



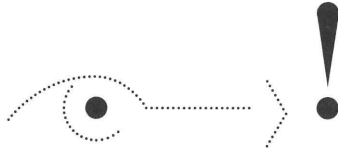
VISIBLE LANGUAGE

THE JOURNAL OF VISUAL
COMMUNICATION RESEARCH

47.2

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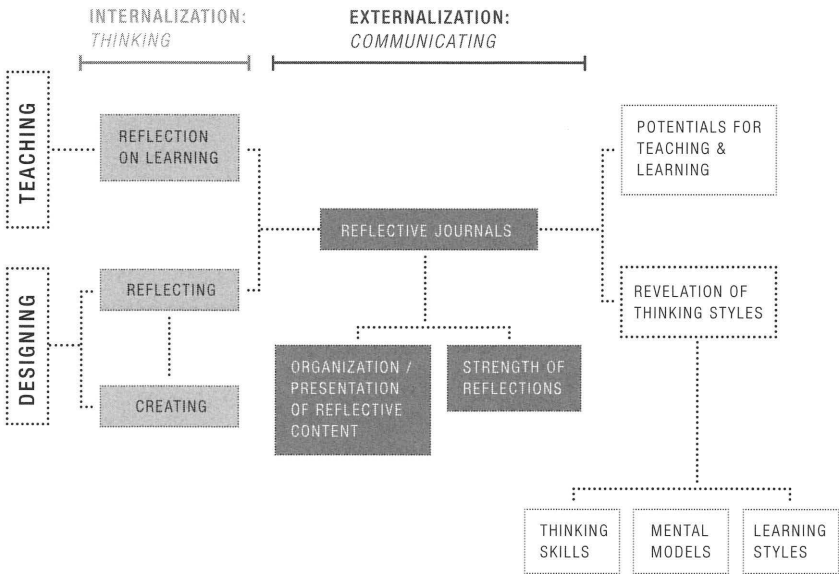
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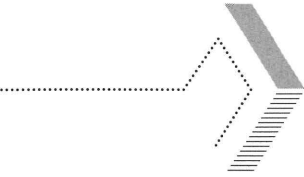
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01 A Study on the Revelations of Design Students' Thinking Styles in Reflective Journals

ARUNA VENKATESH

ABSTRACT

Thinking, considered as part of the core skill set of a designer, is equally significant in learning and design processes. An awareness and understanding of a personal thinking style is therefore important for both teaching and learning. Using well-established theories of thinking and using an in depth multiple case method, the author explores the possibilities of exposing students' thinking styles through the medium of reflective journals. Eight journals are carefully examined in terms of where student attention is located, how they communicate and how they are thinking. A further aim is to provide a guideline that can aid teachers to analyze the journals as feedback for the ease or difficulty associated with their teaching strategy. While the study is framed within a university design program, its findings may be of more general application.

“Design is not one way of thinking, but several. In particular it is a mix of rational, analytical thinking and creativity” (Lawson and Dorst 2009, 28). In a psychological sense, the complex mental processes of design relates to cognition, intelligences and thinking styles thereby having a direct bearing on the process of learning and acquiring knowledge in the realm of education. While the aim of design education has always been the attainment of higher order thinking skills, evidence of such attainment might not be easily apparent. Reflective journals, sometimes promoted by educators as a learning tool, might be a source that could reveal the student’s thinking. This research seeks to not only reveal students’ thinking styles, but to study the reflective process in depth and the importance of reflective thinking in fostering creativity.

BACKGROUND: REFLECTIVE THINKING — DIFFERENT PERSPECTIVES

Dewey, one of the earliest proponents and most influential psychologists in the area of reflective thinking defines reflective thought as “Active, persistent, and careful consideration of any belief or supposed form of knowledge in the light of the grounds that support it and the further conclusions to which it tends” (Dewey, 1960, 9).

Researchers like Boud, Keogh and Walker (1985) and Kolb (1984) have emphasized the role of reflective thinking in experience-based learning. Schön (1983) in his work on reflective thinking in professional practice mentions that the construction of practitioners’ knowledge is by means of “reflection-in-action” which occurs during a learning activity and “reflection-on-action” which occurs after the activity is completed. Further, reflective thinking is often used in conjunction with metacognition. Self-reflection, according to Zimmerman (2000) forms an integral part of self-regulation that is the evaluation and monitoring of one’s cognition in the learning process.

THE IMPORTANCE OF REFLECTIVE THINKING

The importance of reflective thinking in design education and design practice has increased as the pace and demands of study and workplace often compromise the value of design (Meredith Davis, 2007). Its importance in education has been long realized by Dewey (1960) who feels that...

∴ *reflection provides opportunities for students to discern their*
∴ *personal values and beliefs, find meaning in education and*
∴ *learn their strengths and weaknesses.*

Schön (1983) argues that the limitations of “Technical Rationality” in dealing with “divergent” situations in practice can be dealt with by the artistry of reflective thinking.

King and Kitchener's (1994) Reflective Judgment Model is especially useful in improving students' cognitive abilities while dealing with ill-structured or uncertain design problems and is useful in studying the learning process of students as well. Similarly, according to Lawson and Dorst (2009), reflective thinking develops students' problem-solving capabilities in a design situation thus developing design thinking capabilities (Cross, 2001). Reflective thinking generates new forms of thinking, helps to connect the different forms of thinking and promotes the idea of a life-long learning process (Kolb, 1984). Finally, it gives teachers an opportunity to study students' understanding of the subject thereby helping teachers to reflect on their own teaching and pedagogical strategies (Kolb, 1984; Boud et al., 1985).

MODES OF REFLECTIVE THINKING

Not everyone reflects in the same way. The thinking style of each person affects the way they reflect. Thinking styles in turn affect learning style as modeled in Kolb's Experiential Learning Cycle, (1984). In contrast, Sternberg (1997) has categorized thinking styles into the functions, forms, levels, scopes and leanings of mental self-government. Thinking styles can also be classified into perception and divided into visual, auditory and kinesthetic learners. However, there are also several categorizations of thinking styles according to right- and left-brain capabilities. One study on design thinking is based on analyzing design cognition by interpreting design activities (Cross, 2001), another by types of design thinking strategies used during the design process (Lawson and Dorst, 2009).

UNEXPLORED AREAS OF REFLECTIVE THINKING

Reflective thinking and thinking styles are areas that have been extensively researched. Recently, research has been done on reflective thinking tools such as portfolio, journal writing, technologically enhanced reflective tools and critiques. Little work has been done on how different thinking styles affect reflective thinking in design students. An area of exploration in the context of design education was to study the link between reflective thinking and thinking styles through the medium of design students' authorship of journals.

THE RESEARCH QUESTION

∴ *Do reflective journals reveal the thinking styles*
∴ *of design students?*

STUDY ASSUMPTIONS

- 1 Journals are considered an appropriate means for reflection
- 2 They are given importance in the curriculum and assessment
- 3 They have been used to evaluate the students' understanding and learning process

SUPPORT QUESTIONS

- 1 What are the expectations of teachers when they evaluate the journals?
- 2 What do students usually reflect on? Do they meet the teacher's criteria for reflection?
- 3 Are there any changes in the students' thinking based on the teacher's comments or based on contexts?
- 4 Is there any pattern in the thinking styles of design students?

IMPLICATIONS OF THE RESEARCH

- 1 To make students aware of their own thinking styles and for self- improvement
- 2 To provide the teacher with a deeper understanding of the thinking and cognitive styles of students and how it relates to design thinking capabilities
- 3 To provide insights for teachers to reflect on their own teaching style, strategies and methods
- 4 Though the study was conducted in the context of design education, the findings of the research might be applicable to other disciplines as well...

∴ *The research aim was to study how student thinking styles affect their reflective thinking abilities by studying its manifestations in journals.*

The word "reflective" implied that students used reflective thinking while making entries in journals. The "thinking styles" was to be determined by the researcher.

LITERATURE REVIEW

REFLECTIVE THINKING

Dewey (1960) regards reflective thought as a better way of thinking because its structure and purpose leads to a conclusion. Moreover, the act of inquiry aims to give a firm and rational basis to beliefs based on evidence. He stresses the need to make reflective thinking an educational aim by explaining that its values are of an intelligent action directed towards an aim of pre-arranging thoughts and of adding meaning to things. A habit of reflective thinking in students can be developed by drawing on the resources of natural curiosity, spontaneity of ideas in the form of suggestion and mental ordering. Teachers are urged by him to be engaged in reflective practice to add to the quality of teaching and make students realize the connections between their experience and studies.

Reflective activity according to Dewey has five stages:

- 1 suggestions — popping of ideas,
- 2 intellectualization — solving problems,
- 3 generating a hypothesis — observing and forming a guiding idea,
- 4 reasoning — extending and developing ideas
- 5 testing ideas — experimentation and verifying ideas by action.

Dewey's work laid the foundations for studies on experiential learning. Kolb (1984, 38) defines learning as "the process whereby knowledge is created through the transformation of experience."

The learning process goes through four cyclic stages:

- 1 concrete experience
- 2 reflective observation
- 3 abstract conceptualization
- 4 active experimentation.

Kolb goes on to create four knowledge forms based on the four stages that generate the four learning styles (discussed later). His theories seek to link experiential learning to education and work by "translating the abstract ideas of academia into the concrete practical realities of people's lives (p 6).

Focus on the reflection stage was done by Boud, Keogh and Walker (1985). According to them, reflection in experience-based learning occurs in three stages of the activity:

- 1 preparation
- 2 engagement
- 3 processing.

This process is promoted by providing the circumstances for reflection to happen and by offering various techniques and activities to support learning (*figure 1*).

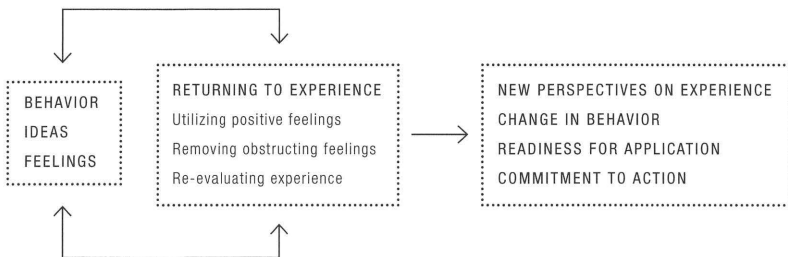


FIGURE 1 *The Reflection Process in Context (Boud et al., 1985, p 36)*

Dealing with problems, especially those of an uncertain nature, according to Schön (1983) cannot be effectively solved through scientific techniques. He proposed a new epistemology in practice called “reflection-in-action” (p 54) which in fact stems from a practitioner’s “tacit knowing-in-action” (p 49). The practitioner when faced with a problem applies his / her experience to invent new methods to solve it directly in situ. Schön has taken examples from architecture and psychotherapy to explore his theories in a collaborative atmosphere where reflection happens conversationally between teacher and student; where the student is pushed into thinking about the solutions for the problems through reflective questions aided by the experienced teacher.

Cowan (1997) extended Schön’s work by adding a “reflection-for-action” which anticipates that a learner brings forward ideas before and after the learning activity and becomes a reflection-for-action regarding the next activity; the process involves analytical questioning.

Levels in reflective thinking are explained by King and Kitchener (1994) in their Reflective Judgment Model. It is comprised of 7 stages grouped into 3 levels of reflection:

- 1 *pre-reflective* — where students believe there is a direct answer to problems,
- 2 *quasi-reflective* — students realize that certain problematic situations will have uncertain answers and that judgments should be based on evidence and
- 3 *reflective* — students acknowledge that judgments on complex problems can never be certain and that knowledge is constructed in a context.

Moon (1999, 123) has classified three approaches to learning by students: Surface, Strategic and Deep. The deep approach implies reflection where the intention is to understand ideas by relating to past experiences, looking for patterns and principles and critically examining course content and establishes its significance in learning, termed “transformative learning.”

Others have contributed to reflective schemas as well (Gibbs, 1998; Rolfe et al., 2001; Flavell et al., 1993; Zimmerman, 1990). See *Table 1* for a summary of these ideas.

ASPECT(S) OF REFLECTIVE THINKING	THEORY/ PROPONENT	MODEL / FEATURES
Inquiry, Experience, Values, Attitudes, Analytical Reasoning	Dewey (1960)	Stages in reflective activity : Suggestion Intellectualization Hypothesis generation Reasoning Testing of ideas
Experience	Experiential Learning Cycle by Kolb (1984)	Concrete experience Reflection Abstract conceptualization Active experimentation
	Boud, Keogh & Walker (1985)	Reflection in stages of learning activity: Preparation Engagement Processing
Problem-solving	Schön (1983)	Reflection-in-action Reflection-on-action
	Cowan (1997)	Reflection-for-action
Questioning	Reflective Model by Gibbs (1998)	Description Feelings Evaluation Analysis Conclusion Action plan
	Rolfe et al. (2001)	What So what Now what
Levels in reflection	King & Kitchner (1994)	Pre-reflection Quasi-reflection Reflection
Reflection in learning approaches	Moon (1999)	Approaches to learning: Surface Strategy Deep
Metacognition / Self-regulation	Flavell (1993) Brown (1987)	Categories of metacognition: Metacognitive knowledge Metacognitive monitoring
	Zimmerman (1990)	Self-regulated learning Use of strategies Monitoring outcomes and decision making Interdependent motivation

TABLE 1 *Theoretical framework for reflective thinking*

THINKING STYLES

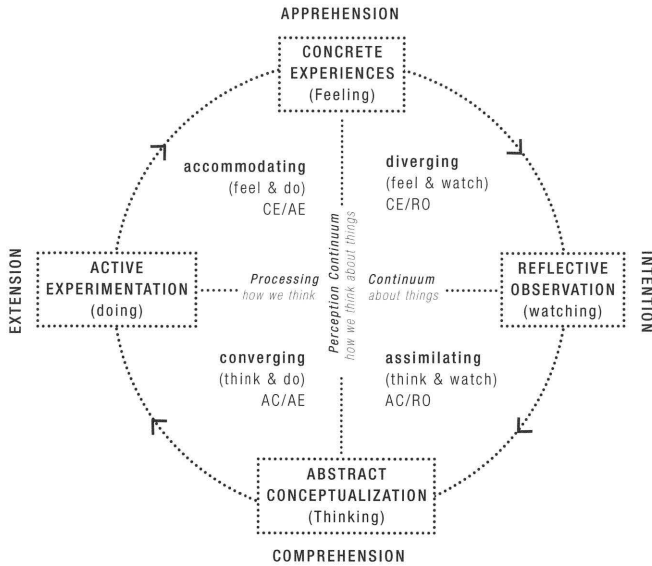


FIGURE 2 Kolb's Learning Styles adapted from www.businessballs.com/kolblearningstyles.htm

Kolb's Experiential Learning Cycle divided the learning process into two basic dimensions: Prehension (perception) and Transformation (processing). The two prehension processes are apprehension and comprehension and two transformation processes of intention and extension are contradictory yet related to one another and "their synthesis produces higher levels of learning" (Kolb, 1984, 61). The combinations of the four modes or processes determine the four learning styles in a matrix proposed by Kolb (figure 2). They are:

- 1 *Divergence* (concrete reflection) — learners are more imaginative, good at brainstorming, feeling-oriented and are observant
- 2 *Assimilating* (abstract reflection)— emphasis is on reasoning inductively, creation of models and theories based on logic
- 3 *Convergence* (abstract action) — strengths are problem-solving, practical application of ideas, decision-making; task-oriented rather than feeling-oriented
- 4 *Accommodation* (concrete action) — learners with this style are action-oriented, adaptive, risk-takers, use trial and error to solve problems

In Kolb's view, an individual programs his/her own unique structure of learning based on psychological characteristics, experiences, environment, decisions and contextualities. There is a tendency to

be stronger or lean towards one or more learning styles. Several other factors might shape and change learning styles (social environment, age, education, job requirements, etc.). However learning is more effective with the emphasis and development of all four modes.

