely ethnographic, I refer to Anna Harris' defense of the artist (and by extension, the designer) as participant observer in the field of medicine – a legitimate contributor to an understanding of that field from outside the social sciences (2008). In several ways, my research builds on the work done by Elizabeth Hallam, in her study of the in-house design of anatomical models at a Scottish medical school, and the learning exhibited by students through interaction with those models (2013). She notes that there is one material to which educators repeatedly turn as a convenient and effective tool for conveying difficult anatomical relationships: a piece of yellow 'hook-up' or electrical wire which the student inserts through foramina in a plastic skull. A comparison can be drawn between the piece of wire and a 3D QTVR, in that both media serve to further understanding through direct manipulation. Another comparison can be made between the medical school

and the hospital, in that both contexts provide similar cues to discussion, such as reference to film studies to explain a pathology. More importantly however, is the similarity between these environments with regard to the siloing of information within their walls. Manipulable cues to discussion, at a level appropriate to medical professionals and specialists, are rarely found outside the walls of medical institutions. The difference between the designer and the ethnographer is the demand for creative disruption from the designer, and an accounting of that disruption in a way that is measurable and culturally significant (Krippendorff 1995).

Murphy and Marcus draw strong ties between design and ethnography, describing both as "product and process" and "anxiously people-centered". They warn however, that "both fields often fall victim to a tendency toward abstraction—for design on the process; for ethnography in the product—and thus a removal from material realities, despite the seemingly self-evident attunement to observations of real-world conditions" (Gunn et al. eds. 2013, pp. 258-9). The conventional safeguard against such abstraction in design is multiple user testing across demographic groups. In the case of a specialist research registry, such a safeguard is unlikely. However, our answer may lie within the role assigned to the productobject at the heart of the design process. In her analysis of the use of drawings by engineers to coordinate participation and distribute tacit knowledge, Kathryn Hendersen describes such drawings as boundary objects, "A boundary object allows members of different groups to read different meanings particular to their needs from the same material. This is possible because the material remains flexible in group use and more focused in individual site use." (1991, p. 450), My research borrows from Henderson in that my interface prototype came to represent the boundary object for two separate user groups. Just as Hendersen's engineers must communicate across role- and site-related boundaries through a drawing, so must the neuroradiologists at two different hospitals communicate through a prototype, agreeing and disagreeing on the intent and accuracy of its representation.

Throughout this study, there is an assumption of user motivation. I am conscious of Krippendorff's definition, "Extrinsic motivation derives from using something as a means to an end. The desirability of this end then motivates the means' use. ... Intrinsic motivation

stems from using something for its own sake, from interactive involvement regardless of possible gains." (Margolin and Buchanan 1995, p. 168). He goes on to add that they are not mutually exclusive, with gameplay being a prime example of mixed motivation for interaction. In the context of my research, all user interaction might be considered mixed but is likely extrinsically motivated, that is, by factors from beyond the design of the registry, but varying in their degree of altruism, interest in publication or dedication to research.



Methods



The purpose of this study was to design the interface to a registry devoted to research on aneurysm treatment. The design would be based on observations of and communication with neuroradiologists at two medical centres in Toronto, Ontario, over a period of seven months. Workflow and prototyping sessions were video recorded (see below). The project timeline is shown in Figure 2. My approach to data gathering, both for the registry and for feedback on interface prototypes, followed the recommendations of Randal et al. in their defense of interaction analysis and conversation analysis for investigating problems underlying 'control room technologies' (2010, pp. 78-88). Imagine a neuroradiology department as a control room, wherein conversation with experts represents replicable data, and design-related concerns circumscribe an 'appropriate granularity of findings'. Conversation analysis uncovers tacit knowledge, while interaction analysis uncovers gestures, gazes and semi-tacit knowledge. The registry was to represent an extension of the workplace, and for this reason it was necessary to see how the potential users construed and managed their work. It was also necessary to see how prototyping the registry interface would enhance shared meaning making, a phenomenon

more often ascribed to talk than to interaction. My role as designer/ethnographer was to act as a bridge between existing technology and 'real world' use, as defined by potential users (Randal et al. 2010, p. 165).

Background observations had revealed that neuroradiologists will scroll through a series of consecutive cross-sectional images, rather than refer to a single key image, when making or confirming a diagnosis. It was therefore important to feature scrolling as function of the interface for the registry. This interactivity required that studies be collected in their entirety, such that they could be edited to within a narrow range of images representing a 'window of discovery' onto the aneurysm.

A hospital's radiology archives are stored in its Picture Archiving and Communication Systems or 'PACS'. The PACS represents the most objective and secure source of patient information available in the hospital. It is a secure repository accessed via networks of local servers located in the various radiology departments throughout the hospital. Data acquired from a scanner or X-ray machine is sent to PACS by the control room technician, and data from a hospital's PACS is in turn sent to provincial archives for permanent storage. In preparation for data collection, Dr. Symons selected 100 of the most recent aneurysm cases from the SHSC PACS, and assigned them to a virtual collection within the neuroradiology department network. This collection could be accessed from one of three resident workstations within the department, using a pre-assigned login (Figure 3).

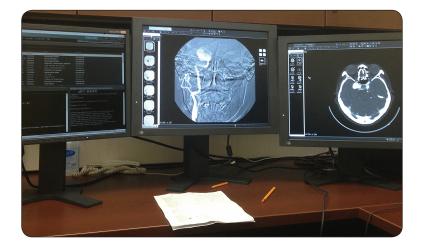


Fig.3 Radiology suite workstation

The term *workstation* highlights the relationship that radiology staff have with the data they access, input and manage. Each CPU represents a designated access point to a part of the hospital's server network, from which pre-assigned patient information streams can be reviewed and supplemented, but not altered or saved separately. The software used for data collection was the SHSC radiology viewing application, AGFA Healthcare's IMPAX® Data Viewer. IMPAX® exports case studies in either .avi or .jpg format, in one of three resolution settings. However, studies of over 100 images require .avi format to preserve the anatomical order of the images. Studies were anonymized prior to export and saved to an encrypted hard drive. As an added security precaution, only workstations designated to neuroradiology staff (as opposed to residents and fellows) permit the download of reports in an editable format (.pdf). From the point of view of the registry's search function and textual content, the diagnostic report companion to a study represented a 'pure', unedited source of keywords. To collect these reports, access to a staff workstation had to be arranged.

The objective of data collection was to provide a sample of images representing the initial presentation, intervention strategy, outcome and follow-up assessment for each patient. At this point, it is worth reviewing the typical course of treatment for an aneurysm patient. From a clinical perspective, there are two types of aneurysm presentation: ruptured and incidental. Ruptured aneurysms require an urgent course of action culminating in an intervention of which the patient is usually unaware (Figure 4).

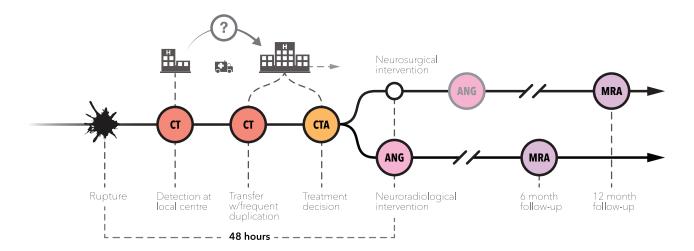


Fig.4 Course of treatment for a ruptured aneurysm (see p. iii for acronyms)

A Computed Tomography or CT scan is performed at the nearest emergency department, to detect the extent of blood leakage in the brain. If an aneurysm is thought to be the cause, the patient is transferred to a 'major centre' for treatment. Films from the first centre may or may not be available at the second centre when the patient arrives, and a second CT scan is often performed. Once blood loss is controlled and intracranial pressure is equalized, a CTA is performed to find the aneurysm. A CTA is a CT scan during which a radio-opaque contrast agent is injected into the cerebral arteries. The vessels then appear much brighter than the surrounding tissue: abnormalities in their shape become detectable. Once the aneurysm's location, size and shape have been verified, an informed decision can be made as to how to treat it. If the aneurysm is to be clipped, then the skull must be opened, requiring the skills of a neurosurgeon. If the aneurysm is to be packed with coils and thrombose, then the skull is preserved and the skills of a neuroradiologist are required. In either case, Angiography (ANG) is the modality of choice for visualizing intracranial treatment. Like CTA it detects radioopaque injection, but through fluoroscopy, which produces real-time images. A Magnetic Resonance Angiogram or MRA is the modality by which a patient's follow-up studies are performed. MRA images do not produce the same degree of clarity as CTAs but give adequate information while not exposing the patient to further radiation.

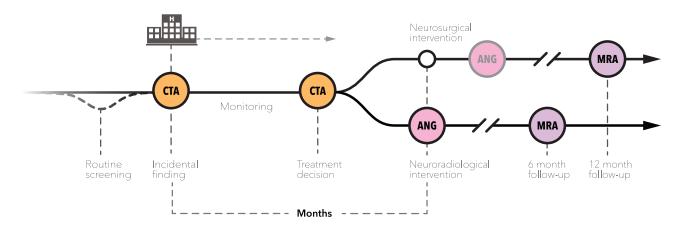
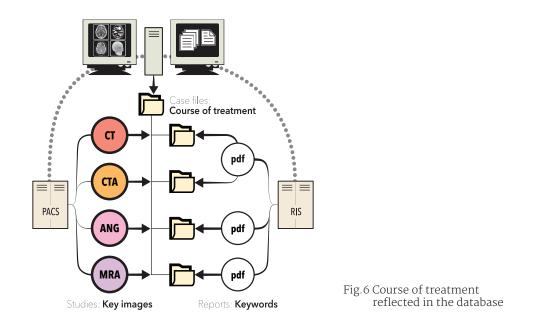


Fig.5 Course of treatment for an incidental finding (see p. iii for acronyms)

An incidental finding of an aneurysm results from a routine examination, performed due to indications like high blood pressure, family history or kidney disease. While not urgent, an incidental finding requires monitoring and eventual treatment (Figure 5). The difference here is that CT scans of intracranial hemorrhage are absent, and MRAs are far less likely to show degenerative changes in the brain. By and large, these two courses of treatment require the same types of studies in the same sequence. For the aneurysm registry to offer meaningful reviews, it needs to present each stage of this sequence, meaning a selection from the CT, CTA, ANG and MRA studies (often more than one) for each case (Figure 6).



As previously observed, 3D QTVR files play a primary role in decision support for aneurysm treatment. It was therefore important that QTVR files be featured for every case in the registry. Unfortunately few of the selected cases included QTVR files, and the existing files could be exported in QTVR format (.avi files would require disassembly and reassembly of hundreds of images per case). I volunteered to create the QTVRs as a means of familiarizing myself with the post-processing software used to generate the files as well as to ensure a consistent appearance for these files. The generation of 3DVR models from scan data is referred to as post-processing, an activity that, for licensing reasons, requires a designated workstation. Studies are downloaded through a link to the department network, enabled in my case by Dr. Symons' authorized and pre-selected collection of studies. Due to circumstance, the workstation available to me was located in a quiet CT scanner control room down the hall from the department. This workstation was a common point of access for post-processing and did not require secure login.

The platform used for post-processing was GE Healthcare's Centricity[™] software on a Dell[™] Precision T5500 workstation. CTA studies were considered the ideal source for QTVR data, since they offer the clearest representation of the size, shape and location of the aneurysm prior to treatment. A 3DVR is generated from a CTA through detection of a differential in Hounsfield units. Difference on the Hounsfield scale also appears as a difference in luminance value on display. Subsequent to the injection of contrast into a patient's cerebral vasculature, a higher luminance value is detected in the vessels, relative to surrounding tissues, and this difference is captured, to be processed later as a volume representing the shape of the vasculature. The density of bone lends it very high Hounsfield units, so bone always appears in 3DVRs of CT scans. Although CT scans are seen in cross section, the data is volumetric. In fact, the entire volume—up to 10 GB of data—can be fully restored at any moment, no matter how much time has been spent creating a render. Meanwhile one's working impression toward the end of a render is one of handling a very small portion of study data.

The objective in creating a 3DVR is to provide a macroscopic view of the aneurysm for an immediate grasp of its dimensions and orientation. Tailoring the 3DVR is achieved by masking information from view, a process which appears subtractive and is termed 'Cut Inside' or 'Cut Outside' on the platform's interface. A clear view requires 'cutting away' vessels and bone to within the vicinity of the aneurysm. Vicinity is a matter of judgment but should include enough information about the course of both the source and tributary vessels to aid the user in planning treatment, and to provide balance for a central focus in the QTVR. Clean 'cutting' (absence of jagged edges) is best achieved when the render is aligned with the standard planes of section (e.g. axial, coronal and sagittal planes). A breakdown of the steps involved in generating a QTVR is shown in Figures 7 and 8.

Saving options were limited and confusing. One cannot alter or substitute source data: my work could be saved to PACS in addition to source data, as part of the patient's file, but

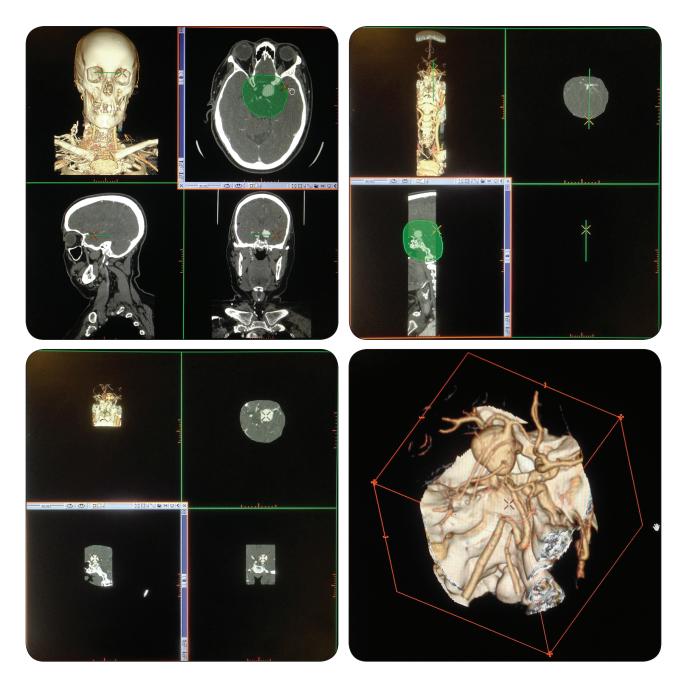


Fig.7 First steps in post-processing a CTA study. The process is most efficient when 'trimming' begins in a standard plane of section, proceeds to the other planes, and then addresses a simplified 3DVR.

only in .avi format. QTVR files could not be saved to PACS through Centricity[™], but could be exported to either a pre-authorized HTTP or FTP channel, an optical disc or, surprisingly, an external USB drive. Files were then transferred to the encrypted hard drive and deleted from the USB drive (see Figure 9).

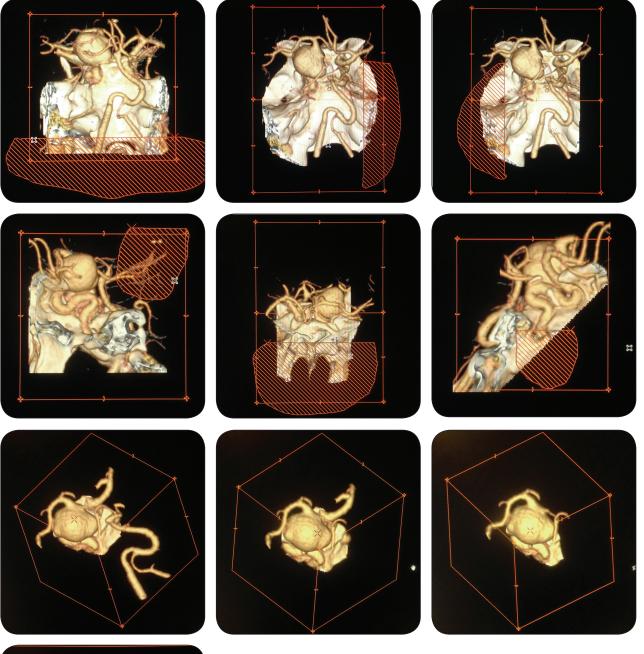




Fig.8 Final steps in the post-processing of a CTA study. Enough bone and extraneous vessels are removed to allow an uninterrupted view of the aneurysm from as many angles as possible. 'Trimming' in standard orientation planes, such as anterior, superior and lateral produces the cleanest results, the fewest jagged edges.

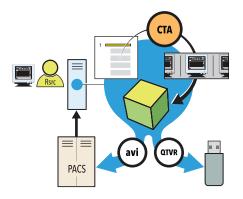
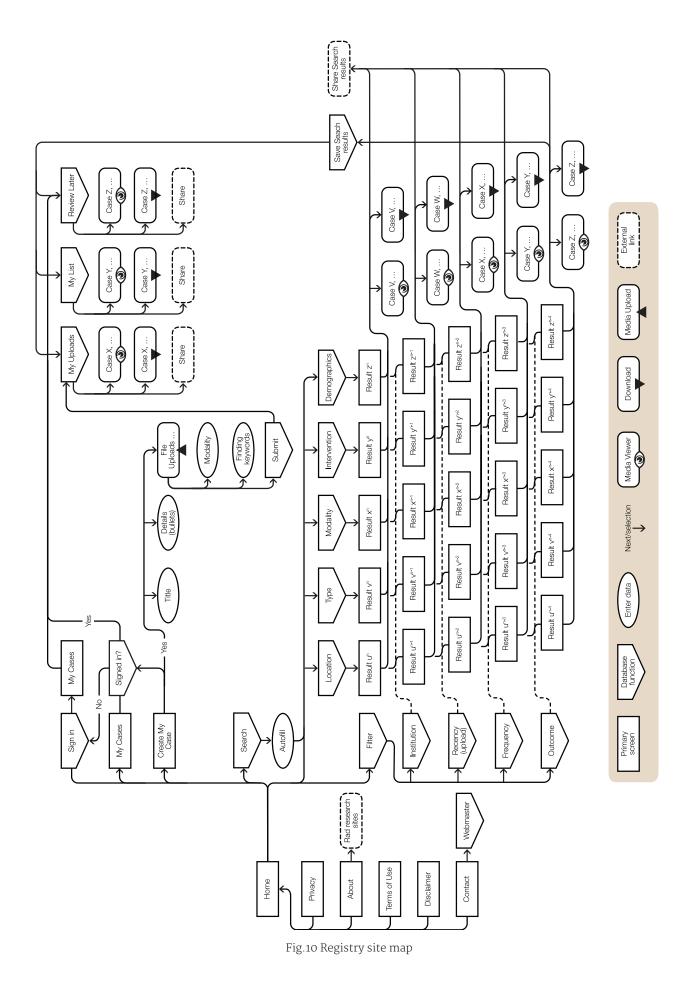


Fig.9 Post-processing workflow

Search terms and search strategies for the registry became clear as case reports were downloaded and briefly reviewed. For example, aside from whether or not an aneurysm has ruptured, its treatment depends largely on its shape and location, therefore 'shape' and 'location' are essential search categories. Other categories considered useful were: demographics (gender and age being permissible), modality (e.g. CT, CTA, Angiography, MRA) and intervention or treatment type. Cross referencing was also an important consideration. A schematic outlining search categories and the presentation of search results was emailed as a PDF to Dr. Symons and his colleagues Dr. Peter Howard (SHSC) and Dr. Aditya Bharatha (SMH) for their feedback (see Appendix B). Responses were not forthcoming. I nonetheless created a site map, based on recommendations from Goto et al. (2005), to assist myself in understanding how the registry should perform (see Figure 10).

Building on Colin Ware's exploration of perception (2008), an attempt was made to create meaningful button iconography for the interface. I presented a number of drawings to Drs. Symons, Howard and Machnowska at SHSC. Following these meetings, I translated the drawings into various digital iterations of button icons. These iterations differed through the character of their line work, edges and visual density. To investigate whether speed of recognition could be related to these differences, I presented the icons in an interactive PDF, by email to the aforementioned. See Appendix B for a copy of the PDF. Responses to emails were not forthcoming, despite mild entreaties.

In mocking up the interface, I referred to various sources. In his work on distributed cognition and visual design (2004), David Kirsh notes that workflow cues operate most effectively in an environment of structured visual elements and hidden metadata (i.e. in the



form of data tips). Lopes et al. (2010), in designing an epidemiological data management platform, highlight the importance of auto-filling and dropdown menus populated with controlled vocabularies. Helpfully, in her book *Designing Interfaces*, Jenifer Tidwell presents a comprehensive analysis of website patterns: "structural and behavioral features that improve the 'habitability' of something ... they make tools more useful and usable" (2011, Preface xviii). As Tidwell describes them, patterns relevant to the registry include:

| • breadcrumbs | \cdot clear entry points | • input prompt |
|--------------------|----------------------------|------------------------------------|
| • dashboard | • deep-linked state | \cdot feature, search and browse |
| • hover tools | • modal panels | • picture manager |
| • print preview | • sign-in tools | • smart menu items |
| • tool & data tips | • two-panel selector | |

For example, 'tool tips'—the standard mechanism for ensuring that users understand the function of a customized tool or button icon—are shown on various pages in the prototype. 'Sign-in tools'—fields that serve to login and identify the user—are represented in 'Sign up' and 'Sign in' panels. 'Smart menu items' are represented by pre-populated pulldown menus and 'modal panels' are represented by numerous pop-up windows. Those most important to this study are 'feature, search and browse' and 'picture manager'. There are numerous examples of these patterns in the commercial realm, such as *Amazon.ca* or *FutureShop.ca*, and I was able to adapt them to the registry interface in ways that are novel to the world of medical research.

Radiologists define patterns as edge detection, and pattern recognition as the ability to diagnose: I did not refer to patterns in my discussions of the interface with them. But given that this group, as users of the registry, would bring a high level of performance expectations and habituated behaviours to the interface, it was important to consider their image Viewer application as a source of these expectations. Using IMPAX® as a representative example, such expectations would include dark backgrounds (to prevent visual distraction from subtle variations within an image), modular panels and windows, and the ability to view an image at high resolution. While much of the functionality of a Viewer would not be replicable,

simulating some functions in the interface would likely help validate the registry. For example, IMPAX® presents all of a patient's available studies as a series of thumbnails aligned in a vertical sidebar. The order of these thumbnails can be arranged according to preference, but a chronological order is standard. I adapted this 'pattern'—representing a single case as a vertical column of thumbnails—to the interface, with great success.

Nelson and Stolterman describe graphologue as "to let a thing be seen through its 'image' " (2012, p.134). A Graphologue is the act of conceptualizing through visual communication between parties, a third stage in the process of design communication. These phases begin as conversation between engaged stakeholders, which progress to dialogue, and then to graphologue, before progressing further to iteration or implementation. As a step toward meaningful iteration, I created prototypes of an aneurysm website and tested their effectiveness—described below—as a graphologue with representative users.