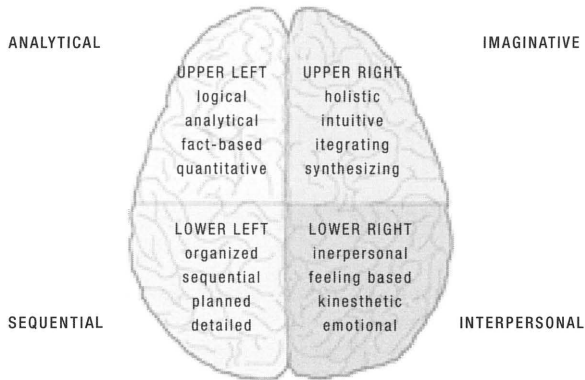


FIGURE 3 Herrmann's Whole Brain Model (Adapted from Herrmann, 1996, p 15)

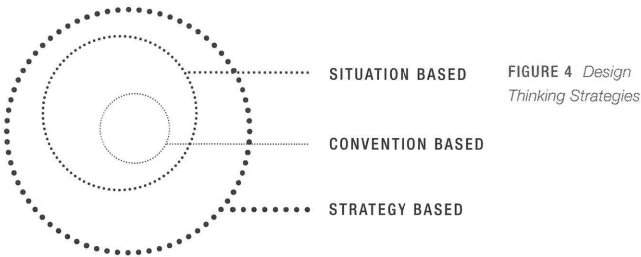
Ned Herrmann's (1996, 17) Whole Brain Model (*figure 3*) is also divided into quadrants, "based on the physiology of the thinking brain" – two halves of the cerebral cortex and two halves of the limbic system. The four thinking parts are interconnected and function "together situationally and iteratively" (p 16), however one is generally more dominant which determines thinking preferences in individuals. Herrmann associates the quadrants with four styles: Analytical, Sequential, Imaginative and Interpersonal. This tool is also useful for understanding creative competencies and limitations at an individual, group and organizational level.

DESIGN THINKING

Analyzing design cognition, Cross (2001) uses concepts quite unlike ones from scientific cognitive studies. Using the method of protocol analysis he has studied the following areas:

- 1 *Problem formulation* – designers look for ways to structure an ill-defined problem; concentrating more on gathering information about the problem than defining it. They tend to frame the problems and simultaneously work on their solutions
- 2 *Solution generation* – designers tend to jump to solutions, get attached to concepts; generate a wide range of solutions. Creativity does not happen suddenly, it is based on problem-framing, co-evolution and generation of concepts, sketching used as a tool to explore concepts

3 *Process strategy* – a flexible approach seems to be the key to success, designers also make cognitive or modal shifts between problems and solutions, “intuitive features of design behavior is most effective“ (p 93) in the design process.



Lawson and Dorst (2009) present three approaches designers use to find solutions to problems (*figure 4*):

- 1 *Convention-based* – applying conventions and rules in design practice in knowledge-based design problems
- 2 *Situation-based* – arriving at a fitting solution through creative application of knowledge and skills in the context of the design problem
- 3 *Strategy-based* – changing the situation to create new situations, resulting in different design proposals that requires a higher form of design expertise

THINKING STYLES BASED ON:	THEORY/ PROONENT	MODEL / FEATURES
Learning preferences	Experiential Learning Cycle Kolb(1984)	Learning styles: Divergent Assimilating Convergent Accommodating
Physiology of the brain (Left and Right dominance)	Whole Brain Model Ned Herrmann (1996)	Thinking styles: Analytical Sequential Imaginative Interpersonal
Design cognition (problem solving)	Cross (2001) Lawson & Dorst (2009)	Problem formulation Solution generation Process strategy Convention-based Situation-based Strategy-based

TABLE 2 *Theoretical framework for thinking styles*

JOURNAL WRITING

Writing is co-related to reflection and learning. Writing gives form to converting experience into learning (Moon, 1999, 187). In the opinion of Rolfe et al. (2001), ...

: *the emphasis should be on the concept of writing-to-learn rather than learning-to-write as writing is not a mere reporting of events or facts but a process of understanding something that results in developing higher and deeper levels of meaning in learning.*

It therefore becomes a purposeful activity that helps the ordering of thoughts, and connecting ideas.

Moon (1999) and Rolfe et al. (1985) agree on the following purposes of writing journals:

- 1 Record experience
- 2 Facilitate experiential learning
- 3 Enhance learning through reflections and metacognition
- 4 Record problem-solving processes of students
- 5 Provide a form of assessment
- 6 Enhance creativity- intuitive understanding
- 7 Promote group interactions
- 8 Improve professional development
- 9 Explore new perceptions

Moon (1999) also mentions the different forms of journal writing:

- 1 *Unstructured forms* — free writing and reflecting, recording an event, double-entry journals (factual recording and then reflecting)
- 2 *Structured forms* — autobiographical writing, exercises, questions and answers on selected issues, portfolios (that include other documents, pictures, stories or poetry)

But the writing process runs into problems generally arising due to a lack of understanding what aspects of the experience or learning are to be analyzed; external demands, the extent to reveal emotions, confidentiality and professional consequences (Rolfe et al., 2001; Walker, 1985). Such reasons, apart from the time the writing process takes are why the desired outcomes of reflective writing are not achieved.

RESEARCH DESIGN AND METHODOLOGY

RESEARCH METHODOLOGY

The research was more of an exploratory and suggestive kind and did not aim to prove a hypothesis. The analysis of the main variables of reflective thinking and thinking styles suggested that they were

rather complex in nature, were more subjective to each student and were to be studied in the context of their personal journals. All these indicated that a qualitative approach was best suited for this research.

RESEARCH METHODS

Owing to the uniqueness and particularity of each student's journal, a case study method of qualitative research was considered appropriate. In this case it was a multiple case study method or a "collective case study" (Creswell, 1998) to illustrate the central issue of finding evidences of thinking styles in reflective journals. The appropriateness of the method was established after studying Guthrie (2010), Denscombe (2007) and Creswell's (1998) descriptions of case study characteristics that include an in-depth and holistic investigation of a particular case that occurs in a natural setting, the study of complexities of the processes and relationship within each situation, comparing case studies for similarities and differences, which allows the use of multiple sources and methods for triangulation of data.

The case studies were chosen from different design disciplines. Moreover they were studied from the perspectives of different tutors and from that of the researcher. The process involved the following:

Semi-structured interview – this method was chosen as it allowed for probing into the subtleties and complications of the research problem. It also proved more effective than other methods like questionnaires and structured interviews.

Content analysis – it is a method that is especially useful to analyze written texts as it can reveal the meanings, thoughts, values and ideas of the writer (Guthrie, 2010, 238). In addition, in this particular study it gave a different viewpoint for analyzing the subject through the eyes of the researcher.

RESEARCH DESIGN

All the participants belonged to The School of Design (SD) in The Hong Kong Polytechnic University. The students whose journals were researched were selected from different year levels of study (B.A Hons in Design) to get a range of reflective thinking capabilities. The selected works were two each from subjects tutored by four SD professors making it a total of eight case studies. The students belonged to different design disciplines. However the students were not interviewed because of time constraints, practicality and availability issues; the journals were considered as spokespersons for their authors.

Content analysis was done prior to interviewing the tutors to ensure that the researcher was not influenced by their thoughts, thus preserving the interpretation of the findings.

Selection of the students and their work was left to the discretion of the tutors. The four tutors were interviewed based on their prior consent with the selected journals displayed. The interviews were conducted in SD and were video-taped subject to the approval of the interviewees. Video-taping of the interview was ideal as it captured the tutor's "pointing out" to the journal while talking. The questions were mostly open-ended; a sample of the interview questions can be seen in *Table 3*. Each interview lasted for about an hour. Other probing questions were also asked depending on the answers.

All the participants (tutors and students) were assured of anonymity and confidentiality.

WARM-UP	<p>How long have you taught in PolyU? What subjects do you normally teach? How familiar are you with reflective journals as a means of assessment (in terms of experience)?</p> <p>Can you give me a brief background about this subject? What are the submission requirements of this subject? How many students were in the class?</p>
ON REFLECTION	<ol style="list-style-type: none"> 1 How would you define or describe reflection? Why do think design students need to reflect? 2 When would you ideally want the students to reflect? 3 When do students need to submit their reflections? 4 What do you expect the students to reflect on? 5 What has this particular student reflected on? Did you find anything unique? What do you think he / she has missed out on? 6 How deep was the reflection? 7 Do you think students have trouble sorting out feedback from tutors and peers in relation to their own ideas? 8 Do you think the students have benefited from reflecting on their work? In what way? Were the students aware of it? 9 What have you learned / didn't learn about the student from his / her reflection?
ON THINKING STYLES	<ol style="list-style-type: none"> 10 In your experience from interacting with this student, what is your impression of the thinking skills of this student? Do you think the students were aware of their own strengths and weaknesses? 11 At their level of studies in the course, what kind of thinking development did you expect to see in the students? 12 Do you think the journal can show evidences of the above? (10 & 11) 13 How do you examine the journal?
ENDING	<p>What are your views on journals as a medium for tracing thinking patterns as well as a medium for reflection?</p> <p>Anything else you would like to add?</p> <p>Thank you for participating in this interview!</p>

TABLE 3 *Sample on interview questions*

DATA ANALYSIS

STAGE 1 — CONTENT ANALYSIS OF CASE STUDIES

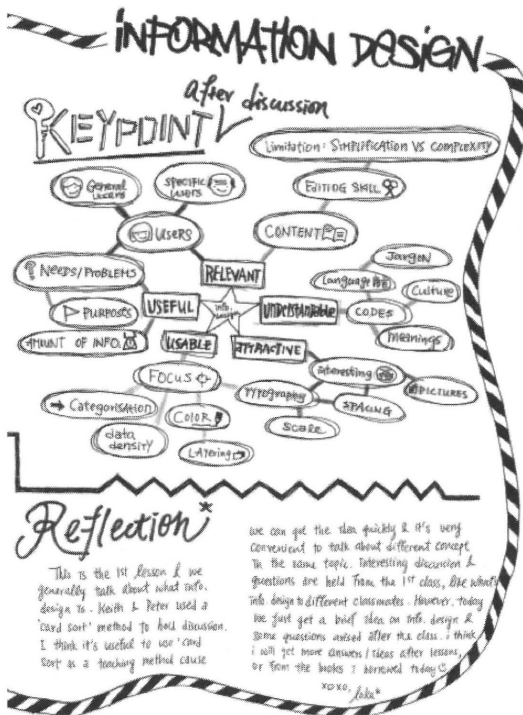
The students and their journals (case studies) were coded from S1 to S8 and J1 to J8 respectively; the tutors were coded from T1 to T4. It should be noted that, depending on the subject requirements, the word 'journals' included all pieces that were reflective in nature. *Table 4* shows the details of the case studies including the coding, student level, discipline and journal type.

STUDENT / JOURNAL	STUDENT LEVEL	TUTOR	SUBJECT	DESIGN DISCIPLINE	TYPE
S1 / J1	Y1	T1	Design	Advertising	Reflective journals
S2 / J2			Thinking	Product	
.....					
S3 / J3	Y2	T2	Information	Visual	Reflective journals
S4 / J4			Design	Communications	
.....					
S5 / J5	Y3	T3	Final Project	Advertising	Reflective reports
S6 / J6					
.....					
S7 / J7	Y4	T4	Cultural Research	Product	Reflective Papers
S8 / J8			Methodologies	Environment & Interior	

TABLE 4 *Case Study Details*

INITIAL CATEGORIZATION OF RAW DATA

A detailed analysis of J3 is shown as a sample of the analytical process applicable to all the case studies. The analytical steps include: memos, keywords from the memos and a conceptual framework based on the previous understandings. To chunk the data, the journal was analyzed page-wise in the form of memos, keeping in mind the three broad categories of reflecting thinking, thinking styles and journal writing. Keywords or phrases were pulled out that gave a clue to reflective thinking. For example, "What is information design? Should we define...purpose of creation?" implies that the student is using questioning as a means to reflect. The way the content was represented was categorized under memo on journal-writing. Based on the writing as well as the visuals, there was an attempt to interpret the overall thinking of the student (represented as memo on thinking). Sample pages of J3 are shown (*figures 5.1, 5.2, and 5.3*).



MEMO ON JOURNAL WRITING
 Use of different fonts and borders, verbal, visual, bold titles, use of symbols, sketches, mapping

MEMO ON THINKING
 Visualization of learning through mapping, verbal, and visual thinking, analytical thinking

MEMO ON REFLECTIVE THINKING

KEYWORDS/PHRASES TAKEN FROM WRITING

Summary and understanding of lesson through diagrams

After discussion, key point, reflections, first lesson, generally talk about, card sort, **I think**

Reflection on teaching method

useful, because, get ideas

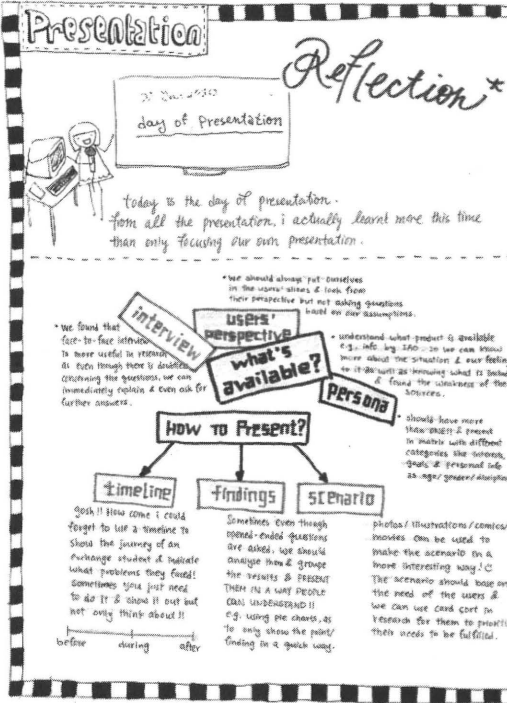
More questions leading to generation of ideas

quickly, interesting questions, discussion, however, brief, **questions arise after class,**

Attempt on furthering knowledge through books

get more ideas after lessons, or from **books borrowed** today

FIGURE 5.1 Sample of page-wise analysis of J3



MEMO ON JOURNAL WRITING
 Scenario depictions, use of cartoons, content divided into parts, feeling expressed

MEMO ON THINKING
 Evaluation, deep analysis of parts, visualization of learning

MEMO ON REFLECTIVE THINKING

KEYWORDS/PHRASES TAKEN FROM WRITING

Group evaluation, but no mention of other groups

Today, from all presentation, I actually learn more. we found,

Analyzing mistakes suggestions for improvements

gosh, how come, sometimes need, should always, but not, assumptions, understand, more than one, in a way understand

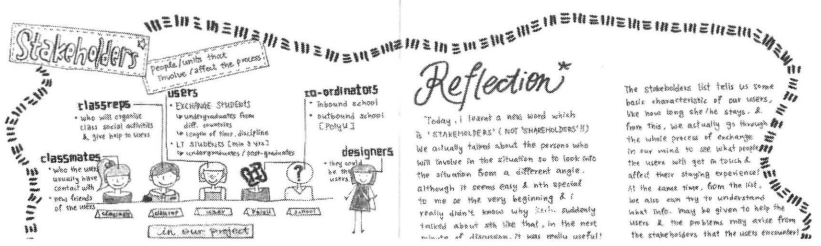
Evidence of new learning

what products, can be used,

Analyzing users' needs

more interesting, need of users, prioritize their needs

FIGURE 5.2 Sample of page-wise analysis of J3



MEMO ON JOURNAL WRITING

Verbal and visual change in border and fonts, pictorial representation, cartoons

MEMO ON THINKING

Visualization of learning, analytical, finding usefulness of learning

MEMO ON REFLECTIVE THINKING

.....

KEYWORDS/PHRASES TAKEN FROM WRITING

.....

Evidence of new learning



Learnt a new word, different

Analyzing user psychology and problems



angle, didn't know why, suddenly, really useful, users, affect their experience, understand, the problems

FIGURE 5.3 Sample of page-wise analysis of J3

Using the memos, a mind map was created to give a holistic picture of the student's reflections with categories that showed a broad grouping of different aspects of reflective thinking derived from the data. Some of these categories were common to all case studies. The areas that had been most concentrated on were chosen for further analysis.

CONCLUSIONS ON ALL INITIAL FINDINGS

At this stage there was more evidence of analytical than creative skills in J1, J2, J7 and J8. Evidences of analytical, creative and strategic skills were shown in J5 and J6. Reflections on the conceptual development in design projects were seen in J3 and J4. There was an indication of a change in thinking in all journals and of learning something new. The journals were used in different ways — as a medium for communication / conversation, as a sketchbook or as a presentation tool. All the students were given guidelines on how to reflect in the respective subjects.

CATEGORIZATION USING A CONCEPTUAL FRAMEWORK

Since there was difficulty in interpreting the thinking styles, the concept of reflection as learning was used to find a link to thinking styles. Accordingly, the reflections were categorized into the 3 interactive areas: ways of learning, ways of thinking and ways of communication; learning and thinking as internal processes externalized through communication. This basic model (figure 6) integrated previously mentioned theories to support journal analysis. There was more concentration on evidence that pointed to thinking skills particular to design.

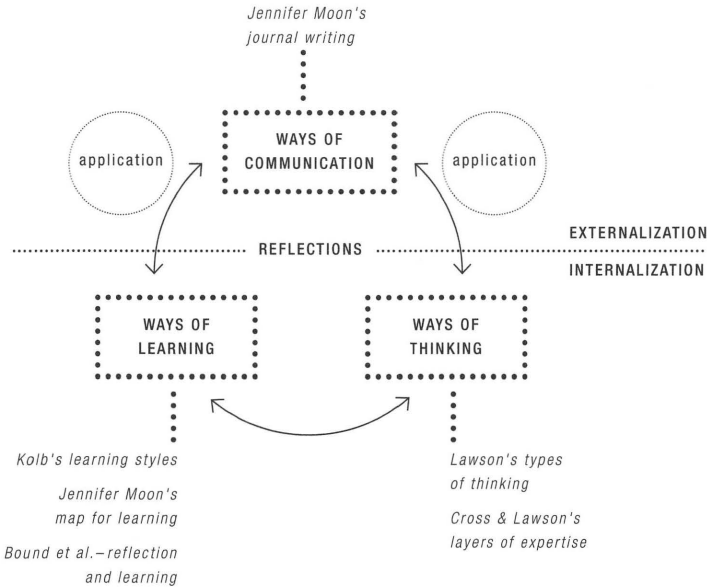


FIGURE 6 Conceptual framework of analysis

Several levels of analyses were conducted to narrow down to areas of reflection that could be interpreted as ways of learning. There was an attempt to generalize the categories for all case studies by finding common patterns of reflection, but this was easier for reflections within the same subject and discipline. Working from the Conceptual framework in Figure 6, a logical chart derived from Journal 3 (J3) shows the main areas that Student 3 (S3) chose to reflect on (figure 7.1). The missing or incomplete areas suggest that these could be possible ways of learning as well as clues for detecting thinking skills.

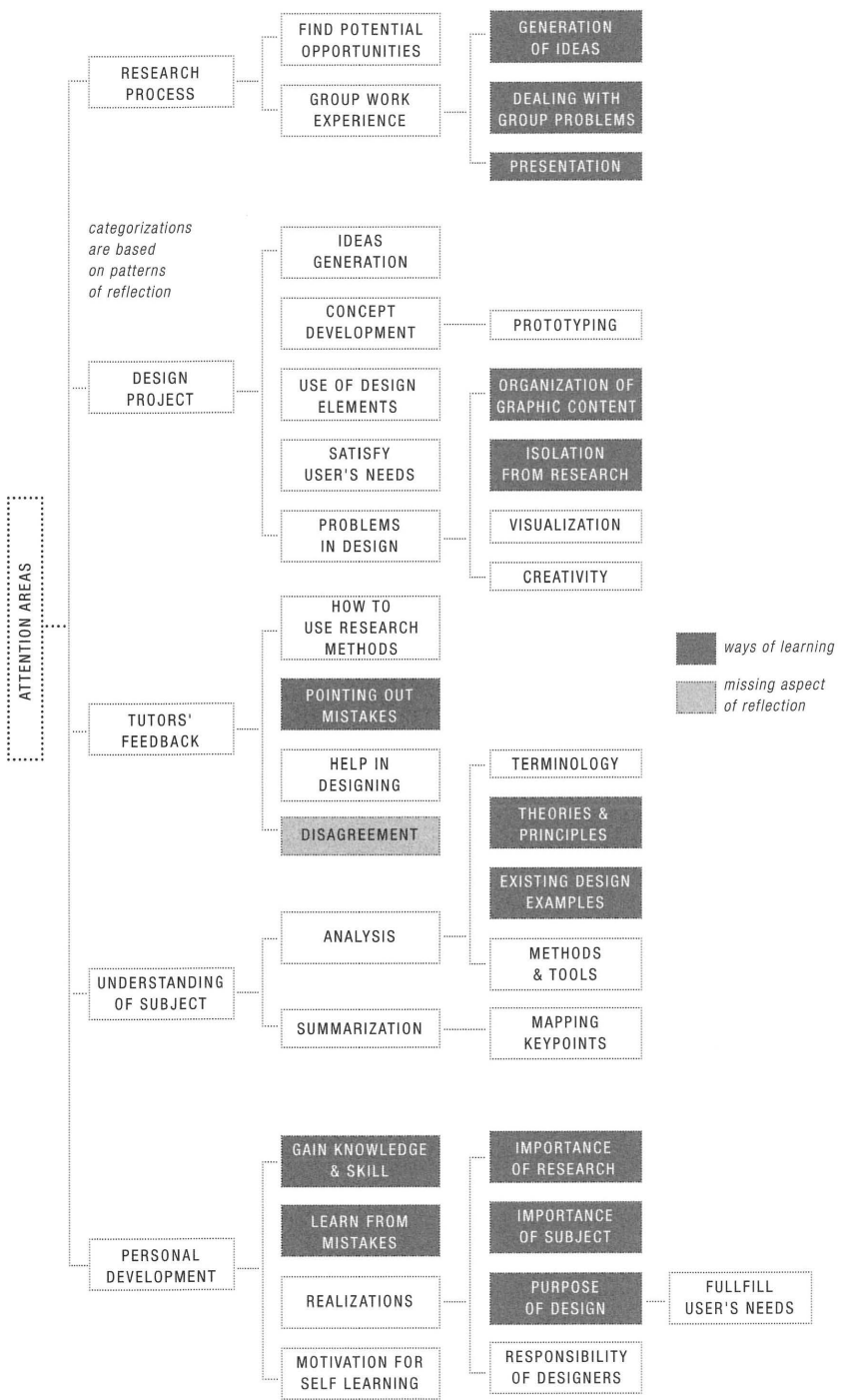


FIGURE 7.1 Analysis of J3 using the conceptual framework

A similar chart (figure 7.2) was made for ways of communicating according to the content layout, use of texts and visuals in the reflections.

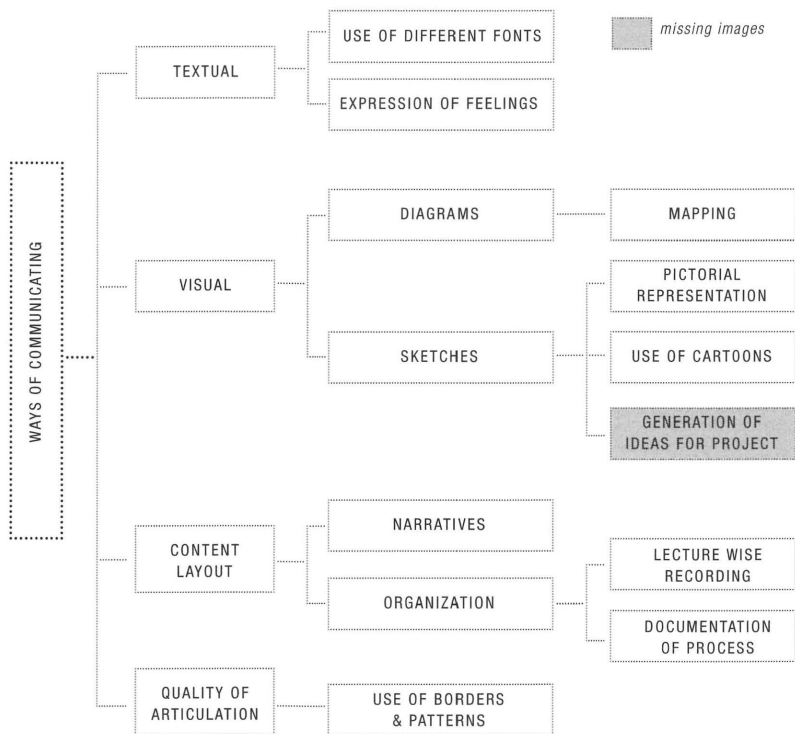


FIGURE 7.2 Analysis of J3 using the conceptual framework

The two charts (figures 7.1 and 7.2) were combined to create a chart for thinking (figure 7.3). Ways of learning might give clues to the preferred learning style. Learning through the design project provided clues of thinking skills that were developed by the student especially for the purpose of design, while communicating is also a way of thinking.

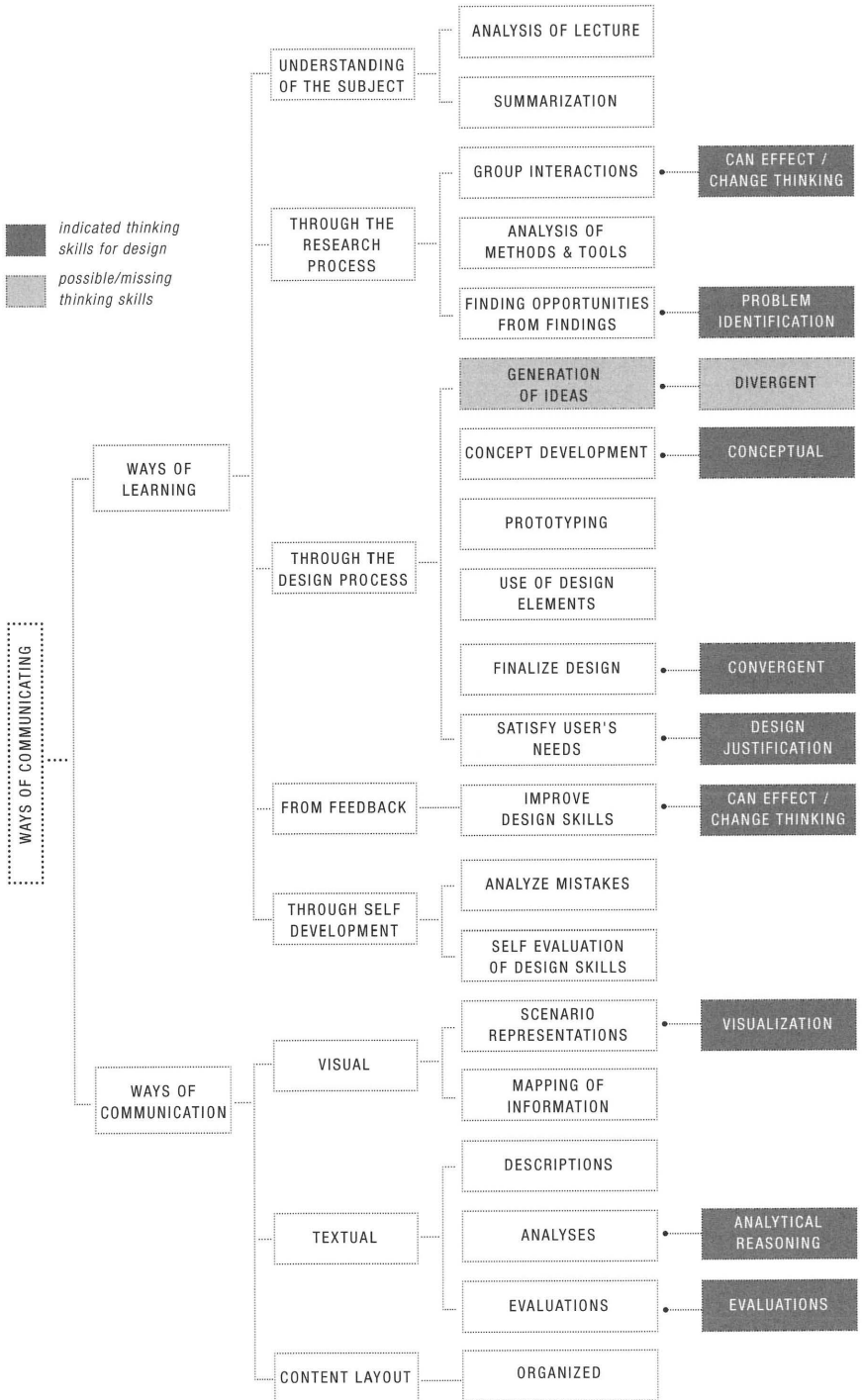


FIGURE 7.3 Analysis of J3 using the conceptual framework

Table 5 is a summarization of the strengths and weaknesses of students' reflections using common categories across all the case studies.