The prototypes were created using Adobe® Illustrator® CS6. They consisted of printed copies of the major pages and panels of the interface, along with rollover tool tips, data tips and input prompts, trimmed and pasted onto boards and strips of tracing paper. The boards were constructed such that user interaction could be simulated by flipping 'panels', 'menus' and 'pop-up windows', or by presenting a new page, in response to the pointing to, or touching of, the image of a button or data field. The pages presented were: a) the Home Page, b) the Selected Cases page, c) a Single Case page, d) various Image Viewer pop-up windows, e) the Create a Case page, and f) the personalized My Cases page.

At the beginning of each prototyping session, I briefly explained the nature of the proposed registry and asked the participant to treat the prototype as if it were an active website. I then presented the Home Page board. I observed the pauses and gestures of the participants, and noted their comments. Initial prototyping sessions were held with 'lay' participants: an architecture graduate, a developer and a nurse. While not representing end users, they nonetheless provided valuable feedback in preparation for end user sessions. Figures 11 and 12 show a number of pages from this stage of iteration. My focus then was on pulldown menus and a scrolling textual sidebar for search results. Pages included input

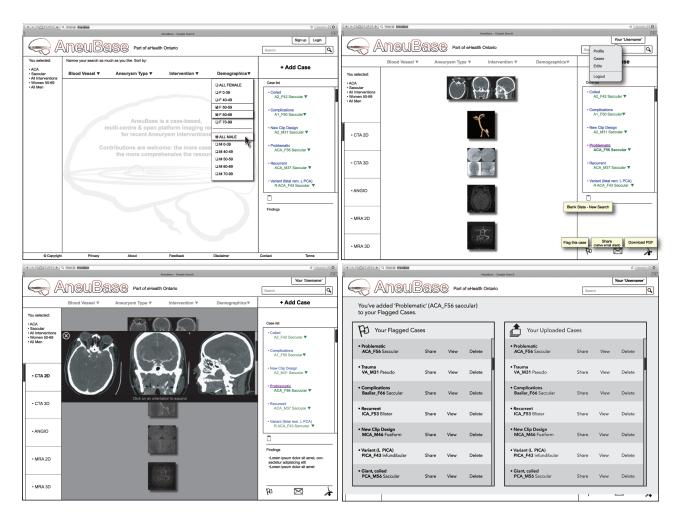


Fig.11 Sample pages from the interface prototype presented to 'lay' users. Moving clockwise from upper left: filtering search, search result, 'Flagged Cases' page, scrollable CTA pop-up.

prompts and grouped button icons for sharing, printing and flagging. iPad versions featured graphics based on previously developed icons and enlarged buttons and selectable areas to accommodate fingertips. Nonetheless, Home Pages were characterized by a prominence of wasted real estate. The 'My Cases' concept page was inspired by both commercial (*YouTube.com*) and research (*radiopedia.org*) websites.

The revisions that followed the initial sessions included a re-working of the Home Page to include a commercially inspired 'feature, search and browse' pattern, with 'Recently Uploaded' and 'Most Troublesome' given prominence as topics. 'Intervention' types were added as a search filter. The 'Selected Cases' page was replaced with a graphics-rich selection of columns reflecting individual cases. The 'My Cases' page was simplified and enlivened



Fig.12 Sample pages from an interface prototype presented to 'lay' users. From left to right: filtering search (iPad version), sharing a case's CTA (iPad version).

with key image thumbnails at the head of each case row. The 'Case Upload' page featured an input field for a title and radio buttons for allowable patient information, including type of intervention and aneurysm. Almost half the 'Case Upload' page was devoted to file upload, including fields for drag-and-dropping graphics files, and for entering modality acronyms and brief descriptions as file extensions. A statistics/analytics dashboard was added to the right-hand side of several pages, as a way to investigate the nature and extent of information that clinicians might expect from the registry. These revisions produced Prototype 1. Examples of the revised pages are shown in Figures 13 and 14.

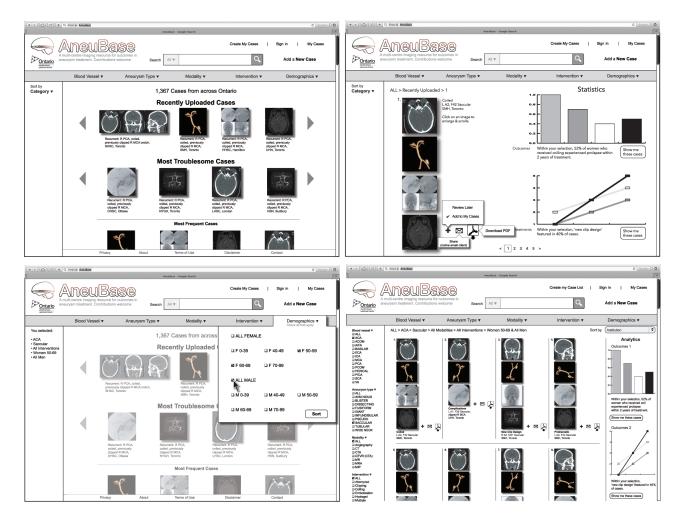


Fig.13 Sample pages from the interface prototype presented to end users. Moving clockwise from upper left: home page, selection from 'pre-sorted list', selecting by category, result of a filtered search.

Prototyping sessions were then arranged with two groups of clinicians, representing end users. I have already mentioned Alac and Hutchins and their study of videotaped interactions between scientists using visual communication (2004). I adopted their strategy and with the assistance of Professor Bill Leeming, gained permission to videotape the participants in their offices. The first three sessions included Drs. Symons, Yeung and Howard (separately) and were held at SHSC on January 31, 2014. Each session took approximately thirty minutes. The fourth session included Dr. Bharatha at SMH and was held on February 10, 2014. This session, together with an impromptu meeting with a colleague, ran over two hours. During these sessions, Professor Leeming took notes, as did I when opportunities arose. After each session, we debriefed and compared notes.



Fig.14 Sample pages from the interface prototype presented to end users. Moving clockwise from upper left: scrollable CTA pop-up, QTVR pop-up, 'My Cases' page, 'Create Case' input page.

Some of the participants' selections required a compromise solution, since not every piece of implied content could be efficiently simulated by the prototype. In such cases, I explained that I was presenting the closest available example of a result to their selection. To ensure that key concepts were addressed, I presented certain boards even when the user's navigation strategy had not directed him to them. Interaction with and reactions to these boards were duly noted. Photographs of the paper prototypes that were used in the sessions are reproduced in Appendix C.

Most notable were reactions to the Case Upload page. This page features a Title field followed by radio buttons grouped by patient data, intervention type and aneurysm type. 60% of this page's real estate is devoted to File Upload, with a Choose File button (implying a hard drive browse function), a drag-and-drop field for specified file formats, a Modality field and a Comment field for associated notes on findings and outcomes. For every file, there is an Upload button. At the end of each section, there is an option to cancel the process (see Figure 14, lower right). The layout offers easy options for data entry, and users brought forward their knowledge of treatment procedure, the time required for data entry and file export from PACS, and of the duplication of efforts to administer patients in a group practice, in their criticism of the layout. These comments are detailed below in Observations.

In response to reactions to the Case Upload page during session four, which included a discussion of departmental patient tracking problems, I built Prototype 2—a browserenabled interactive wireframe—using Adobe® InDesign® CS6. This rudimentary wireframe 'sketch' represents a multi-purpose data feed for the registry: a modified Electronic Medical Record (EMR) application that would collect data while providing patient management and missed appointment alerts. Features include buttons and responsive disclosure fields grouped according to the medical indications as described in discussion. Also featured are a monthly calendar for reviewing appointments, a hover tool for reviewing scanner suite schedules, multiple links and cues for contacting assistants and colleagues, and a 'Print Report' icon. Most importantly, the medical-legal 'hook' for engagement, in the form of a missed appointment alert, was represented on the desktop. To present the wireframe, I arranged another round of sessions with users at both centres. These sessions were reduced in scope relative to the earlier sessions: they were not videotaped and no third party was available for note-taking. I presented the wireframe as a walk-through rather than as a use test, to Dr. Symons (SHSC) on February 21, 2014 and to Drs. Bharatha and Julian Spears (SMH) on February 25, 2014. Reactions and comments were noted and later reviewed with Professor Leeming. Sample states from the wireframe are reproduced in Figure 15.

The features of Prototype 2 were included to represent not only medical data collection but also group practice dynamics and medical-legal requirements for patient follow-up (very important in aneurysm cases). Unlike the Case Upload page, these features had been determined not through familiarization over time but through granular discussions that

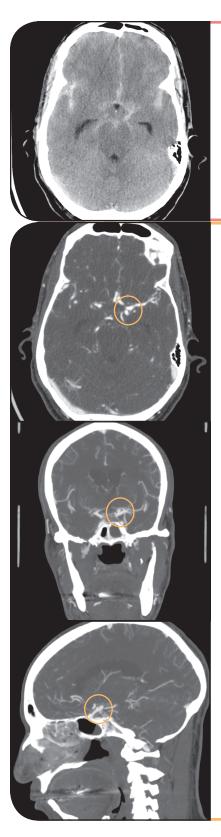


Fig.15 Sample states from a wireframe presented to end users. Moving clockwise from upper left: assigning the admission date, blood pressure control fields, 'No Show Alert' message, browsing the imaging suite schedules.

built upon this familiarization. The topic was pragmatic but assumed extensive background: at this point, my role as a designer was to remain engaged in the conversations through direct reference to specific functions in the prototypes. While my role during the first round of prototyping sessions was restrained, my role during the second round was more verbal, requiring a level of dialogue that demonstrated understanding of the illness, clinical practice and process of treatment.