TABLE 5 *Summarization of Stage 1 analyses*

	REFLECTION STRENGTHS				WEAKNESSES
	Demonstration of Understanding of Subject	Construction of Learning	Personal Development	Development of Thinking Skills	
S1	Through self-learning and analysis of the subject's purpose	Through interactions and analysis of learning activities	Discerning values, developing new perspectives, learning new skills and abilities, understanding design and role of designers, expressing feelings	Analytical, reasoning, unclear creative skills	No reflections on learning difficulties, group work problems (too positive), tutors' feedback No evidence of concept development and divergent thinking Few sketches or diagrams
S2	Through visual representations and analysis of learning activities	Through interactions	Understanding the purpose of the subject, learning new skills and abilities, drawing inspiration	Analytical, visualization, unclear creative skills	Little reflection on tutors' feedback No evidence of concept development and divergent thinking Analysis not deep
S3	Through visual representations and applications in research and project	Through interactions, from feedback, critical analysis of experience, through mistakes	Deep understanding of subject's purpose, purpose of design, role of designers, expression of feelings	Analytical reasoning, conceptual, problem-solving and visualization, unclear creative skills	Little evidence of divergent thinking No mention of disagreements with tutors' feedback (personal viewpoint) Not enough critical evaluation of designed product
S4	Through analytical reasoning and applications in research and project	From feedback, critical analysis of experience	Strong opinions on the subject's purpose, role of designers, deep self-evaluation	Analytical reasoning, evaluation, problem-solving, unclear creative skills	Little evidence of divergent thinking Too textual, few visual representations
S5	Through design and execution	Through interactions, by pausing =for reflection, through self-evaluation	Discerning values, achievement of design purpose	Analytical reasoning, evaluation, strategy, problem-solving, change in thinking and new approaches, unclear creative skills	No reflection on research methodology, final presentation critique No mention of learned theories No images of final presentation or product

S6	Through design and execution	Through feedback, by stepping back, through self- evaluation	Justifying design actions, achievement in translating the concept	Analytical reasoning, evaluation, creativity, strategy, problem-solving, change in thinking and new approaches	No reflection on choice of topic, team-work process, final presentation critique No mention of learned theories
S7	Unclear	Through interactions, through analysis of research findings, personal experiences, comparison	Discerning values, developing new skills	Maybe analytical, reasoning and logical skills, no creative skills	No reflection on subject (research methodologies), tutors' feedback, design project No visuals
S8	Unclear	Through interactions, through analysis of research findings	Realization of the importance of the subject	Maybe analytical, reasoning and logical skills, no creative skills	Brief reflection on subject (research methodologies) No reflection on tutors' feedback Brief mention of design project No visuals

STAGE 1 — COMMON PATTERNS

While it was difficult to create general categories across all the case studies, certain common patterns emerged as mentioned in *Table 5*.

S1, S2, S7 and S8 all had not reflected on tutors' feedback; this was something that needed to be clarified while interviewing the tutors.

At the same time, since both S7 and S8 had not reflected on 'research methodologies' (the subject's focus) this indicated that it might have been a missed learning goal with regard to understanding the subject. Therefore, while not aiming to be prescriptive, the chart developed in Figures 7.1, 7.2 and 7.3 provides an idea for tutors on how to examine the journals in terms of their own expectations and goals.

Additionally, at the discipline and program outcomes level, it is possible to look for evidences for transferable skills like critical thinking, strategic thinking, visualization skills and perhaps communication and interpersonal skills. Creative thinking was found only in one instance (S6). This is again dependent on the strength, scope and requirements of reflections and the nature of subject, project or course. Examples of thinking processes that involved the use of different thinking skills could be also be understood, such as problem-solving or concept development as suggested in the table.

The conceptual model that was developed was partially helpful in detecting learning styles. For instance, in the case of S4 it

was clear that the preferred learning style was that of 'Assimilating,' as the student showed an inclination towards learning theories and concepts. Similarly S1 and S3 were more of the 'Divergent' learning style as they seemed to be imaginative and feeling-oriented. S6 could be both 'Divergent' and 'Accommodating.' But it was not possible to be as conclusive in the other case studies, because of the subjective and personal nature of reflective writings, the diversity of students and subject context. Ways of communication however revealed the verbal (S4) and visual thinkers (S2 and S3).

STAGE 2 — INTERVIEWS WITH TUTORS

The aim of the interviews was to not only obtain the tutors' views on reflective thinking and its importance in the curriculum but to also learn about their expectations, way of assessing and use of journals to reveal students' thinking styles. The transcribed interviews were re-organized into common categories across all the transcriptions for the purpose of cross analyzing against the researcher's analysis and to cross analyze among the four tutors, to triangulate the data and to get different perspectives.

Cross analyses of the case studies were performed in two ways: *Table 6* compares each tutor's analysis of their students' case studies with that of the researcher's, concentrating on the aspects of reflective thinking, journal writing and thinking styles; data from the tutor's interviews were examined. Some of the significant categories used for cross analyses were:

- 1 Meaning of reflection
- 2 Strong vs. weak reflections
- 3 Benefits of reflection
- 4 Disadvantages of reflection
- 5 Factors affecting reflective thinking
- 6 Advantages of and hurdles in journal writing

POINTS OF AGREEMENT WITH TUTOR		DIFFERENCE IN OPINION / NEW PERSPECTIVES	
		TUTORS'	RESEARCHER'S
S1	Self-critical, lots of questions, justifications, reflection on design, different perspectives, self-motivation to learn, strong analytical and reasoning skills	Reflections on a wider context, creativity through reflections, no theoretical basis for rationale	No reflection on personal problems and feedback, no concept development sketches, expressive writing
S2	Good summarizations and documentation, descriptive, analysis not deep	No wider context	Strong visualization skills, organized, no reflection on feedback, no concept development sketches
S3	Pictorial representations of subject, deep understanding and analysis of subject, strong visualization skills	Interpreted teaching, hierarchical and nested thinking, taxonomy, reflection on a wider scale, poor creative skills, not a good doer of design	No evidence of divergent thinking, too much agreement with tutor's feedback
S4	Deep analysis of the subject and theories, connections, strong opinions on purpose of design and role of designers, strong writing skills, unclear thinking pattern	Linear thinking, contemplative and deep, intellectual approach, poor creative skills, not a good doer of design	No evidence of divergent thinking, too much agreement with tutor's feedback, few sketches
S5	Reflections on feedback, few sketches, no evidence of final product, random and unrelated images	No evidence of creativity, no expansion of ideas, linear and fragmented thinking, realistic thinker	Indication of change in thinking, evidence of analytical reasoning, conceptual, evaluative and strategic skills, no reflection on research, no indication of theories
S6	Constantly questions actions, needs confirmation through feedback, evidence of creative thinking, new approaches, strongly linked writing, good guided report	Creativity through clear reflections, pattern of linked segments and reflection, creative process, idealistic thinker	Strong justification of design, evidence of analytical, reasoning, conceptual, evaluative, strategic skills, no reflection on team work
S7	Good critical thinker, organized and logical	Comprehensive - project and progress, asks questions	Related learning to personal experience, discerning values, evidence of analytical and reasoning skills, no reflection on the subject and feedback, no evidence of concept
S8	-----	no time to process the thinking	Not organized, stopped short, no time to process the thinking Logical and clear, evidence of analytical and reasoning skills, no reflection on subject and feedback, no evidence of concept development, no sketches

TABLE 6 *Cross analyses of Case Studies*

There were points of agreement between the tutors and the researcher. However, the tutors were sometimes more successful in tracing thinking patterns, primarily because of their constant interactions with the student, although such evidence was not found in the journals. Though learning was a central purpose of reflections, they were also looking at the scope of reflections (breadth and depth). All of them believed in the connection between reflective thinking and creativity. But the tutors differed in their expectations of subject reflections, discussed in the next section.

DATA SYNTHESIS

SYNTHESIS OF STAGE 2 OF ANALYTICAL FINDINGS

The following topics inform and synthesize the main results of the analyses of stage 2 backed by some of the theoretical perspectives explored earlier.

Reflection and learning: T1, T2 and T4 mentioned reflection as a process of internalizing the teaching, and interpreting it in a new way, of making connections (T1, T2, T4) or for self-awareness (T1 and T4) also known as metacognition (Flavell, 1997 and Brown, 1983). This closely follows Kolb's Learning Cycle (1984) of reflecting on experience to make abstract conceptualizations to be tested later. Questioning is an important aspect of reflection (T1, T2, T3 and T4) and is supported by reflective models of Gibbs and Rolfe et al. (1998). See *Figure 8*.

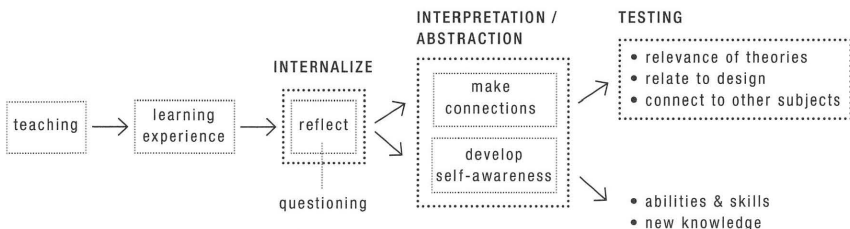


FIGURE 8 Relationship between reflection and learning

Reflective thinking vs. creative thinking: Another way of looking at Kolb's cycle is mentioned by T3, action or creative action is reflected on to change the outcomes for the better (T1, T4). According to T3 design is a 3 step process: research-creation-reflection. Additionally research involves analytical thinking (T1); the insights are used for creation, and reflection again starts after evaluation to aid the decision and implementation of design (*Figure 9*). According to T4, students who are good at critical thinking are good designers. However T3 felt

that reflection can sometimes restrict creative freedom. But T2 and T3 strongly felt that designers need a balance between the left and right sides of their brain (Lawson and Dorst, 2009).

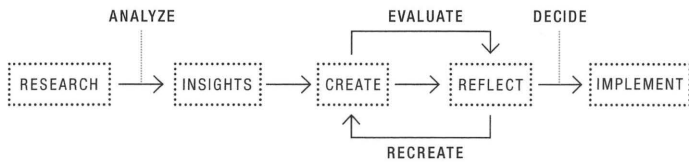


FIGURE 9 *Reflective thinking vs. creative thinking*

Attitudes towards reflection: The importance of project-based learning in design education implies that students are more involved in the 'doing' of design (T2 and T3) and are more instinctive in their approach (T4). Thus, visual-based subjects require little or no reflection (T3). Besides, reflection takes time, energy and concentration, and the system might not support it (T1, T2 and T4). Therefore, it might be difficult to motivate students to reflect or develop a habit for reflection. At the same time there is also a difference in the disciplines' attitudes towards or requirements for reflection (T1 and T4).

Assessment of reflection: T1 said that there are discrepancies among disciplines while grading reflective works but these might be solved by common agreement despite the nature of design. T4, however, thought that assessment is difficult because of the subjective nature of reflection and because of the abstract nature of subjects; it also becomes difficult to give students concrete guidelines for reflection. The tutors often used their own discretion while assessing or used comparison for assessment (T2, T3 and T4). T1 on the other hand felt that the descriptors in the assessment matrix needed to be improved.

Expectations vs. responses: Though all the tutors provided guidelines and some sort of criteria for reflection, T2 and T4 preferred not giving too many parameters, and rather welcomed the unexpected response that reflection provides. T1 and T2 both expressed their surprise on finding the student emphasized something that they did not think was important in their teaching. T2 was especially excited when one of the students re-interpreted the teaching through diagrammatic reflections. T4 mentioned some of the learning difficulties students expressed through the reflections that were not otherwise revealed in tutorials.

These were important pointers for teaching and for tutors' reflection on their teaching (*figure 10*).

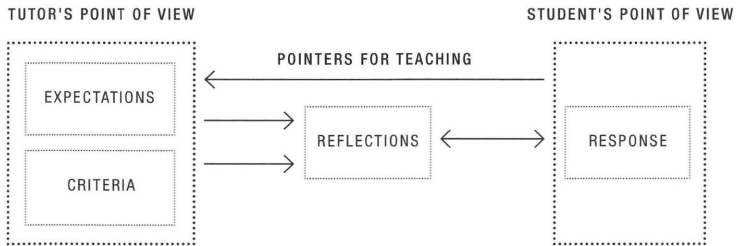


FIGURE 10 *Expectations vs. Responses*

Reflective learning through interactions: In the subjects lead by T1 and T4, students were immersed in an interactive environment and were encouraged to reflect on peers' works. T2 however felt that the learning environment was lacking and students relied too much on tutors' feedback. T3 echoed this thought and felt that students thought they were not good judges of the quality of their own work. T3 and T4 felt that tutorials and critiques were premises where students sometimes gained insights, that is Schön's reflection-in-action (1983), but according to T4 it was a matter of retaining information and noting these insights.