Observations, Findings & Considerations

To illustrate the content of the database from a user's perspective, a sample case is presented on the following pages. The films belong to a patient who was brought to a local



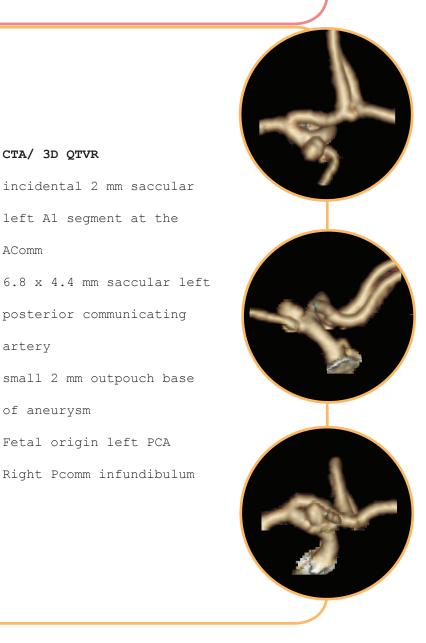
СТ

AComm

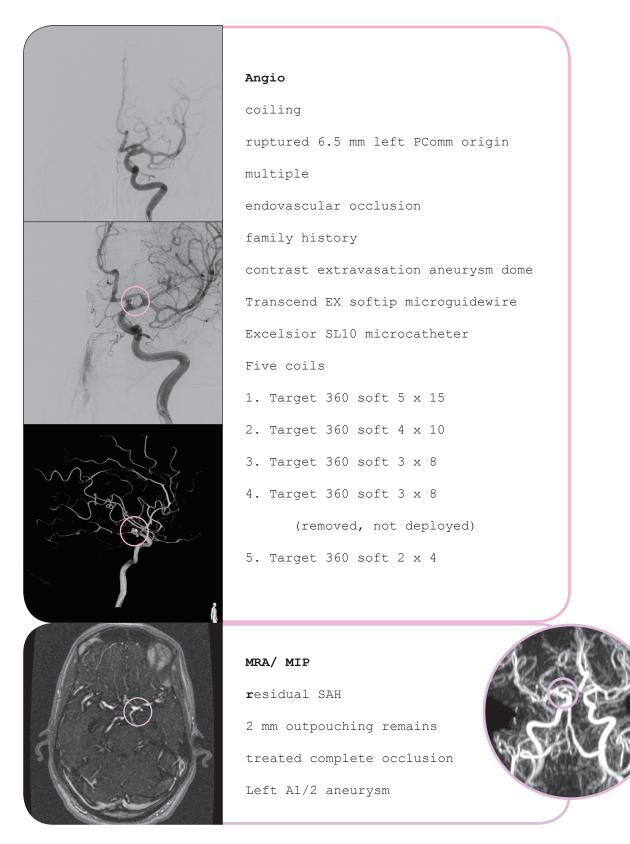
artery

of aneurysm

subarachnoid hemorrhage interventricular hemorrhage mild hydrocephalus



Emergency department sometime in the two past years. The keywords next to the films were taken from companion reports to serve as search terms linked to the film's file. They will also appear as bullet points in the footer of the file's pop-up window. The story behind the reports



and films is of a fifty four year-old man who presented with a sudden and splitting headache, with a family history of intracranial aneurysms. He was found to have multiple aneurysms but only one that had ruptured. The ruptured aneurysm was treated by packing with fine platinum

| Findings | Observations & Comments | Design Considerations |
|--|---|--|
| Habituation to workplace application | Quickly clicks through to large format graphics Assumes scrollable 2D graphics Assumes spinnable 3DVRs Expects deep level navigation between graphics Confused by 2x2 format for scrollable graphics Expects that content organization will mimic Viewer's sidebar overview tool Unclear where a case begins and ends | Strive for large scrollable pop-ups Easy navigation between pop-ups Avoid use of movie player formats 1x2 or 1x3 allowable for side- by-side presentation Organize content in columns to reflect typical hanging protocol Strong separators between columns Extra space at the bottom of every column |
| Focus on clinical practice | Does not respond to commercially inspired search options until prompted Does not move to Search field Refers to browsing as 'idle' Refers to content grouping as 'the patient' Confused by multiple cases shown together | Assume pulldown menus are the primary search filters Ensure tight visual association between a case's title and its uppermost study placeholder |
| Expectation of resources | Positive responses to pre-sorted lists, especially 'Recently uploaded' and 'Most challenging' themes Neutral responses to PDF report export function Downloading of images—especially those from outside institution— important for teaching purposes Frequent online searches for presentation-appropriate images Group practice patient tracking tool | Offer pre-sorted lists on home page, featuring most recently uploaded and most unusual or challenging cases Assume .ppt presentation as the user's final destination for content images Ensure easy download options for images even at pop-up stage Ensure informative titles, e.g. in the form of familiar acronyms Add accurate keywords to the graphic file extension Requires pivoting |
| Interest in sharing | Does not respond to commercially inspired 'personal channel' option, until prompted Expects limited sharing options— email client considered sufficient Social media seen as inappropriate forms of sharing information | Direct development resources to searching, cross referencing and graphics viewing functionality Provide deep links to native email clients Avoid social media links |
| Interest in contributing | Case Upload page requires more thorough input options Many cases are ongoing and develop complications: there may be a need to update an earlier contribution | Add pre-populated 'modality' pulldown menu to graphic file upload fields Enable user to add to and edit their personal case contributions |

Table 1. Observations, findings and considerations following sessions with Prototype 1

| Findings | Observations & Comments | Design Considerations |
|--|---|--|
| Interest in contributing (continued) | An interesting case is equivalent to a complicated case (e.g. trauma, unusual type of aneurysm, recurrence or treatment failure) The most interesting aspect of a case may lie in the details of its treatment strategy (e.g. type and length of framing coil) Inclusion of AVM cases in registry implies that certain types of treatment options, film studies and case outcomes will be searchable Too many steps and too much time required to upload a case Skepticism toward contributor motivation based on recent local evidence | Add fields to the Case Upload page that either compel or remind the user to include specific pieces of information regarding the case, its treatment procedure and its outcome. Discussion with neurosurgeons required to ensure adequate presentation of AVM cases Ease input with drag & drop and appropriately populated pulldown menus and autofill dictionaries Expect little user contribution |
| Interest in research | The likely biased nature of registry data lends any statistics/analytics associated with a search result dubious value Usefulness of statistics depends on: frequency of contribution, motivation of contributor (e.g. obligation v. interest) and granularity of information provided Distinguishes between retrospective and prospective research potential Presenting statistics/analytics in a dashboard separates the prospective from the retrospective research intents of the website and creates a focus for prospective research Requests visible dates of upload to demonstrate livelihood of website (referring to pre-sorted list on home page) Recency of upload implies recency of procedure Long-term outcomes highly prized information: recency by which older cases were updated is also important Current search strategies require a lot of UI: if serious research registry, then restrict searches to Boolean queries | If providing statistics/analytics, include disclaimer attesting to their bias and purpose as a searching aid Only control is through upload page If providing statistics/analytics, consider separate dashboard. Further research required as to appropriate content Ensure date of upload, or date of case update, readily visible for every case Chat line feature for advice or feedback on user's uploaded case Requires pivoting |
| Mobile use | Limited use of mobile applications for work Patient tracking tool mobile application | Develop the application for desktop Requires pivoting |
| Naming preferences | 'Aneu' prefix limits expectations Include 'neuro' and 'vascular' in the name to infer a broader but defined scope of content | • As per comments |

Table 1. Observations, findings and considerations following sessions with Prototype 1

coils, via a microcatheter that had been guided into the cerebral vasculature from the groin. The aneurysm was found to be bleeding during the procedure, due to patient movement and coughing, but stasis was achieved. A total of five coils were used: the packed aneurysm is visible in the second angiogram.

Our observations of user actions and comments are summarized in Table 1 (see pages 28–29). They are grouped according to themes that either emerged through presentation of the prototype or as a result of direct questioning: users' habituation to their native workplace application (e.g. IMPAX®), their focus on clinical practice, their expectation of resource provisions from the registry, their interest in sharing, contributing and conducting research, their use of mobile and finally their opinion regarding an appropriate name for the registry. An observation is paired with the design consideration most likely to resolve the problem being addressed. Observations and comments that reflect a general approval of the prototype are not summarized in the table.

As previously mentioned, a dashboard pattern had been added to the 'Selected Results', 'Selected Case' and 'PDF Report' pages, as a cue to discussion of users' expectations from the registry. Dr. Symons, who had initially indicated a need for a website devoted to aneurysms, was tentative in his consent to the dashboard because of the inherently biased nature of the website's self-selected content. However, the other three users expressed strong interests in information that extends beyond the presentation of images related to a search. These interests differed in their focus: for one user it was patient history, for another user it was the details and outcomes of treatment. It became important for me to consider the long-term nature of aneurysm cases and users' needs to update their case files as patients progressed or deteriorated. As one user said, "these people are followed for years". The last user's research interest was the cross referring of patient outcome data. This last focus speaks to a distinction between the two standard approaches to medical research, prospective (concerned with the future) and retrospective (based on the past). To be meaningful, both approaches require diligent contribution but of the two, prospective research is more relevant to procedural change. Most importantly, these two approaches require different tools to achieve their ends.

The aneurysm website was intended as a retrospective research tool: accommodating the first two user interests would be possible by allowing updates and edits via the user input and personal channel portals. Accommodating the third interest however, would require significant re-direction of intent. For the website to become a legitimate prospective research tool, a new set of input portals and search options, as well as a separate and fully articulated dashboard, would be required. Paramount to this tool's effectiveness would be a means of ensuring consistent input through greater integration into clinical workflow than a public website could provide.

With regard to the prototype's 'Case Upload' page, I found a very interesting difference between the reactions and comments of the two medical centres, as represented by their users. The SHSC users had not actively pursued the page during their sessions. Upon its presentation, their reactions to the page were passive, while at the same time recommending higher granularity of input. In contrast, the SMH user—Dr. Bharatha—actively sought the page but upon studying it, became highly skeptical of user participation in the website. This difference stemmed from efforts at SMH to launch—in the past two years and unbeknownst to me—an online registry of cerebral aneurysms! According to its author, Dr. Julian Spears, this registry is stagnating through lack of user participation. Surprisingly, the neuroradiology department at SHSC is aware of this registry and is considered a significant group of potential contributors. The skepticism from SMH with regard to 'Case Upload' is therefore understandable. As we discussed barriers to participation and the daily concerns of a neuroradiology practice, Dr. Bharatha recalled that his most pressing worry was missed follow-up appointments, due to their legal and health-related ramifications. He mused that a means of marrying irritant to altruism would likely lower the barrier before us, and we reviewed this idea during an impromptu conference with his colleague, Dr. Walter Montanera.

As described earlier, Prototype 2 was created and presented as a response to these discussions, and then presented on two occasions. My findings with regard to Prototype 2 are summarized in Table 2. Interestingly, these findings have parallels with those of Hendersen, concerning 'boundary objects' (1991) and of O'Malley et al., concerning physicians' use of

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| Findings | SHSC | SMH |
|-----------------------------|---|---|
| Research intent of registry | RetrospectiveKnown data valueEducational | Prospective Unknown data value Clinical trial prep |
| User base for registry | Generalist Residents Compromise position | • Specialist • Clinician • Clinical trial manager |
| Assumed level of engagement | VoluntaryRole-based accessInput prompts only | Guaranteed input Legal & group practice pressures Required fields |
| Tool use | • Public website | EMR application/ data entry Mobile alert Integration with Hospital Information System |
| Needs assessment | Existing resources Mimicry/ created need Capped purpose | Desideratum, a wishNo comparable productRegistry ultimate aim |

Table 2. Findings and considerations following sessions with Prototype 2

EMRs (2009). As a springboard for discussion and as a reference point for divided thinking, Prototype 2 was an ideal boundary object. Through their reactions to this prototype, Dr. Symons, representing SHSC, and Drs. Bharatha and Spears, representing SMH, articulated clearly distinct positions. Dr. Symons' department does not suffer the same workflow-related problems as does Dr. Bharatha's department, and he viewed an EMR tool as superfluous. He saw voluntary contribution to a registry as dependable and supported his view by showing me examples online (authored by radiologists or radiological organizations). He nonetheless conceded that these examples were generalist – intended for residents rather than for specialist users. He also conceded that a website devoted solely to aneurysms would not likely draw visitors: online resources in radiology feature dramatic or unusual examples from a wide range of topic areas. In comparison, Drs. Bharatha and Spears saw Prototype 2 not only as a positive step toward data gathering but also as a way to address patient management at a finer level of detail than previously discussed. In addition to the scheduling, alert and email integration functions that I had simulated in the prototype, the tracking of referrals and care, and the auto-generation of consultations and form letters were also discussed. This discussion took place with reference to sample letters and forms drawn from a patient folder on hand, and echoed many of the findings of O'Malley et al. (2009). Many of the findings from the prototyping sessions are summarized visually in Appendix D.

The discriminating factor between Prototypes 1 and 2 is their acknowledgment of workflow as a source of leverage for research contribution. Whereas Prototype 1 represents a direct response to the problem of an online resource, its input portal cannot be linked to a clinician's practice. Its data feed is thereby left to chance. On the other hand, Prototype 2 does not respond to an online resource directly but indirectly, by leveraging the time-consuming aspects of clinic management and by streaming the resulting input into a feed for a nascent registry. This registry's usefulness would thereby be guaranteed to grow. While the online presence of the registry implied by Prototype 2 is not as yet identifiable, its appearance would likely differ from Prototype 1, as the value of textual data relative to the value of image data would likely evolve with the iterative process.

Regarding the iterative methods used in prototyping, the paper-based method was effective at verifying the appropriateness, accuracy, organization and extent of the proposed content: session participants were inclined to study the boards carefully without encouragement. In contrast, the browser-based method was found to elicit comments regarding functionality and desired outcomes. In retrospect, an interactive 'sketch' may have been more useful as the initial prototype, though its success in session would have been contingent on earlier cooperation of the second site (SMH). As useful as these methods were, further iterations (Prototype 3 and on) will require the use of dedicated tools for database construction and design. Recent inquiry (Melo, personal communication) has provided some information about the dormant registry established by Dr. Spears. It is run via a role-based

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data capture service provided by Medidata Rave[®] (a Health Canada-approved, US-based company). As per Canadian law, the registry data is stored on-premise. The registry interface operates fifty forms with 644 fields, containing 839 variables and referring to seventy three separate dictionaries. Logic checks notice missed information and can trigger any of eighteen calculations depending on the entry. This represents a small number of data categories (twenty nine) relative to other medical conditions. Nonetheless, it is a sizeable amount of information to organize for fast and easy acquisition. Medidata's API accepts external XML data: continuing iterations of the data entry application should therefore include the use of relational data management tools that can export XML data, such as Microsoft[®] Access. Future and more mature iterations will likely rely on findings from a combination of iterative methods, including paper, wireframes, data forms, tables and queries, and coding in SQL.

Discovery, Reflection & Further Development

Following the Prototype 2 sessions, I was left with a choice: to pursue Prototype 1 to its live, if compromised iteration, or to pursue Prototype 2, with the ultimate aim of creating a fully fledged and self-sustaining version of the registry in the future. Given Dr. Spears' lack of success in his own endeavour, my first choice held little hope of user engagement or SMH participation. Nor was there promise of remuneration from SHSC or a third party. My second choice brings a guarantee of user engagement from SMH as well as a commitment of funds toward development, but implies that Prototype 1 and its associated database will not see further development in the near future.

In describing the desiderata assessment, Nelson and Stolterman distinguish creating need from examining desire. Desiderata is the expression of a client's original desire, but only dimly perceived. Once desiderata is articulated and examined, the development process that stems from it "reveals an understanding of purpose for this particular case and ultimately expands to include the general..." (2012, p.114). The transition from Prototype 1 to Prototype 2, together with its findings, was a process of articulating and examining desiderata. These desiderata were not those of my users (clients): their desires, while not always timely, were

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clearly expressed. They were in fact my own desiderata: as the ultimate client in this study, I discovered a desire to design meaningfully for medical research.

Nelson and Stolterman define stance as the challenge of overcoming one's point of view and listening filters, while arriving at a solution that is adequate to its problem. They closely associate stance with intention, likening paying attention in a particular way to aiming in a particular direction (2012, p. 65). The relationship of intention to adequate design is therefore as a process of choosing, not of reaching an end state: "... it is this judgment of intention that ultimately determines what direction or bearing the strategy of inquiry for action will take in any particular situation" (2012, p. 112).

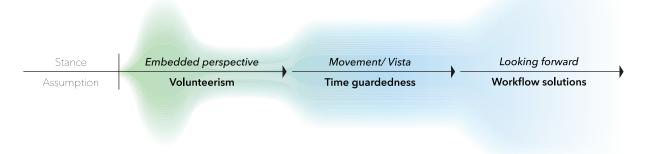


Figure 16. Stance and assumptions within and following the study (after Nelson and Stolterman, 2012)

The following paragraphs refer to Figure 16 which reflects my trajectory both within and following this study. This trajectory was unavoidably influenced by advice from the experts involved, due to the technological density of the subject area and working environments.

This study was initially intended as a response to a need, as expressed by an expert within an institution. The study's aim was to provide a task-based solution to that need. But a solution pre-existed, having been forgotten or deemed inadequate: the need remained embedded in the institution. The intention of the aneurysm registry, though broad enough to address the need, was itself embedded in the consequence of decisions that had been made with regard to Dr. Spears' earlier attempt, and in the assumption of volunteerism from users, whose contributions would be essential to the registry. I therefore refer to my stance during the design of Prototype 1 as a *confined* stance or an *embedded perspective*. The test of this perspective was in the migration of the study to another institution— SMH—with its own culture and history. This migration revealed a risk to which my assumption exposed the study—a risk corroborated by numerous observations—that time is the currency of exchange for an interface to any medical resource. Were the registry to be launched without a secured feed, and relying on the goodwill of busy practitioners, its purpose would not likely be fulfilled. At the same time, graphalogue at SMH revealed that another, indirect solution was possible. That a time–saving tool for daily practice could serve a research registry was a significant discovery for me. I therefore describe my stance during the design of Prototype 2 as one of movement, of re–positioning toward the future.

With respect to the future, the need for an active, multi-centre registry remains unmet. There are eight medical centres in Ontario currently offering endovascular treatment of aneurysms, including SMH and SHSC. Given that clinicians' practice management frequently fails to keep pace with technological advances (Croll 2010, Horan et al. 2006, Janols et al. 2010, Lapointe et al. 2006, O'Malley et al. 2009), it is likely that the neuroradiology departments at many of these centres are experiencing workflow-related needs similar to those at SMH. It is therefore also likely that space for innovation exists for an application customized to meet the needs of each of those departments.

I present Figure 17 as a model for design of such an application. The model implies that each department feeds the registry through a variant of a neuroradiology-specific EMR tool. While all applications make use of random number generation and image annotation blocking to ensure patient privacy, each variant provides a particular service for the department and interface with the registry, as dictated by department staff. For example, *EMR App n* (conceived in discussion with Drs. Bharatha, Montanera and Spears) is the 'Missed Appointment Alert' application previously discussed. It features patient tracking, mobile missed appointment alerts and form autofill. To do so, it requires the following input: WFNS Score, family history (positive or negative), smoking habit (rated) and presence of PKD (positive or negative). Output from the registry is in the form of metrics related to this input. Another example would be *EMR App n*⁺¹—conceived in part through discussion with Drs. Howard and Bharatha—an 'Aneurysm

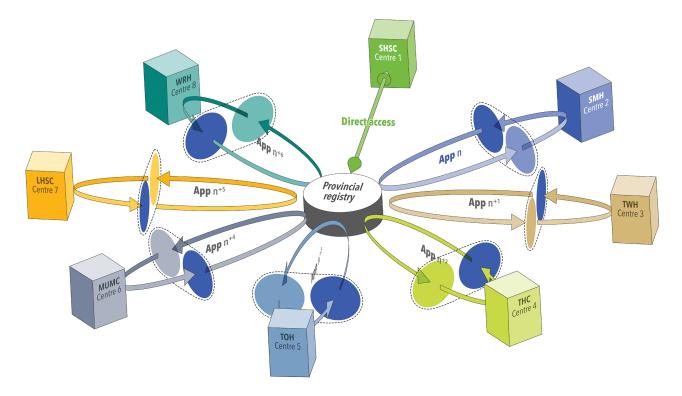


Figure 17. Design model for a multicentre workflow application suite serving as a feed/access tool to a medical research registry. See page iii for acronyms.

Consult' application. It keeps users abreast of new treatment options, patient outcomes and treatment durability through an RSS feed, while enabling sharing of this information within one's network. To do so, it requires input of a patient's treatment details (menu), follow-up assessments (menu) and a study thumbnail (optional). One last conception is *EMR App* n^{*2} , a 'Tomorrow's News' mobile application, which would borrow from the previous two applications, offering a natural language search of patients' images and follow-up schedules, and a chat line, to resolve last-minute conflicts between members of a group practice. Input requirements would include patient information (buttons and autofill), relevant history (menu) and a study thumbnail (required).

Establishing contact at the various centres would rely on their network of colleagues, much as the contact with SMH was established through the relationship between Drs. Symons and Bharatha. Medical centres are generally more interested in promoting their own endeavours than in sharing success. However, the needs of their neurovascular departments may overlap such that a workflow-enhancing application tailored to departmental needs may tip the balance in favour of multicentre contribution, provided that the data pool is shared. This tipping point would likely require a change in the management protocols for shared databases, to ensure non-duplication and non-competition of related efforts. Such a change could have a profound effect on the design of future research registries, by eliminating the delays and expense associated with the entry of data that has already been recorded elsewhere.

Since the leveraging of clinical workflow to instantiate and sustain a database can be adapted to many areas of healthcare, this model could apply to the design of *any* medical database which would benefit from the provision of anonymized, verifiable and related pieces of patient information. But the model begs a question: "Could a single application or suite of applications be developed for all eight centres, such that they could sustain an aneurysm registry with meaningful, timely data?"

Another development of the application would be to address the concept of meaningful data itself. Designing for clinicians could limit the nature of the data collected: re-interpreting 'meaningful data' in this case would require designing for a broader range of stakeholders than is represented by clinicians. By engaging nurses, primary caregivers and patients themselves at the interface stage of prototyping, the application could conceivably provide separate interfaces tailored to role-based login. Different user types would provide streams of data into separate but related and searchable matrices, all revolving around the need for comprehensive and ongoing outcome data for aneurysm treatment. For example, patient-derived data regarding headaches may be found to correlate with clinician-derived data, once a certain number of cases have been registered. With the current movement toward ownership of one's own healthcare data, patients' motivation to contribute may be high.

It is my intention to pursue the answer to these questions through the development of a patient management application for SMH (represented by Prototype 2), by maintaining my relationship with SHSC and if necessary, through future academic work that enables me to investigate and test the remaining six centres. While it is difficult to say how my stance will be re-directed over the course of this work, it is my expectation that its underlying desires—those of clinicians, researchers and myself—will be commonly held.

38

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Interviews

Dawn Marie King, CRO, St. Michael's Hospital, interviewed on October 18, 2013

Frank Garcea, CTO, St. Michael's Hospital, interviewed on October 28, 2013

Leon Goonaratne, CIO, University Health Network, interviewed on November 4, 2013

Magda Melo, Manager, Observational Epidemiology and Qualitative Research Unit, St.

Michael's Hospital/AHRC, interviewed on May 02, 2014

Embedded perspectives: Considerations for the design of a multi-centre research registry

Appendix A

REB Application, Consent Form & Questionnaire

OCADU Invitation Letter & Consent Form

Date:

Project Title: Design of an Online Research & Decision Support Tool for Neurovascular Intervention Procedures

Principal Investigator: John Harvey Masters Candidate Faculty of Design, Digital Futures Initiative OCAD University (647) 233-9966 jh12pj@student.ocadu.ca

INVITATION

You are invited to participate in a study that involves research. The purpose of this study is to design an online research & decision support website for neurovascular intervention procedures. The study is multi-site, involving participants from Sunnybork Health Sciences Centre and St. Michael's Hospital, Toronto.