Writing vs. visualizing: All the tutors agreed that writing didn't come easily to design students because of the perception that writing and reflection were left-brained activities and students couldn't relate it to design (T2). Academic background and lack of language skills might also affect the quality of reflection (T2). T1, T2 and T4 stressed the importance of writing in organizing, filtering and editing thoughts. T2 mentioned that reflections can be a combination of texts and diagrams. Journals served as an effective communication tool for presenting thoughts; communication and presentation skills are vital for designers (T2 and T3). The above skills were noted as learning outcomes, common to all disciplines and served as evidence of learning in the Outcome Based Education System (T1, T2 and T3).

Journals as a means to reveal thinking styles: Though journals were good for tracing the reflective process, evidence for the creative process was in the form of sketches (according to T3) and so the portfolio was a better medium. T2 also felt that the creative part was not seen much in the reflection unless concept development was included. T4 agreed that reflection on the design project should be included in the reports.

All the tutors found it possible to trace thinking patterns of students through the journals as seen in Table 5. In the case of students S4 and S5 it was difficult to trace a pattern because S4's writing was organized in a linear form and S5's writing had no structure and was segmented. On the other hand S3 had a hierarchical structure of thinking from the way the content was re-organized, similar to Sternberg's Theory of Cognitive Styles (1997) and S6's writing was clearly linked. However, T2 commented on the fact that both S3 and S4 were strong thinkers but not good doers. S1 and S3 showed reflections on a wider perspective while S4 was deeper. But S2 showed a reflective pattern of being constantly descriptive. Students S1 and S6 also showed a change in their thinking through their reflections; from convergent to divergent. S5 in comparison did not show progress in thinking. All tutors indicated that personality among other factors (for example, age, background) was associated with reflective writing and thinking skills.

Therefore, there are different versions of thinking in terms of patterns, skills and styles, as seen in *Figure 11*.

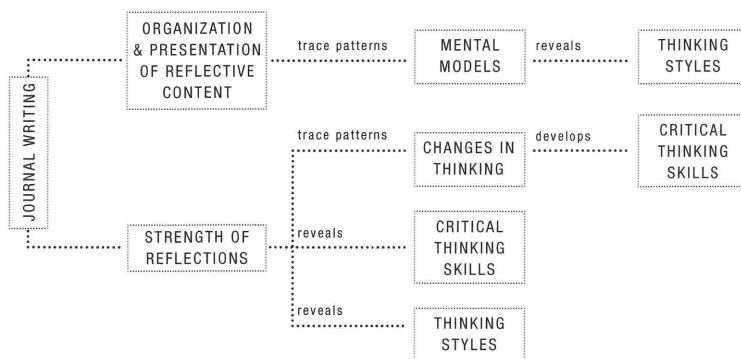


FIGURE 11 Journals as a means to reveal thinking styles

SYNTHESIS OF STAGE 1 AND 2

The goal was to find a closer relationship between the three main components of reflections, thinking styles and journal writing and to address the research question.

Learning styles can determine thinking styles, the evidence was found in critical self-reflections of the learning experience. Evidence of thinking skills might be another way of revealing thinking styles. It also could indicate left and right brain thinking abilities and conform to Ned Herrmann's Whole Brain Model (1996).

At the same time, as already discussed, tutors had different interpretations of thinking patterns according to levels of reflection, scope of reflections and reconfiguration of teaching. This depended on what the student chose to reflect on and how it was represented. These have been narrowed down in terms of re-organizing and prioritizing of thoughts supported by Sternberg's Theory of Mental Models. Re-configuration could also be an indication of creativity. Notwithstanding the fact that there are several factors such as teaching styles, assessment criteria and student diversity that affect reflective writing, the above ways of finding learning styles, thinking skills and mental models might be able to reveal thinking styles (figure 12).

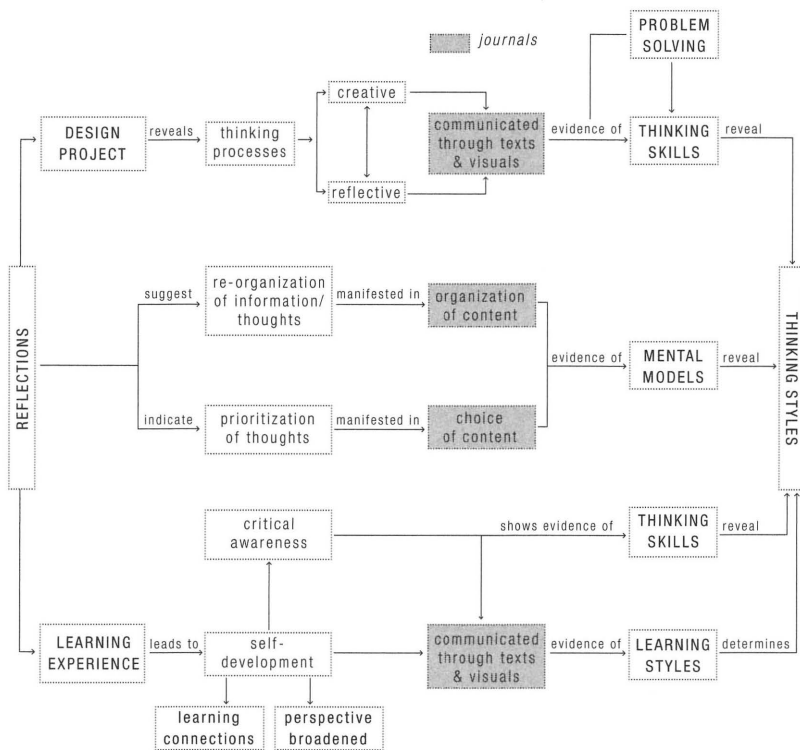


FIGURE 12 Synthesis of findings to answer the research question

Following the above synthesis, a guideline was developed that could give tutors pointers to assess reflective journals and also give them clues to detect students' thinking styles. It covers the various facets

of reflective thinking and writing, as shown in *Figure 13*. This could also help to focus on what the tutor thinks is essential in the course being taught.

INTERPRETATION OF LEARNING	PERSONAL DEVELOPMENT	SCOPE OF REFLECTION	DEVELOPMENT OF THINKING SKILLS	COMMUNICATION OF THOUGHTS
purpose of learning	awareness of values	prioritization of thoughts	problem-solving <i>divergent</i> <i>convergent</i> <i>strategic</i>	representations <i>textual</i> <i>visual</i>
personal viewpoint on teaching	evaluation of strengths & weaknesses	subjectivity & objectivity	conceptualization & visualization	organization of content
testing relevance of theories	achievement of goals		critical	expression of feelings
expansion of taught concepts	awareness of thinking process		reasoning & evaluation	
making connections	broadening of perspectives			

FIGURE 13 *Guideline for assessing reflective journals*

DISCUSSION

The revelatory nature of the reflective journals with respect to thinking styles and learning styles of students provide an opportunity for tutors to test the quality of their own teaching, their teaching methods or strategies and to test the tutors' effectiveness in conveying the intent of their expectations to students. It was evident that the students' responses sometimes presented challenges to those expectations.

The guideline encompasses different aspects of reflective writing from various theoretical perspectives. Tutors can select an appropriate approach with which to understand the thinking of the student; they can then communicate this to the student. In this way, the use of reflective journals becomes more focused for both tutors and students. However the effectiveness of the guideline to reveal a holistic picture of the students' thinking is dependent on certain factors such as choice of reflective content and method of communication. It emphasizes the subjective nature of reflectivity and various interpretations in its assessment. As the guideline was synthesized from analyses of a limited number of journals, one might question its validity. In a wider context of research strategies, there is always a question of reliability and validity of a case study method because its results cannot be generalized. However, the study manages to explore the potential of reflective journals to reveal thinking styles and has found some patterns.

∴ *Essentially, this research is about depth rather than*
∴ *breadth, and is exploratory with suggestive results.*

Although a gamut of thinking styles were explored, the study might have fallen short of exploring students who have a disposition to learn by doing, a learning style that is also supported by the studio teaching style and project-based learning in design education. All the same, according to Edward de Bono (1985) it does not imply that doers do not need to think. What might be highlighted in studio-based learning and especially in design practice is the tacit nature of design. Creativity, anticipation of problems, imaging, visualization, perception, aesthetics, intuition and using judgment are all examples of this dimension, a dimension that has been deeply developed by Michael Polanyi (1983). Though Schön (1983) also subscribes to the concept of tacit knowing-in-action, he also appreciates the importance of reflection on the tacit knowledge to improve a task and perhaps provide a way to make that knowledge explicit.

The importance of writing as a reflective communication tool cannot be ignored by students when they present their design work in practice in the form of writing design statements or justifying their design choices especially in a trans-disciplinary environment. The acts of writing and the idea of literacy are however undergoing a change, because digital media alters thinking in many ways as creative interactions or reflective conversations. Similarly, observing interactions in tutorials and critique; recording and analyzing the change in thinking in these situations could provide new directions for research into student thinking patterns. The study also is incomplete and biased because there was no chance to interview and learn the students' perspectives on journal keeping and on their own reflections.

CONCLUSION

Reflective thinking is an important part of the design thinking process and is critical to learning, therefore it is vital in both the 'knowing-what' and 'knowing-how' of design education. The findings of the research and the assessment guideline might provide tutors with a means to use reflective journals to test the alignment between teaching and learning in the curriculum. While the study offers a glimpse into the existing climate in one school that supports reflective thinking, it can also provide clues on what remains to be examined and incorporated.

: The results of the study can help design students become
: more aware of their own thinking and become motivated
: to pursue reflective thinking more actively, developing it into
: a life-long and transferable learning and designing skill.

They might come to appreciate that ironically, reflection, as described by Biggs and Tang (2007, p 43) has the possibility to transform them from what they are to what they might wish to become.

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ACKNOWLEDGMENTS

The author would like to thank the research supervisor, the interviewed tutors and the students who lent their reflective journals for their respective contributions in conducting this research.

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ABOUT THE AUTHOR

Born in India, Aruna Venkatesh graduated with a Diploma in Architecture from Rachna Sansad, Mumbai, India. With a brief experience in working with architectural firms in India, she joined the interior design industry in Hong Kong, working mainly on hotel design projects. In the capacity of an assistant interior designer she has been involved in the various aspects and phases of hotel design from concept development, design development, material co-ordination and site inspections. She later started practicing interior design as a freelancer for a project in India. Having developed a keen interest in teaching design, she went on to do a Masters in Design (Design Education) from The Hong Kong Polytechnic University. Her final dissertation was a research project in reflective thinking studied through the premises of design students' reflective journals. During the course she discovered her passion for design research and hopes to find opportunities to pursue this interest either in academia or in the industry. Her current areas of interest lie in design cognition; to explore how creativity is nurtured in education and then works in the framework of practice.



CLINICIAN

Abbey Pain Scale
For measurement of pain intensity with dementia and/or complex verbalities.

How to use scale: Write (starting the resident, such as resident 1141)

Name of resident: _____
Name and designation of person completing the scale: _____
Date: _____ Time: _____ of _____

Latest pain relief given was: _____ at _____

01. Verbalisation (No response) (Scale 1) (Score 1) 01

02. Facial grimaces (No response) (Scale 2) (Score 2) 02

03. Change in breathing pattern (No response) (Scale 3) (Score 3) 03

04. Physiological change (No response) (Scale 4) (Score 4) 04

05. Physiological change (No response) (Scale 5) (Score 5) 05

CARER

Royal Berkshire NHS Foundation Trust

5. Where does it hurt them?
Please draw on one of the drawings

6. Do they cry out with pain? (Please tick)

None Sometimes Frequently Constantly

7. Does their face ever show pain?
For example by looking tense or rigid, or by frowning

None Sometimes Frequently Constantly

Can you describe this? _____

CARER + CLINICIAN

Royal Berkshire NHS Foundation Trust

Is your friend or relative in pain?
If yes, go to tick, after the particle you can't do it.

People who have difficulty understanding and communicating may find pain hard to describe but you can tell it when it makes them uncomfortable or when they show discomfort or physical signs of distress.

The number 1 on pain scale for you friend or relative. The number 2 on pain scale for you friend or relative and you help completing the questionnaire.

1. Does it prevent you from completing a task?
 No Yes, please provide an example question that seems relevant to you

2. How much is this pain bothering you?
For example: sleeping, walking, sitting, getting something done.

Are there other things they do when in pain?

3. How often do they feel pain?
None Sometimes Frequently Constantly

4. Do they cry out with pain? (Please tick)

None Sometimes Frequently Constantly

5. How they complained of pain in the past but not now?
 No Yes

Royal Berkshire NHS Foundation Trust

6. Has their body language changed recently?
For example: looking restless, squinting or frowning, or looking uncomfortable.

7. Has their behaviour changed recently?
For example: looking restless or agitated, talking, or making unusual sounds, or pulling at their clothes.

8. Has their face ever shown pain?
For example: looking tense or rigid, or by frowning.

9. How often do they feel pain?
None Sometimes Frequently Constantly

10. Do they have any possible cause of pain?
For example: an injury, infection, sore, bruise.

11. Why have you been on painkillers in the past?
For example: an injury, infection, sore, bruise.

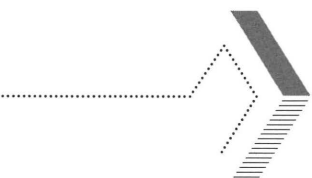
12. Are there things that seem to help to reduce their pain?
For example: heat, cold, massage, distraction, or anything else.

Thank you for filling in this questionnaire.

first iteration

second iteration

clinical trial



02 Designing a Questionnaire to Gather Carer Input to Pain Assessment for Hospitalised People with Dementia.

**ALISON BLACK, ANNETTE GIBB, CLARE CAREY,
SARAH BARKER, CLAIRE LEAKE, LUKE SOLOMONS**

ABSTRACT

We describe development of a questionnaire to elicit pain symptoms and experience, for use by people with dementia or their carers, at hospital admission. The questionnaire provided contextual information to support professionals' use of the Abbey Pain Scale, a validated tool used by nursing staff internationally. Appropriate information and physical design were required in order, not only to create an approachable questionnaire for patients and carers, but also to ensure fit with hospital processes. Fit with hospital process had significant influence on the final form of the questionnaire, compromising some aspects of design for patients and carers, but this compromise was considered essential to ensure pain management procedures were supplemented by wider, contextual information.

Management of pain symptoms in hospitalized, older people can be compromised by communication difficulties, particularly if patients' ability to describe their experience is limited by conditions such as dementia (Horgas, Elliott and Marsiske 2009; Manias 2012). Coe and Miller (2000) have highlighted the importance of both relatives and nursing staff in mediating communication between physicians and older patients. However relatives are rarely able to remain with a patient all the time they are in hospital and so their contribution to such communication can be limited. Manias (op cit.) has described situations where pain symptoms may go untreated because nursing staff mistakenly attribute expressions of pain to delirium or dementia. Such attribution may be more likely if no family carer, with knowledge of the patient, is available to give clarification. Furthermore delirium and dementia symptoms can, themselves, be exacerbated by pain, increasing the difficulty of recognizing and assessing pain symptoms (Herr and Garand 2001).