WHAT'S INVOLVED

As a participant, you will be asked to provide career-related information, such as your place of work, years of practice and aspects of your work habits. You will also be asked to review designs and/or test prototypes for the website being built for the purpose of this project. Participation will take approximately 30-45 minutes of your time, ideally on separate occasions. Please see attached questionnaire for clarification. With your agreement, we would like to contact you again in 6-8 weeks to ask you another set of similar questions. You may decide at that time whether or not you wish to participate in that part of the study.

POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include increased knowledge dissemination, improved decision support and enhanced practice of neuroradiology. Possible publication in peer-reviewed journals may also provide an indirect benefit to the field. There also may be risks associated with participation: while your name is not recorded or reproduced anywhere in this project, information about your place of work and length of practice *could* possibly be used to identify you in publication.

CONFIDENTIALITY

Your name will not be recorded. Instead your participation will be recorded by way of a unique file number (e.g. '110713_1'). Interview data gathered will be stored on a password-protected hard drive in a locked office cabinet at OCAD University. Data collected during this study will be stored. Data will be kept for the duration of this project (through April 2014) after which time it may be re-analyzed by either the principal investigator or the faculty supervisor for the purpose of co-publication. Access to this data will be restricted to Peter Coppin, Bill Leeming and John Harvey (Principal Student Investigator and MDes Candidate)

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time, or to request withdrawal of your data (prior to data analysis during the Winter of 2013/2014), and you may do so without any penalty or loss of benefits to which you are entitled.

PUBLICATION OF RESULTS

Results of this study may be published in the student's thesis, presented at a regional design conference, or published in an academic journal (e.g. *Science, Technology and Human Values, Social Science and Medicine, Science Communication* and *Journal of the American Medical Association*). Quotations from interviews or user tests will not be attributed to you without your permission.

Feedback about this study will be made available to you by contacting the Principal Student Investigator: John Harvey (416) 423 6567

Jh12pj@student.ocadu.ca.

Should you decide to provide contact information, you will be sent a feedback letter following completion of the project.

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact the Principal Investigator (Peter Coppin) or the Faculty Supervisor (Bil Leeming) using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at OCAD University [insert file #]. If you have any comments or concerns, please contact the Research Ethics Office through jburns@ocadu.ca.

OCADU Invitation Letter & Consent Form

CONSENT

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: _____

Signature: _____ Date: _____

Thank you for your assistance in this project. Please keep a copy of this form for your records.

For the sake of interview recall and accurate representation of responses, I would like to take extra notes, audio record interviews and video record user tests, but only with your permission. Please indicate if you prefer **not** to be audio or video recorded:

No, do **not** audio record me (but video is OK).

No, do **not** video record me (but audio is OK).

Shortly after the interview has been completed, I may endeavour to verify the accuracy of our conversation and to clarify certain points made during the interview. Please indicate if you are willing to be contacted for this purpose:

Yes, I am available to confirm the accuracy of statements made during the interview. You may reach me by (choose preferred means):

Email: Phone:

OCADU Study Questionnaire_1/3 (participant background)

Date:

Project Title: Design of an Online Research & Decision Support Website for Neurovascular Intervention Procedures

Questionnaire #:

Confidential survey/questionnaire

All information you provide is considered confidential; your name will not be included or, in any other way, associated with the data collected in the study. However, with your permission attributed quotations may be used.

Yes, I wish to be attributed for my contribution to this research study. You may use my name alongside statements and/or quotations that you have collected from me.
(Name: ______)

- 1) Please provide your place of work______ and years of practice _____.
- To what extent do you rely on personal communication w/ colleagues to support your decisions? (est. %) ______. (range 1-5) _____.
- 3) How would you rate the efficiency/ effectiveness of this strategy?

(est. %) ______ (range 1-5) _____.

Related comments

4) To what extent do you use IT in your practice?

(est. %) _____ (range 1-5) _____

a. Do you use IT to help with decision making? (yes/no) ______.

b. If yes, how so?

5) What is your usual routine when diagnosing and preparing for an intervention?

6) Would you ever include an authoritative web-based search specific to your practice in your routine (assuming conditions)?

Would site mobility make a difference? _____

OCADU Study Questionnaire_2/3 (design interview)

7) As you consider the designs before you, please relate your impressions:

8) Please give your opinion of the functionality represented by particular design features:

9) What features are missing, unnecessary, or require greater emphasis?

10) Any other suggestions? Magic wand?

OCADU Study Questionnaire_3/3 (user test)

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11) As you consider the website prototype before you, please relate your impressions:

12) Please give your opinion of the functionality represented by particular website features:

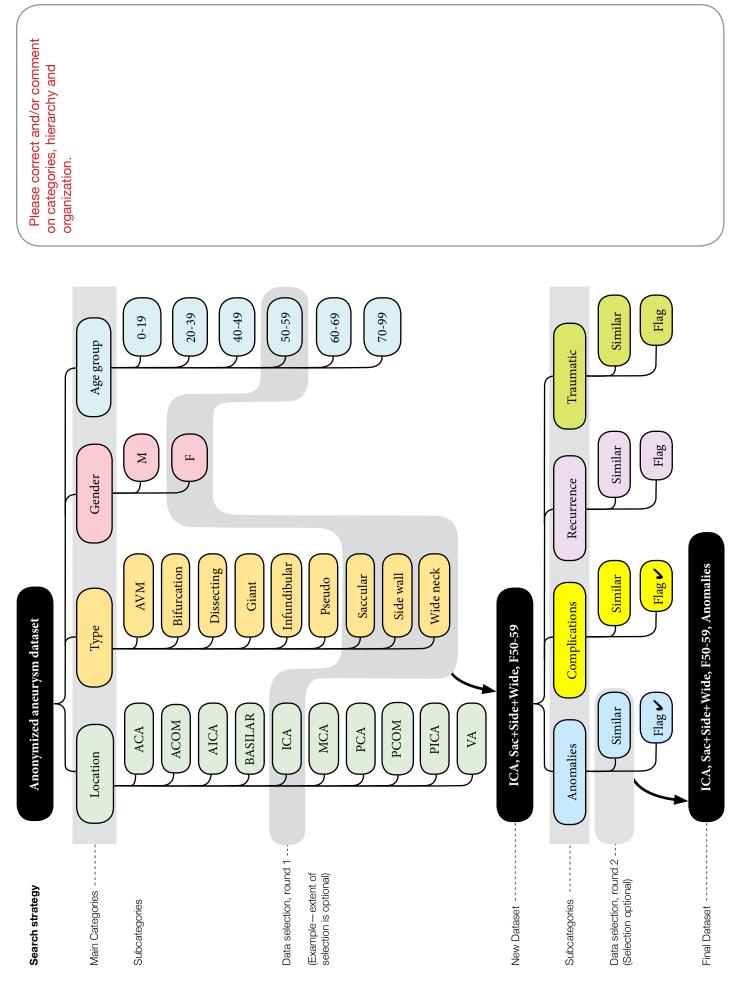
13) What features are missing, unnecessary, or require greater emphasis?

14) Any other suggestions? Magic wand?

Appendix B

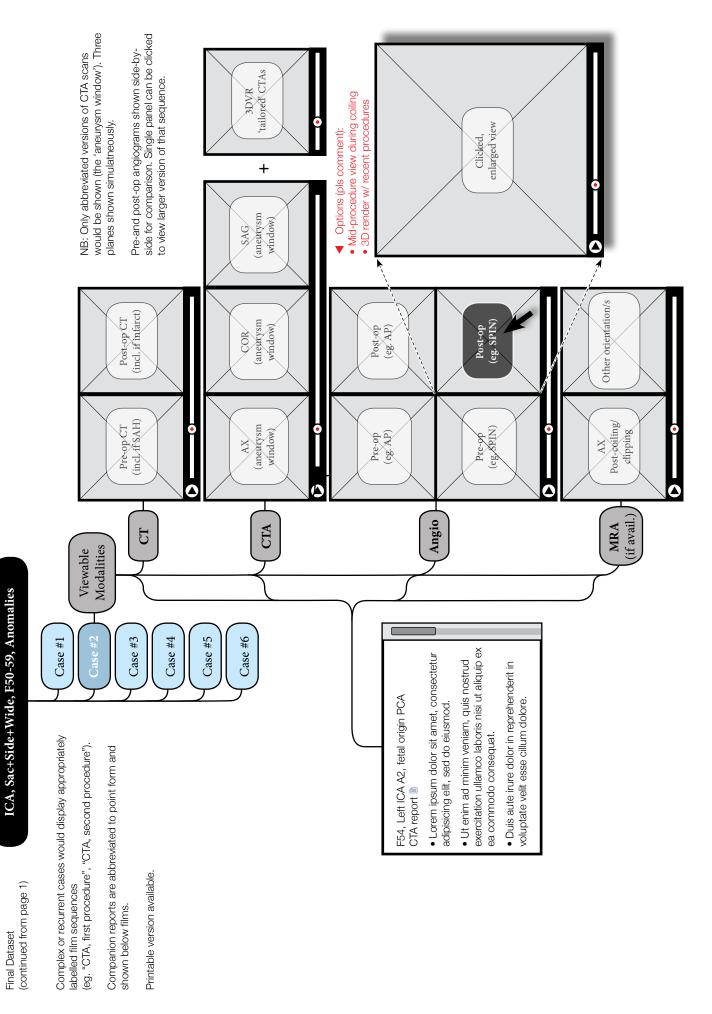
Supplementary documents (emailed PDFs):

Search strategy schematic and Button iconography



Cerebral Aneurysm Case-based Website Project (AneuBase), Content Hierarchy v1, p. 1/2

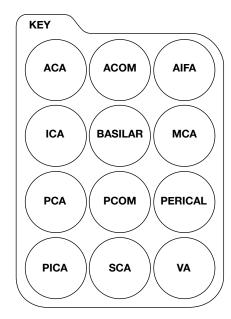
Nov. 5, 2013



Cerebral Aneurysm Case-based Website Project (AneuBase), Content Hierarchy v1, p. 2/2

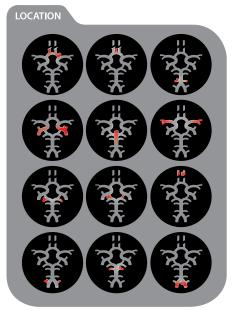
Nov. 5, 2013

AneuBase Icon Test — User Feedback

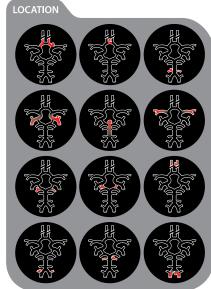


Please have a look at these icon groupings. They differ by style only: please note which one is best for distinguishing & understanding the icons.

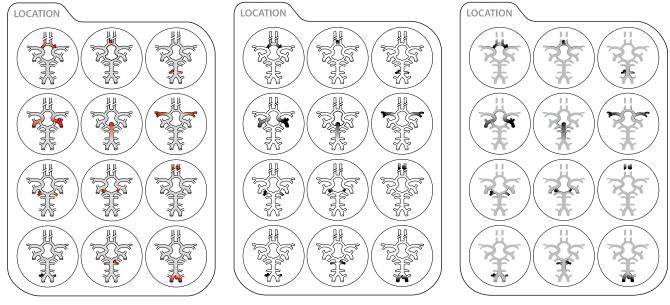
Please check the button for your preferred style. Feel free to make comments (e.g.: is something missing or unnecessary, difficult to interpret, etc.)