In this context of potentially limited communication between patient and hospital staff and practical constraints on how much a carer can contribute we describe development of a questionnaire to be used as a communication tool for family carers of people with dementia. The aim of the questionnaire (which might be completed by a family carer on their own or in consultation with a member of hospital staff) was to elicit information from carers about their relative's experience of and response to pain. This information would then be available to hospital staff to help disambiguate pain symptoms in patients who were unable to communicate their experience themselves and, hence, support appropriately targeted pain relief. Note that the purpose of the research described in this paper is the development of a viable questionnaire, the effectiveness of which (on pain relief procedures and outcomes) could then be assessed through subsequent clinical trial.

The setting for this study was a large (800 bed) district general hospital in the UK. The hospital had made effective pain relief for people with dementia a clinical priority, in line with guidance from the UK Department of Health to reduce inappropriate anti-psychotic prescription (Banerjee and Owen 2009, ch. 5). Systematic monitoring of pain symptoms had been newly instigated, using the Abbey Pain Scale (Abbey et al. 2004), a professional monitoring tool, designed for assessment of pain symptoms in people with dementia. The scale is used internationally and, simple and quick to use, is recommended by UK national guidelines for assessment of pain in older people with impaired cognition/communication (Royal College of Physicians 2007). Used at regular intervals, the scale (*Figure 142*) tracks and assigns a score to pain symptoms, along six dimensions, in order to guide prescription of pain relief.

Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise.

How to use scale: While observing the resident, score questions 1 to 6

Name of resident:

Name and designation of person completing the scale:

Date: **Time:**

Latest pain relief given was **at** **hrs.**

Q1. Vocalisation
eg: whimpering, groaning, crying
Absent 0 Mild 1 Moderate 2 Severe 3 **Q1**

Q2. Facial expression
eg: looking tense, frowning, grimacing, looking frightened
Absent 0 Mild 1 Moderate 2 Severe 3 **Q2**

Q3. Change in body language
eg: fidgeting, rocking, guarding part of body, withdrawn
Absent 0 Mild 1 Moderate 2 Severe 3 **Q3**

Q4. Behavioural Change
eg: increased confusion, refusing to eat, alteration in usual patterns
Absent 0 Mild 1 Moderate 2 Severe 3 **Q4**

Q5. Physiological change
eg: temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor
Absent 0 Mild 1 Moderate 2 Severe 3 **Q5**

Q6. Physical changes
eg: skin tears, pressure areas, arthritis, contractures, previous injuries.
Absent 0 Mild 1 Moderate 2 Severe 3 **Q6**

Add scores for 1 – 6 and record here **Total Pain Score**

Now tick the box that matches the Total Pain Score

0 – 2 No pain	3 – 7 Mild	8 – 13 Moderate	14+ Severe
------------------	---------------	--------------------	---------------

Finally, tick the box which matches the type of pain

Chronic	Acute	Acute on Chronic
---------	-------	------------------

Dementia Care Australia Pty Ltd
Website: www.dementiacareaustralia.com

Abbey, J; De Bellis, A; Piller, N; Esierman, A; Giles, L; Parker, D and Lowcay, B.
Funded by the JH & JD Gunn Medical Research Foundation 1998 – 2002
(This document may be reproduced with this acknowledgment retained)

- B 1 Vocalization e.g. whimpering, groaning, crying
- 2 Facial expression e.g. looking tense, frowning, grimacing, looking frightened
- 3 Change in body language e.g. fidgeting, rocking, guarding part of body, withdrawn
- 4 Behavioral change e.g. increased confusion, refusing to eat, alteration in usual patterns
- 5 Physiological change e.g. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor
- 6 Physical changes e.g. skin tears, pressure areas, arthritis, contractures, previous injuries.

FIGURE 1 *The Abbey Pain Scale tool used by hospital nurses for regular pain monitoring (A), shown with listing of scoring criteria used in the tool (B).*

As part of the introduction of the Abbey Scale, the hospital's Pain Team conducted an education programme for care staff who were implementing it and became aware of potential misinterpretation of patients' pain symptoms, similar to that described by Manias (op cit.). Working in collaboration with the hospital's Older People's Mental Health Liaison Team, the Pain Team sought the involvement of patients' relatives or carers in improving identification of patients' pain symptoms. This kind of involvement has been recommended by Herr et al. (2006) and, similarly, in the UK's national guidelines on pain assessment (op cit.), although no specific process for this involvement has been set out.

A precedent for carer involvement in providing contextual information, valuable to the care of hospitalised, older patients, had been set by a tool, *Information About Me* (Figure 2), developed through collaboration between the UK Alzheimer's Society and National Health Service (NHS) hospitals. The tool was already in use at the hospital (similar discursive questionnaires are used widely across the NHS and in other health care systems).

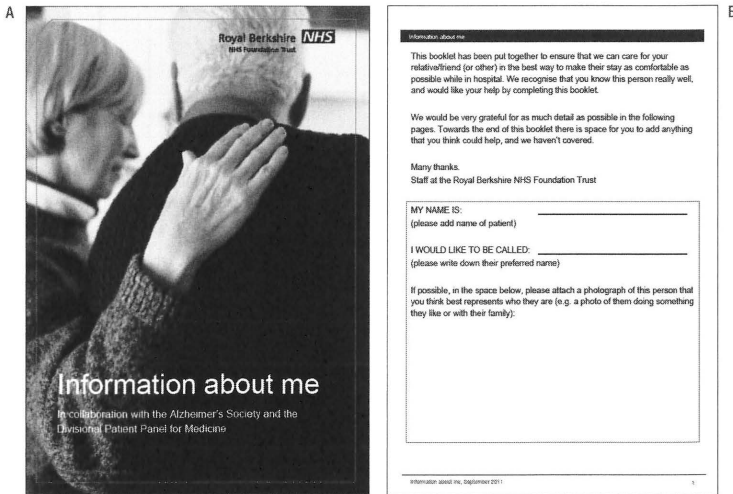


FIGURE 2 Cover (A) and first page (B) of the *Information About Me* questionnaire, developed by the UK Alzheimer's Society and National Health Service hospitals, in order to gather information about hospitalised patients and help build a personalised relationship with care staff.

The hospital Pain Team proposed a questionnaire, designed along similar lines to *Information About Me*, that could be completed by patients or, more likely, their family carers (who might be more able to articulate their relative's history) on hospital admission. The aim of gathering carers' perspective on patients' response to pain and manifestation of pain symptoms was twofold:

- 1 *Firstly, to help disambiguate expression of pain that staff would assess using the Abbey Pain Scale, so reducing potential misattribution of responses to pain to symptoms of dementia or delirium;*
- 2 *Additionally, to provide contextual information about past causes of pain and response to pain relief which would help guide clinical and care staffs' treatment decisions.*

While the Abbey scale was used as the starting point for developing the new, carer-facing tool, we planned to augment questions about expression of pain with questions about interventions that would increase patient comfort (for example, use of heat pads or manipulation) which, if used, could reduce the need for medication.

We agreed on a user-centred development process, involving informants typical of those who would use the developed questionnaire, both professionals involved in pain assessment and end-users i.e. family carers of people with dementia. Note that the project team comprised clinical and care staff (an old age mental health liaison psychiatrist, a pain nurse and a mental health liaison nurse) and that two of the designers had experience of family members with dementia. However we wished to broaden consultation beyond the design team and consideration was given early on to confidentiality and the ethics of involving consenting carers in the design process. The project was designed in the manner of a clinical survey or technology appraisal with anonymisation and no patient identifiable information.

FIRST DESIGN ITERATION

DESIGN DEVELOPMENT

CONTENT

The first four and sixth questions of the Abbey Pain Scale were taken as the core of the new questionnaire.¹ These five questions focused on the behavioural responses to pain (vocalisation, facial expression, body language, behaviour) and physical changes (cuts, bruising etc.) that hospital staff would need to interpret and assess when using the Abbey scale. No attempt was made to replicate the numeric rating of the Abbey scale (the numeric ratings on the scale are used to aid professionals' decisions about pain relief intervention) but, instead, the questions were refocused to gather family carers' descriptions of patients' typical pain responses and known physical symptoms. The fifth question from the Abbey scale, relating to physiological changes as a result of pain (temperature, blood pressure etc.) was excluded as it was thought inappropriate for people without clinical experience to respond to. The project team, through team discussion, generated further questions they considered relevant to pain management, based on their experience of caring for people with dementia, resulting in a list of fifteen questions. An additional question, to gather feedback on the questionnaire itself, was included in this trial version. See *Figure 3* for a listing of questions in the first design iteration.

IS YOUR FRIEND OR RELATIVE IN PAIN? HELP US TO LOOK AFTER THE PEOPLE YOU CARE ABOUT

1. Does..... ever complain of pain?
2. What words have they used to describe their pain? For example, burning, shooting, stabbing, pinching, stretching, aching. Are there other things they say when in pain?
3. How often do they feel pain? For example, is it constant, does it come and go, is it very sudden and short, or is it only during specific activities?
4. Have they complained of pain in the past but stopped telling you about it recently?
5. Where does it hurt them? [body map image]
6. Do they cry out with pain?
7. Does their face ever show pain? For example, by looking tense or frightened or by frowning? Can you describe how?
8. Has their body language changed recently? For example fidgeting, rocking, guarding part of the body, or hunching. Can you describe how?
9. Has their behavior changed recently?
For example increased confusion, refusing to eat, problems sleeping, irritable or aggressive behavior, increase in swearing, wanting to be left alone? Can you describe how?
10. Are there specific activities that they find painful and resist doing?
For example washing, getting out of bed, climbing stairs.
11. Have you noticed any possible causes of pain?
For example, cuts, bruises, arthritis or recent falls.
12. Have they been on painkillers in the past? If yes, do you know what kind and why?
Were there any side effects as a result of the painkillers?
13. Are there things that seem to help to soothe their pain?
For example having a hot drink, blankets, hot water bottles, cold compress, smoking, having an alcoholic drink.
14. Is there anything else you think is relevant or could help us to help them?

FIGURE 3 List of questions, brainstormed by the project team, for inclusion in the first iteration of the carer-facing questionnaire.

Since the questions were verbal, the clinical team suggested inclusion of a body map, recommended by UK national guidelines on pain assessment (op cit.), to provide a graphic parallel to the questions. Gender neutral outlines of front and back body views were drawn. The design team discussed whether to ask carers to use the body map both to describe pain experience as well as show pain locations but decided this would duplicate other questions on the questionnaire and that there could be benefit to hospital staff using carers' input in maintaining a set of questions that, as far as possible, paralleled those in the Abbey scale. Hence the body map was shown with a simple request to show pain location.

The questionnaire title 'Is your friend or relative in pain? Help us to look after the people you care about' was proposed in order to orient the reader to the questionnaire purpose. An explanatory introduction reinforced the role of relatives or carers in providing information that was useful to hospital staff.

LANGUAGE

The language of the questionnaire was direct and non-technical. Where questions were thought likely to require interpretation, example answers were given. For instance:

Has their body language changed recently?

For example fidgeting, rocking, guarding part of the body or hunching.

For questions drawn from the Abbey Pain Scale, the examples given were based on those used by Abbey. They were then modified to exclude any examples that could be difficult to interpret by non-professionals and to include additional examples that might help support broad responses from family carers. So, for example, where the Abbey scale exemplified changes in behaviour as:

Increased confusion, refusal to eat, alteration in usual patterns
the carer questionnaire gave more examples, particularly to clarify what might be meant by the Abbey scale's reference to 'alteration in usual patterns':

Increased confusion, refusing to eat, problems sleeping, irritable or aggressive behaviour, increase in swearing, wanting to be left alone

Similar ranges of examples were given for questions that had been generated by the project team, for instance:

Are there things that help to soothe their pain?

For example having a hot drink, blankets, hot water bottles, cold compress, smoking, having an alcoholic drink

Note that smoking and alcohol were included to help elicit as realistic a picture of the patient's experience and needs as possible.

There was a possibility that examples would constrain, rather than encourage, responses; see Rose (1981) and Schwartz (1999) for discussion of the interpretation of the intentions of questions that respondents must make. However, given the wide range of potential users and circumstances of use (in some cases a carer may not feel confident enough to ask for clarification), supporting interpretation of the question seemed appropriate.

GIVING FORM

A combination of practical and emotional factors influenced initial decisions regarding document format. The precedent set by *Information About Me* suggested an A5 format (close to American half sheet). Within the project team, it was perceived as 'friendlier' in format than the larger A4 (close to American letter), associated with office use (a perception also noted by Perez et al. 2012). A5 format might also be easier to complete in a setting where a table or other surface might not be available to support the document as a respondent wrote on it. Our initial aim was to produce a single sheet (A4) that could be folded to a four page, A5 booklet. This document format could be

printed on demand within the hospital (in many NHS hospital settings, on-demand printing and photocopying are currently preferred over other forms of document reproduction).² However, early attempts to use a single sheet, with typeface Bliss, at 14pt, the upper end of size recommendations for legibility (RNIB 2011), delivered a layout that was too cramped to allow the kind of discursive response to questions that was anticipated (Figure 4).

Is your friend or relative in pain?

People who have difficulty understanding and communicating may feel pain but may not be able to tell us about it. In many cases, simple pain medication can make them more comfortable and prevent distress and suffering.

This leaflet is to help plan care for your friend or relative. We recognise that you know this person really well, and would like your help completing their pain assessment.

Name of patient: _____ Date: _____
 Questionnaire completed by: _____
 Relationship to patient: _____

Does _____ ever complain of pain? YES NO

What words would they use to describe their pain? For example, burning, shooting, stabbing, pinching, stretching, aching.

Talking about pain...

How often do they feel pain? For example, is it constant, does it come and go, is it very sudden and short, or is it only during specific activities?

Have they complained of pain in the past but stopped telling you about it recently? (4-7)

Where does it hurt them? Please describe

Does he/she cry out with pain? Please circle

Never Sometimes Frequently A lot of the time

Does their face ever show pain, for example by looking tense or frightened or by frowning? Please circle and describe how

Never Sometimes Frequently A lot of the time

Showing pain...

Showing pain...

Has their body language changed recently, for example fidgeting, rocking, guarding part of the body, or hunching? Please circle and describe how

Not at all Hardly A bit A lot

Has their behaviour changed recently, for example increased confusion, refusing to eat, problems sleeping, irritable or aggressive behaviour, increase in swearing? Please circle and describe how

Not at all Hardly A bit A lot

Are there specific activities that he/she finds painful, for example washing, getting out of bed, climbing stairs?

Have you noticed any possible causes of pain, for example cuts, bruises, arthritis or recent falls?

FIGURE 4 Initial attempts to create a single sheet questionnaire incorporating all the desired questions were thought by the project team to be too cramped to take forward to trial.

Instead we agreed on a more generously-spaced, eight-page, A5 leaflet, at least for initial feedback. We were aware that this format reduced the options for local, on-demand printing.

END USER INPUT

INFORMAL FEEDBACK

A draft questionnaire leaflet was prepared and distributed to four informants for informal feedback on its content and design. The informants (ages ranging from their 50s to their 80s) were currently caring for or had cared for relatives (parents or spouses) with dementia. Informants were asked to fill out the questionnaire as if it applied to their relative and to note any comments about the questionnaire itself that occurred to them while they were completing it (see, for example, *Figure 5*). They were then interviewed about the experience of filling out the form and comments they had made. Additional input was gathered from dementia care support staff (care assistants trained specifically to support nursing of people with dementia, who would be implementing the questionnaire) and one of the hospital's consultant geriatricians, who were asked to review and comment on the draft questionnaire.

5 Where does it hurt them? Please show us on this drawing.

So often it is a generalised pain - can this be indicated?

Page 4

6 Do they cry out with pain? Please circle

0 Never 1 Sometimes 2 Frequently 3 Constantly

7 Does their face ever show pain? For example by looking tense or frightened or by frowning?

0 Never 1 Sometimes 2 Frequently 3 Constantly

Can you describe how?

(MORE HELP WITH WORDING)

Page 5

8 Has their body language changed recently? ^{NOT CLEAR WHAT SHOULD BE CIRCLED?} For example fidgeting/jocking, guarding part of the body, or hunching. Please circle

0 Not at all 1 Hardly 2 A bit 3 A lot

Can you describe how?

IT IS MORE "RESTLESS" - I WOULD LIKE THIS WORD SHOULD BE INCLUDED

9 Has their behaviour changed recently? For example increased (confusion) refusing to eat, problems sleeping, irritable or aggressive behaviour, increase in swearing? Please circle

0 Not at all 1 Hardly 2 A bit 3 A lot

Can you describe how?

SHE DOESN'T ALWAYS RECOGNISE ME, AS IS WHERE SHE IS

Page 6

10 Are there specific activities that they find painful and resist doing? For example washing, getting out of bed, climbing stairs

SHE RESISTS THIS, BUT IT MAY NOT BE BECAUSE OF PAIN

11 Have you noticed any possible causes of pain? For example cuts (rough) arthritis or recent falls

THESE GIVE SOME CAUSE FOR CONCERN AS SHE CANNOT EXPLAIN - HE MIGHT BE DUE TO NEUR. PAIN OR OVER?

12 Have they been on painkillers in the past? YES NO

If yes, do you know what kind and why? Were there any side effects as a result of the painkillers?

PROBABLY ONLY PARACETAMOL SIDE EFFECTS DIFFICULT TO DETERMINE

Page 7

Figure 5 Examples of feedback from one of the informants who reviewed drafts of the questionnaire during its development.

Across carer informants and staff the response to the use of such a questionnaire on hospital admission was positive. After project team discussion, some of the proposals that informants and carers had made for amendments to the detailed presentation of the questionnaire were fed into a subsequent editorial and design iteration before the next stage of trialling the questionnaire on hospital wards.

QUESTIONNAIRE TRIAL

A three month trial was arranged to assess the questionnaire's intrinsic effectiveness, i.e. whether it elicited appropriate responses from its intended users. We had some specific questions about its design:

Was the questionnaire too long – would carers flag before completing it?

Were individual questions relevant and comprehensible?

*Did use of example responses constrain carers' own responses?
Could carers use the body map effectively?*

What were carers' and staff members' views of the questionnaire's usefulness?

We were also concerned to establish the questionnaire's extrinsic effectiveness, i.e. its fit into hospital routine and potential for impact on prescription of analgesic and antipsychotic medication.

As mentioned in Section 1, this trial was a precursor to a study of the questionnaire's actual impact on pain treatment, and particularly medication prescription, which would need to be assessed through a larger-scale, controlled trial.

Two hundred finalized questionnaires (see thumbnails in *Figure 6*) were distributed to the dementia care team at the hospital, for use in two pilot patient areas. Distribution was preceded by presentations to care staff introducing the questionnaire and the thinking behind it. Staff were asked either (according to circumstances) to give the questionnaire to relatives of newly admitted patients to complete independently or to support relatives in completing the questionnaire. Staff were asked to return completed questionnaires to the research team after the patient had been discharged. A collection box was placed at the nursing stations of the pilot wards and completed questionnaires were collected by members of the project team. We were aware of the potential pitfall of this method of gathering data, since returning questionnaires could be forgotten, but we had the commitment of care staff to the project. As is reported in the results section, returns were limited even though staff were prompted throughout the trial to ensure that questionnaires were used and returned for analysis. A further 50 questionnaires were presented to family carers of people with dementia at a local carer education meeting, where some attendees consented to complete trial questionnaires.

Royal Berkshire NHS Foundation Trust

Is your friend or relative in pain?

Help us to look after the people you care about

13 Are there things that seem to help to soothe their pain?
For example having a hot drink, blankets, hot water bottles, cold compress, smoking, having an alcoholic drink.

14 Is there anything else you think is relevant or could help us to help them?

This is a trial leaflet. Your comments on filling it out would be helpful.

Thank you very much for your time.

Page 8

FIGURE 6
Thumbnails showing structure of the first iteration questionnaire.

Name of patient _____

Today's date ____/____/____

Questionnaire completed by _____

Relationship to patient _____

People who have difficulty understanding and communicating may feel pain but may not be able to tell us about it. In many cases, simple pain medication can make them more comfortable and prevent distress and suffering.

This leaflet is to help plan care for your friend or relative. We recognise that you might know this person really well, and would like your help completing their pain assessment.

Video: People's shared health beliefs from: <http://www.bbc.com/health>
<http://www.bbc.com/health>
 © 2012 BBC. Permission is granted under a CC BY Licence
 Research Institute for Health, Learning & Social Sciences
 a collaboration with Department of Psychiatry & Social, Learning & Clinical Psychology, University of Bath, Bath BA2 9AT
 Version 1.0 March 2012

Page 2

1 Does _____ ever complain of pain? YES NO

2 What words have they used to describe their pain?
For example: burning, shooting, stabbing, pinching, scratching, stinging.

Are there other things they say when in pain?

3 How often do they feel pain?
For example, it is constant, once a minute and so on, it is very sudden and short or it is only during specific activities?

4 How they complained of pain in the past but stopped telling you about it recently? YES NO

Page 3

5 Where does it hurt them?
Please show us on the drawing.

Page 4

6 Do they cry out with pain? Please circle:

Never Sometimes Frequently Constantly

7 Does their face ever show pain?
For example by looking tense or tightened or by frowning?

Never Sometimes Frequently Constantly

Can you describe how?

Page 5

8 Has their body language changed recently?
For example fidgeting, moaning, grinding teeth of the body or hunching. Please circle:

Never Sometimes Frequently Constantly

Can you describe how?

9 Has their behaviour changed recently?
For example increased confusion, refusing to eat, problems sleeping, irritability or aggressive behaviour, increase in sweating, sweating to the left, drowsy? Please circle:

Never Sometimes Frequently Constantly

Can you describe how?

Page 6

10 Are there specific activities that they find painful and more than?
For example walking, getting out of bed, drinking water.

11 Have you noticed any possible causes of pain?
For example cuts, bruises, infections or sprain falls.

12 Have they been on painkillers in the past? YES NO

If yes, do you know what kind and why? What other side effects as a result of the painkillers?

Page 7

RESULTS

NUMBER OF RETURNS: Pooling the returns from hospital wards and the carer education meeting, of the 250 questionnaires distributed, only 25 were returned. Even taking into account concern about relying on staff to return the questionnaire, this poor return was a strong indicator of the questionnaire's limited potential impact.

QUALITY OF RETURN: Despite low return numbers the quality of returns was instructive. They were fully filled out, suggesting that those who consented to complete the questionnaire did not find it too long. Some respondents provided expansive answers to questions, through to the last page (see *Figure 7*), although others gave answers of one or two words. We did not find any questions that were misunderstood. Answers to questions with example responses (discussed in section 2.1) showed sufficient variation to convince us that the examples did not constrain respondents.

A

8 Has their body language changed recently?
For example fidgeting, rocking, guarding part of the body, or hunching. Please circle.

0 | 1 | 2 | 3
Not at all | Hardly | A bit | A lot

Can you describe how?
HUNCHING WHEN SITTING
TOUCHING FOREHEAD WITH LEFT ARM

9 Has their behaviour changed recently?
For example increased confusion, refusing to eat, problems sleeping, irritable or aggressive behaviour, increase in swearing, wanting to be left alone? Please circle.

0 | 1 | 2 | 3
Not at all | Hardly | A bit | A lot

Can you describe how?
VERY SLEEPY, NOT EATING
WELL, MORE CONFUSED

Page 6

10 Are there specific activities that they find painful and resist doing?
For example washing, getting out of bed, climbing stairs.

GETTING OUT OF BED

11 Have you noticed any possible causes of pain?
For example cuts, bruises, arthritis or recent falls.

FELL 17/12 - FRACTURED
RIGHT HI?

12 Have they been on painkillers in the past? YES NO

If yes, do you know what kind and why? Were there any side effects as a result of the painkillers?

CAN'T REMEMBER NAME - BUT
THIS WILL BE 10 PAGES FROM
ONCE HOME

Page 7

B

13 Are there things that seem to help to soothe their pain?
For example having a hot drink, blankets, hot water bottles, cold compress, smoking, having an alcoholic drink.

BLANKET

14 Is there anything else you think is relevant or could help us to help them?

JUST CHEERFUL REASSURANCE
SHE CAN BE FEARFUL AND
CAN BE "NEEDY"
SHE LOVES ICE CREAM (VANILLA)

This is a trial leaflet. Your comments on filling it out would be helpful.

HOPE THIS HELPS HER DEMENTIA
DOES MAKE CARE MORE DIFFICULT
I THINK THIS FORM IS A GREAT
THANK YOU VERY MUCH FOR YOUR TIME.

GOOD IDEA. IS FROM
MISSUS SCOTLANDS.

Page 8

FIGURE 7

Examples of returns of questionnaires completed by carers in the trial, showing variation in response length. 7A and B are from the completed questionnaire of one participant, 7C and D from a second participant. The diversity of responses demonstrated that the questions (particularly those with example responses) had not constrained the information given by respondents.

C

8 Has their body language changed recently?
for example fidgeting, rocking, guarding part of the body, or hunching. Please circle.

0 Not at all 1 Hardy 2 A bit 3 A lot

Can you describe how?
He clenches his jaw and his fists
while experiencing those spasms of
pain

9 Has their behaviour changed recently?
For example increased confusion, refusing to eat, problems sleeping, irritable or aggressive behaviour, increase in swearing, wanting to be left alone? Please circle.

0 Not at all 1 Hardy 2 A bit 3 A lot

Can you describe how?
Refusing to eat and increased confusion

10 Are there specific activities that they find painful and resist doing?
For example washing, getting out of bed, climbing stairs.

Swallowing

11 Have you noticed any possible causes of pain?
For example cuts, bruises, arthritis or recent falls.

He is in a cast shown by x-ray

12 Have they been on painkillers in the past? YES / NO
If yes, do you know what kind and why? Were there any side effects as a result of the painkillers?

Don't know which specifically.
Aspirin

Page 6 Page 7

D

13 Are there things that seem to help to soothe their pain?
For example having a hot drink, blankets, hot water bottles, cold compress, smoking, having an alcoholic drink.

14 Is there anything else you think is relevant or could help us to help them?
Because he has been non-communicative
for much of the time while in hospital,
it's difficult to be specific. He also has
Ativan's and therefore has trouble with
his short-term memory.
This is a trial leaflet. Your comments on filling it out
would be helpful.

Thank you very much for your time.

Page 8

In two cases the body map, which we had seen as a parallel means to gather information to verbal questions, elicited responses that were not given elsewhere in the questionnaire. Particularly striking was an instance where a carer noted a second site of pain, which had not been the cause of admission. The pain was investigated and found to be the result of a pre-presentation, untreated fracture, which was then treated. In the second case the husband of a patient used the body map to illustrate pain in his wife's pubic area, which he had not discussed with a clinician or described verbally on the questionnaire.

Those who responded to the trial feedback question at the end of the questionnaire made positive comments on the questionnaire's potential usefulness, similar to the responses of staff when the questionnaire was introduced to them.

DISCUSSION

Our trial demonstrated that we had produced an intervention that was intrinsically effective, and was liked by its potential users. However the low level of uptake across the trial suggested limited potential for impact on clinical practice. It may have been that the relatively informal trial methods did not embed the questionnaire well enough in everyday ward process. However, as discussed in section 2.2, effort had been made during the trial to promote the questionnaire's use.

Subsequent discussion with dementia care support staff, the key link in this trial between hospital systems and patients, revealed that, while staff appreciated the potential benefit of the questionnaire, they felt they did not have time to introduce it into their routine. Other reasons given for lack of implementation included disruption of typical ward arrangement, following ward closures for cleaning. However, such disruptions are not unusual in busy hospitals and any design proposal should be robust enough to persist given such eventualities. There was no indication from staff reports that any relatives who had been asked to complete the questionnaire had declined.³

It appeared that, despite involvement of potential users in questionnaire development, we had stumbled over the problem, highlighted by Wright (1998, p 61), of producing an effective design, but not an appropriate design solution for the context in which it was to be used.

As Wright continues, in these circumstances testing indicates the need for a change of approach, rather than refining the existing solution. This trial suggested the potential effectiveness of the questionnaire as a means of gathering information about patients, but not as a tool that could be implemented in routine patient care. Hence, rather than abandon a project that was agreed by all parties to be well founded, we then sought a new approach to questionnaire design that would increase the likelihood of implementation and eventual impact on pain relief and prescription practices.