1) Comments:



2) Comments:

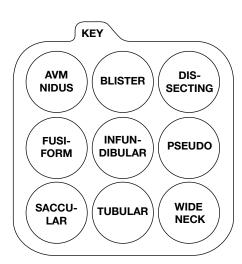


3) Comments:

4) Comments:

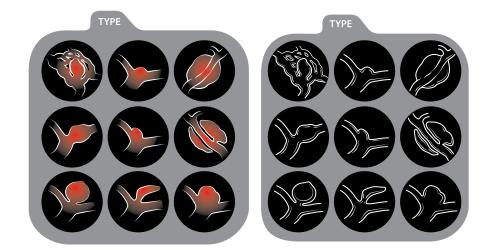
5) Comments:

AneuBase Icon Test — User Feedback



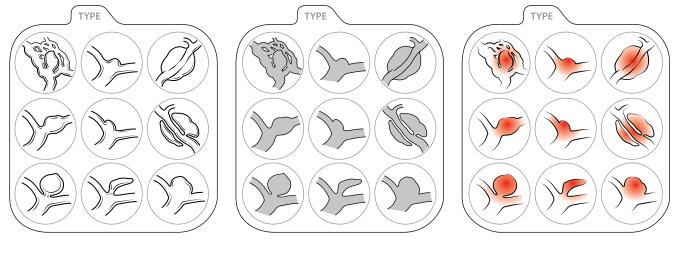
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Please check the button for your preferred style. Feel free to make comments (e.g.: is something missing or unnecessary, difficult to interpret, etc.)



1) Comments:

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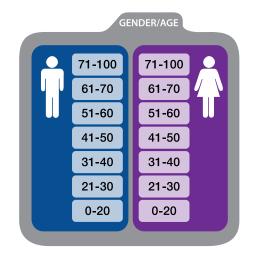
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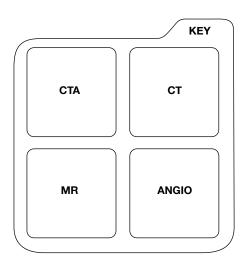
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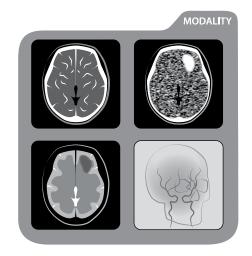
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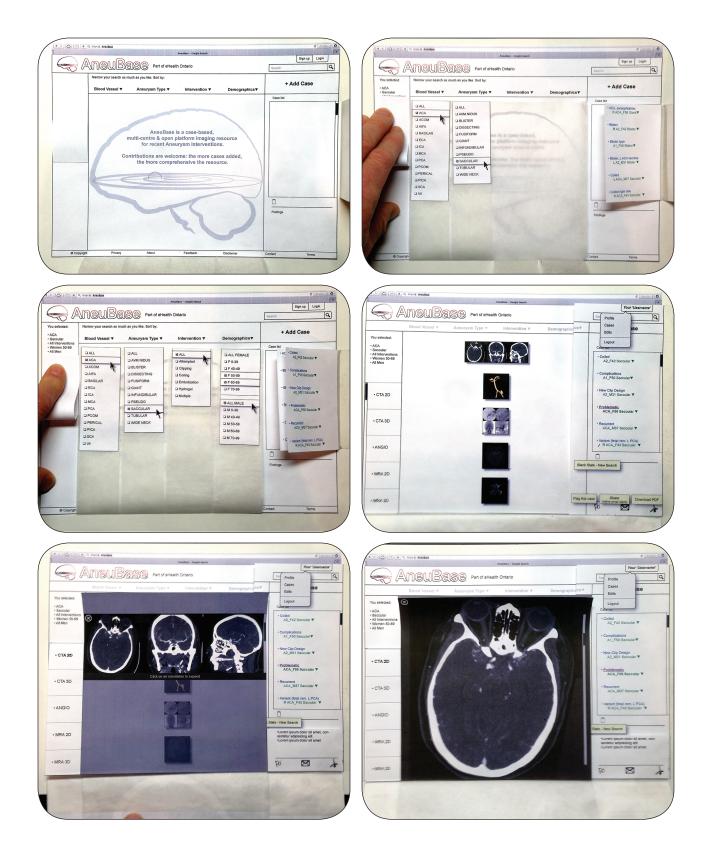
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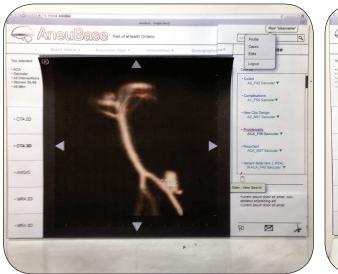
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Appendix C

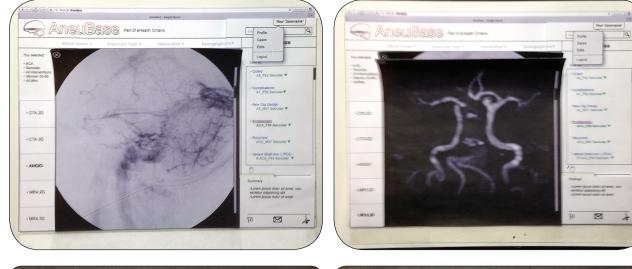
Prototyping documentation:

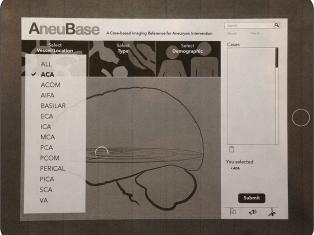
'Lay' iterations (p. 56), End user iterations (p.58) and additional Wireframe states (p. 62)



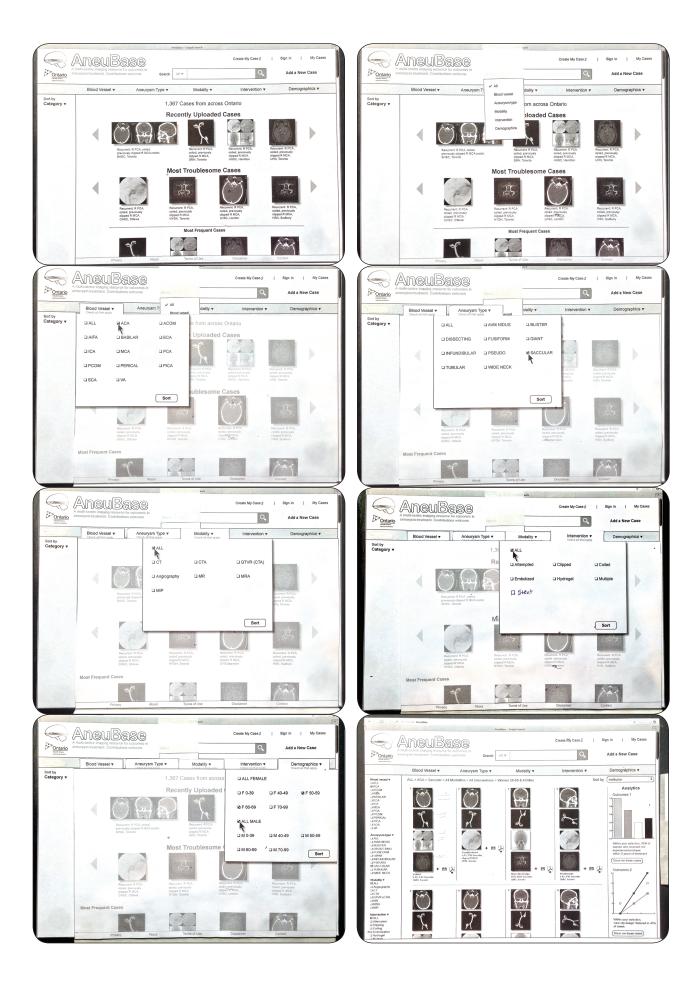


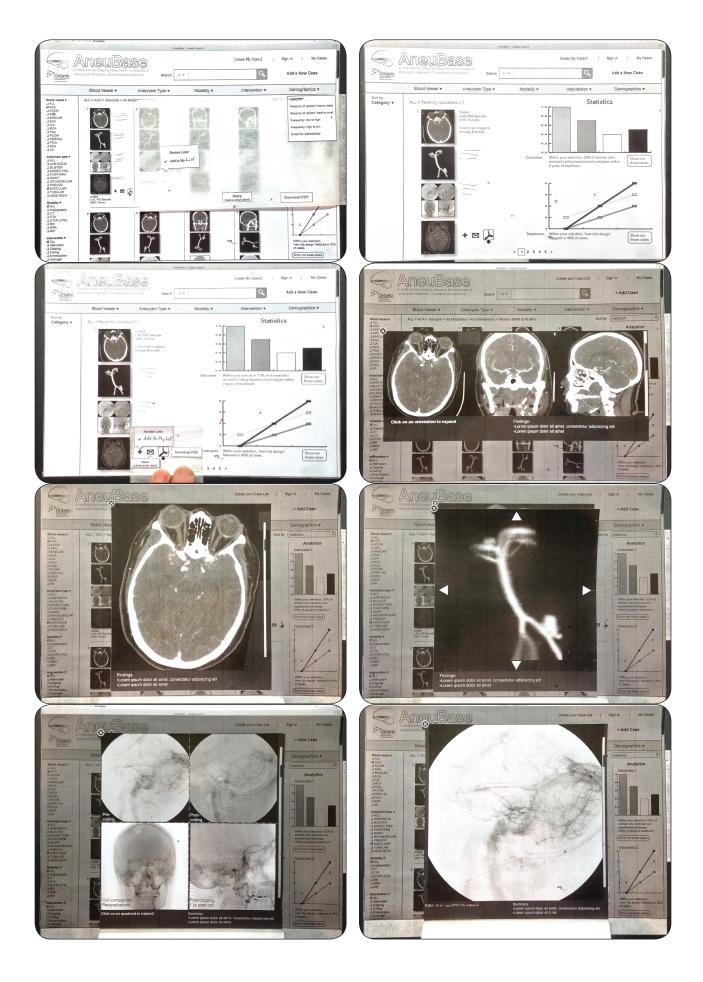


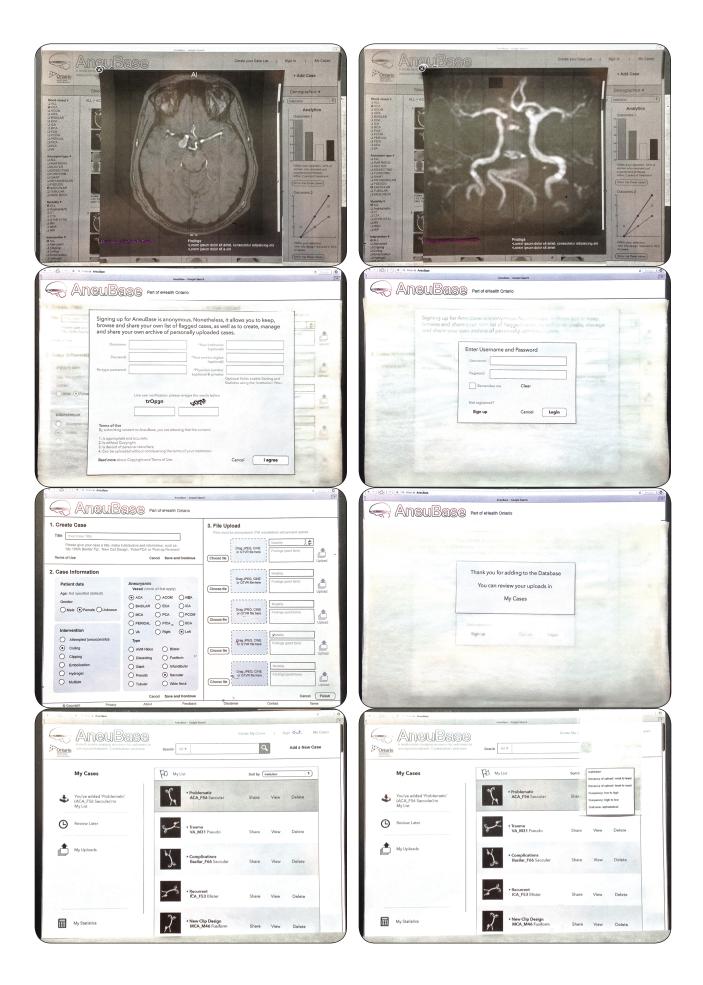


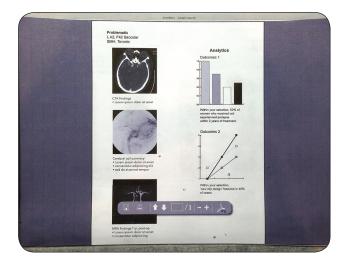




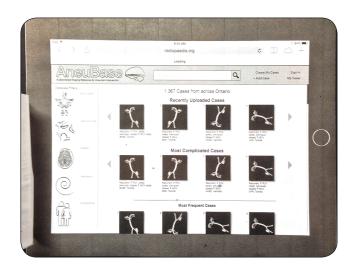


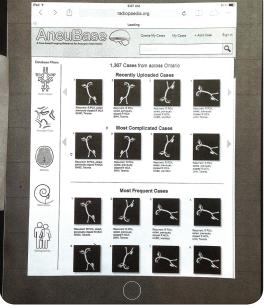




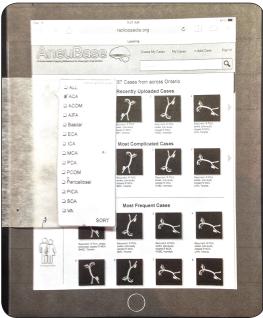


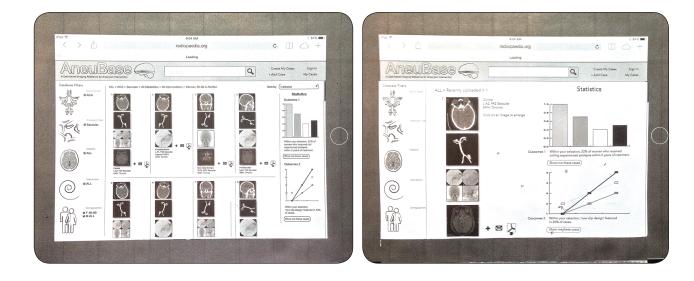
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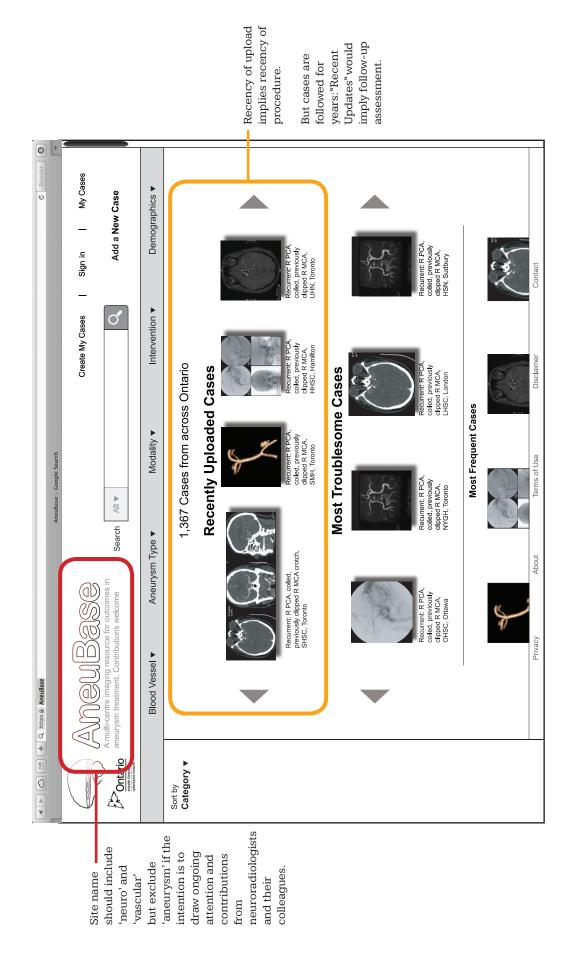


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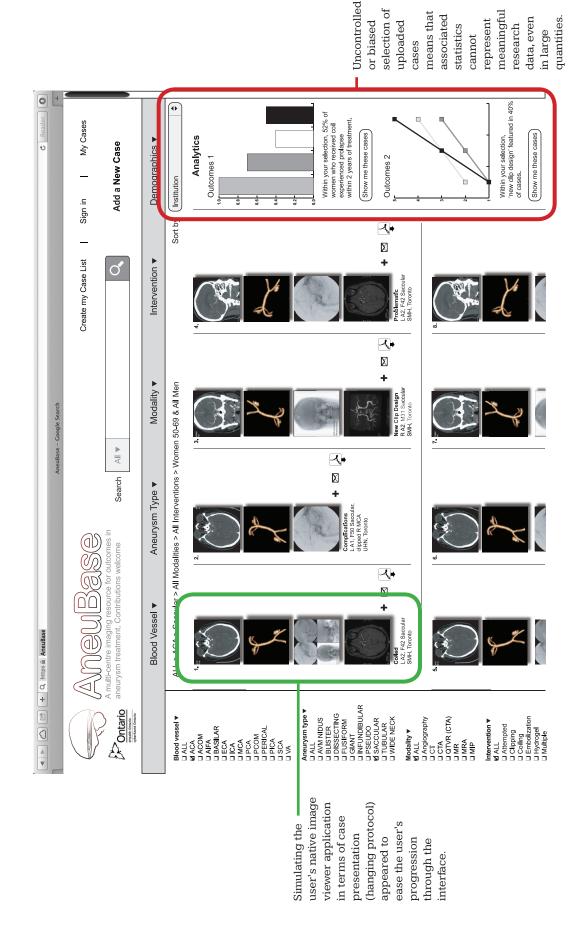
Appendix D

Selected findings from prototyping sessions

Home Page



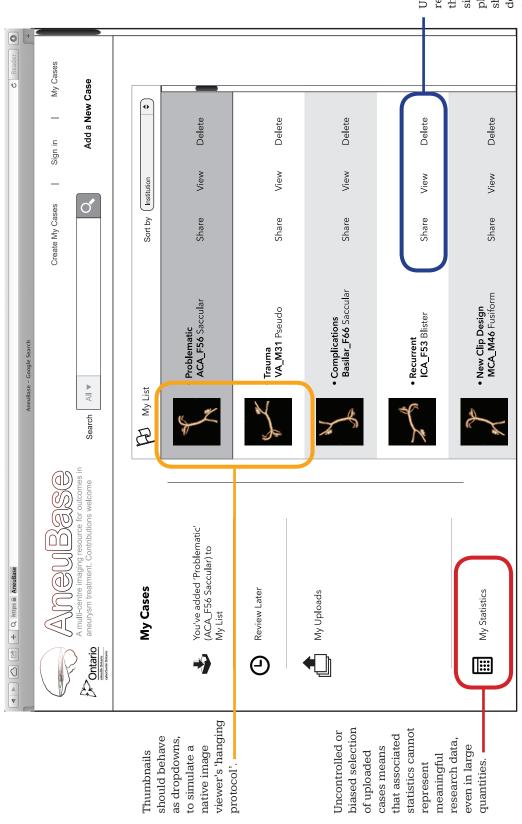
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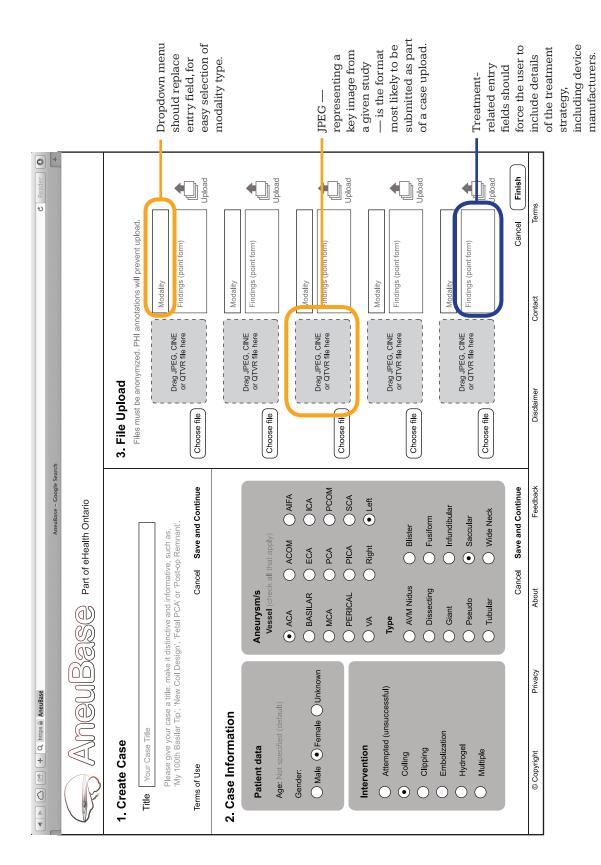
Angiogram Viewer Pop-up



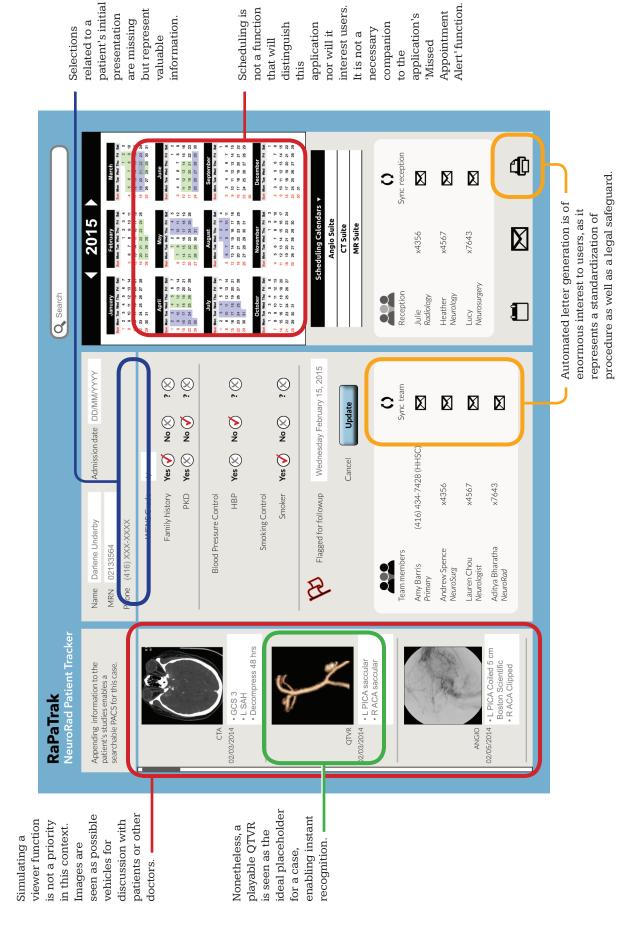
Personal Collection Page



Users expect resources from this type of site. Studies in playback format should be easily downloadable in a presentationready image format. **Case Upload Page**



Patient Management Tool Input Screen



Patient Management Tool Alert Pop-up