SECOND DESIGN ITERATION

BUILDING ON FIRST ITERATION FEEDBACK

In order to ensure uptake of the questionnaire, without adding significantly to the burden of care staffs' daily routine, we needed to integrate it directly into existing practice. We were aware that the professional version of the Abbey Pain Scale was administered routinely on patient admission to a ward and, subsequently, at regular time intervals. Therefore we decided to link the carer pain questionnaire to the first use of the Abbey Pain Scale, by combining the two

in the same document. We also sought to minimize any further barriers to uptake by reducing the questionnaire to a single sheet that could be printed on demand (as discussed in Section 2.1), rather than an eight-page, pre-formatted booklet. These two, new requirements created a 'squeeze' on the spatial layout of the questionnaire which we had sought to avoid initially. Hence there were compromises in subsequent design, which we felt would be offset by increasing the likelihood of carer input to pain assessment.

CONTENT AND LANGUAGE

We tightened the focus of questionnaire content, removing two questions that did not target pain relief directly: a general question, 'Is there anything else you think is relevant or could help us to help them?' and the trial feedback question about the usefulness of the questionnaire. The general question received some extensive answers in the trial but these tended to diverge from pain relief. Since there was no clear nursing route for response to information carers gave here, it may have set up an expectation of response that might not have been met.

The remaining questions were the same as those in the first iteration design but, following input from a carer while this revision was in preparation, we added an instruction to guide the user to continue filling out the form, even if their response, to the first question 'Does the patient ever complain of pain?' was negative. We partly reordered the question sequence to ensure best fit of content into the available space.

Debate about whether to exclude the body map, which took up considerable space in the first iteration design, concluded that it should be retained, since it had revealed information that had not been given elsewhere in trial questionnaires. It was also seen as a direct means of communication with staff, which did not rely on their reading detailed information (Nygren, Wyatt and Wright 1998).

GIVING FORM

The most significant changes in the re-design resulted from the move from A5 booklet to a single A4 sheet, and the inclusion of the professional Abbey Pain Scale. In consequence, the new form featured reduced type size, reduced space for responses and smaller body map images, all set within a two column layout (see *Figure 8*).

Royal Berkshire NHS
NHS Foundation Trust

Is your friend or relative in pain?

Help us to look after the people you care about

People who have difficulty understanding and communicating may feel pain but may not be able to tell us about it. In many cases, simple pain medication can make them more comfortable and prevent distress and suffering. This leaflet is to help plan care for your friend or relative. We recognise that you know this person well, and would like your help completing their pain assessment.

1 Does the patient ever complain of pain?
 Yes No, please continue with any questions that seem relevant to you.

2 What words do they use to describe their pain?
 For example, burning, shooting, stabbing, pinching, stinging, aching.

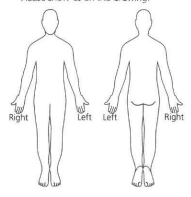
 Are there other things they say when in pain?

3 How often do they feel pain?
 For example, is it constant, does it come and go, is it very sudden and short, or is it only during specific activities?

4 Do they cry out with pain? Please circle.
 0 1 2 3
 Never Sometimes Frequently Constantly

5 Have they complained of pain in the past but stopped telling you about it recently?
 Yes No

6 Where does it hurt them?
 Please show us on this drawing.



7 Does their face ever show pain?
 For example by looking tense or frightened or by frowning?
 0 1 2 3
 Never Sometimes Frequently Constantly
 Can you describe how?

Please turn over →

© Royal Berkshire Medical Health Liaison Team, Royal Berkshire Hospital, Reading RG2 9AT, Tel: 0118 322 8115 (text/voice), www.royalberkshire.nhs.uk
 Written by: Annette Gibbs, Matt Longwell & G. L. Last, published in collaboration with Department of Paediatrics & Paediatric Communication, University of Reading, February 2013. Review due March 2014.

FIGURE 8A
 Second design iteration with questionnaire revised to fit a single A4 sheet and to include a professional pain assessment (using the Abbey Pain Scale) alongside the carer questionnaire (see 8B).

Since some of the carers' responses in the first trial were brief we felt the compromise in response space was acceptable, even though less than ideal and potentially limiting to those who wished to respond expansively. Type size reduction (to 12pt Frutiger) maintained a relatively large appearing size, albeit at the lower end of the 12–14pt range that is usually specified in accessibility guidelines (RNIB 2011).

We reduced the size of the body map images as far as we felt acceptable to allow a respondent to mark a pain area accurately. The map was smaller than typically presented in medical settings. However relatively small body map images have been used successfully; for example, those used in Kwikpoint communication cards to support communication across language barriers in war zones (Eldredge 2013).

The compressed space allowance necessitated the use of horizontal rules to separate the questions. A tinted (grey) rule was used in order to reduce interruption as carers read down the questionnaire. The rules had the benefit of reinforcing the column structure of the document and, together with prominent question numbers, indicated direction of reading.

FOR HOSPITAL USE

The Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise

How to use scale: While observing the resident, score questions 1 to 6.

0 1 2 3
 Not at all Hardly A bit A lot

8 Has their body language changed recently?
 For example fidgeting, rocking, guarding part of the body, or hunching. Please circle.
 Can you describe how?

9 Has their behaviour changed recently?
 For example increased confusion, refusing to eat, problems sleeping, irritable or aggressive behaviour, increase in swearing, wanting to be left alone? Please circle.
 Can you describe how?

10 Are there specific activities that they find painful and resist doing?
 For example washing, getting out of bed, climbing stairs.

11 Have you noticed any possible causes of pain?
 For example cuts, bruises, arthritis, recent falls.

12 Have they been on painkillers in the past?
 Yes No
 If yes, do you know what kind and why?
 Were there any side effects?

13 Are there things that seem to help to soothe their pain?
 For example having a hot drink, blankets, hot water bottles, cold compress, smoking, having an alcoholic drink.

Thank you for filling in this questionnaire.

7 Patient Name: _____
 Name and designation of person completing the scale: _____
 Date: _____ Time: _____
 Pain relief given: _____ at: _____

Q1 Vocalisation eg. whimpering, groaning, crying
 Absent 0 Mild 1 Moderate 2 Severe 3

Q2 Facial expression eg. looking tense, frowning, grimacing, looking frightened
 Absent 0 Mild 1 Moderate 2 Severe 3

Q3 Change in body language eg. fidgeting, rocking, guarding part of body, withdrawn
 Absent 0 Mild 1 Moderate 2 Severe 3

Q4 Behavioural change eg. increased confusion, refusing to eat, alteration in usual patterns
 Absent 0 Mild 1 Moderate 2 Severe 3

Q5 Physiological change eg. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor
 Absent 0 Mild 1 Moderate 2 Severe 3

Q6 Physical changes eg. skin tears, pressure sores, arthritis, contractures, previous injuries
 Absent 0 Mild 1 Moderate 2 Severe 3

Add scores for Q1 to Q6 and record here
 Total pain score

Now tick the box that matches the total pain score

0-2	3-7	8-13	14+
No pain	Mild	Moderate	Severe

Finally, tick the box which matches the type of pain
 Acute Chronic Acute on chronic

Abbey J, De Bellis A, Piller A, Espartero A, Giles L, Parker D, Lomasco B
 The Abbey Pain Scale. Funded by the Jt & St. Doris Medical Research
 Foundation 1988-2002. This document may be reproduced with the
 acknowledgement (see above)

The professional Abbey Pain Scale was included on the sheet in a tinted column, to distinguish it from the carer-facing questionnaire. While acknowledging that all users need to see text at a legible type size we felt it appropriate to reduce the type size here to a (still legible) 10pt Frutiger, increasing the distinction between professional and public-facing tools.

END USER INPUT

During this iteration we gathered informal input from potential users (as with the first iteration four current family carers and, additionally, members of dementia care support staff), paying particular attention to navigation through the new, two-column structure and the potential impact of reduced space available for responses. As mentioned in discussion of Content and Language, above, this consultation led to the inclusion of additional instructions to continue completing the form, even if the answer to the first question was negative.

The re-designed questionnaire is now due for further trial which will provide the opportunity to reassess its extrinsic effectiveness (i.e. its fit with hospital routine and potential for impact on pain relief practices). Longer term, once the questionnaire has become an established part of clinical practice, it will be possible to assess its impact on prescription of analgesic and anti-psychotic medication.

DISCUSSION AND CONCLUSION

The contribution of family carers (typically adult children or spouses) to the health outcomes of people with dementia is well understood (Brodaty, Green and Koschera 2003). Published strategies for dementia care in many countries recommend involving carers as partners in care-giving, e.g. in the US (Alzheimer's Association et al, 2004), UK (Banerjee and Owen 2009) and Australia (Dow et al. 2004). Our study draws attention to the requirement for design to respond to the communication needs of both sides of such a carer-professional partnership.

In many reported cases of forms or questionnaire design initial, systems-focused design solutions require adaption to satisfy the needs of end users (Barnett 1988, 12–19). Unusually, perhaps, in our case the situation was reversed with an initial approach that favored the end user at the expense of the organizational user or system. Our initial approach was taken with the full endorsement of organizational users (professional dementia care staff) but it failed as a communication tool because they found it difficult to integrate it into their ward routines. It is possible that staff were already aware of the potential difficulties of the first design iteration but felt unable to express their concerns when the intervention was presented to them (Kramer and Schmalenberg 2003). Alternatively they may have overlooked practical difficulties

with the first iteration design because of its visual similarity to the popular *Information About Me* booklet (a similar effect has been reported in Keller-Cohen, Meader and Mann 1990) or because its visual simplicity gave an immediate impression of usability (Song and Schwartz 2010). However, sometimes contextual influences, such as the communication demands of a busy hospital (Coeira and Tombs 1998), can only be discovered through testing within the full context of use and constellation of potential users (Black 1998).

Design literature, in common with the literature of other disciplines (see, for example, Rosenthal 1979, Giner-Sorolla 2012), rarely reports failure of an intervention (although design failures are often highlighted in popular Internet design forums). Nor does design literature tend to report solutions where user feedback changes a design approach significantly, i.e. where the initial design solution appears to be substantively wrong. In our case, feedback resulted in a shift in approach from a discursive questionnaire to a far more constrained means of information exchange. As mentioned in Section 3.1, we are aware that the limited space for responses in the second iteration design solution may constrain family carers who wish to supply detailed information. However our priority is to ensure family carers' knowledge feeds into professionals' decision-making and have aimed to balance carers' and professionals' needs in developing this tool for information exchange. Further ahead we might envisage digital versions of such a tool which, provided they could be made available for carers to give input, might place less constraint on the amount of information a carer provided (although would also need to take into account the demand on professionals of absorbing the amount of information given). However, in the setting described, where electronic patient records and prescribing systems are not yet linked, paper forms provide an interim system.

Many academic design research reports do not extend to testing in context of use or after implementation (see, for a recent medical forms example, Frascara and Guillermina 2010). Testing interventions in a clinical setting is complex and the timescales needed for approval and permissions can be an impediment to it being carried out at all. The focus in health care research on clinical interventions, rather than on communication or other aspects of care, may also reduce the likelihood that such interventions will be tested. However concern that design interventions are not tested through to impact on patient outcomes has been expressed by Katz, Kripalani and Weiss (2006). With this concern in mind we await the outcomes of a trial of the revised questionnaire, aware that further refinement may be needed to ensure its effectiveness as a communication tool. Once its usability for both carers and professionals has been established we will then be able to progress to full trial in order to establish its impact on prescribing practice.

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ACKNOWLEDGMENTS

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ENDNOTES

- 1 We are grateful to the authors of the Abbey scale for their permission to draw directly on their work.
- 2 Designers may be surprised by the constraint of on-demand printing but this is common practice for many documents used in NHS settings and we aimed to work within existing constraints. Since the study reported here, two of the authors have attracted funding to develop professionally reproduced post-diagnosis documentation to support family carers of people with dementia, and this new project will allow some comparison of the impact of the new documentation with current, photocopied provision.
- 3 Another possible explanation for low uptake might have been lack of compensation to staff for taking part in a trial. Compensating staff would be unusual in an NHS trial such as this, where a new process is being piloted as part of everyday care practice.

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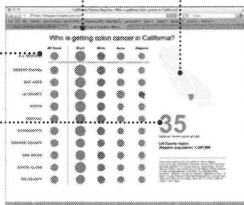
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United Kingdom



rates plotted together,
organized by groups
& coded by color;
macro view of all data

rates show as
precise numbers



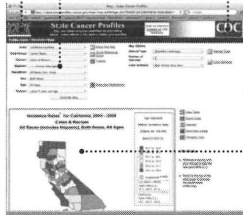
straightforward
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map identifies
location of
10 regions

recognizable
brand

drop-down menus require
pre-selection of data

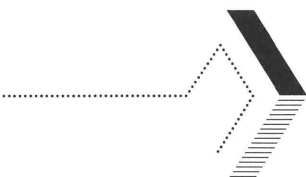
recognizable
brand



rates plotted for
selected group by region;
data shown as color-
coded to ranges, not
by precise numbers;
map broken down
to many regions

A	78% CORRECT	62% CORRECT
B	91% CORRECT	61% CORRECT
C	75% CORRECT	16% CORRECT

- A** Who gets more colorectal cancer in California, people living in Orange Country or in La Country? 78/62
- B** Who gets more colorectal cancer in California, Blacks or Whites? 91/61
- C** Who gets colorectal cancer the least in California? 75/16



03 Making Cancer Surveillance Data More Accessible for the Public Through Dataspark.

**HEATHER CORCORAN, MATTHEW KREUTER,
CHRISTINA CLARKE**

ABSTRACT

This paper describes findings from an experiment to determine whether visual design could enhance the effectiveness of the presentation of cancer surveillance data online. The research team included designers who created an interface called Dataspark (DS) for California citizens to see incidence rates for colorectal cancer in the state. The design of the display used principles of relative scale, color, shape, and arrangement. In a randomized experiment, this interface was compared to two displays that are hosted by established cancer organizations but do not use principles of scale, color, shape, and arrangement in the same way. Approximately 550 California citizens participated in the experiment, during which they were assigned at random to use one of the three displays and then asked questions about understanding, ease of use, engagement and personal relevance. Results showed that the Dataspark display was significantly more effective in helping participants understand the data and explore the interface. User engagement and personal relevance were modest for all three displays. This paper analyzes the results and introduces some strategies to address engagement and personal relevance in future work.

> **A**pproximately 1 out of 2 Americans born today will be diagnosed with cancer in his or her lifetime (National Cancer Institute, 2011). Worse yet, those who are poor, African American, or uninsured are more likely to get cancer, be diagnosed at more advanced stages when cancer is more difficult to treat, and have a shorter period of survival after diagnosis compared to other Americans (American Cancer Society, 2013, 42).

Because cancer is one of the leading causes of death in the U.S., all 50 states have made the reporting of cancer diagnoses mandatory. Cancer registries compile and compute cancer incidence and mortality data, looking for trends over time and variability by geography, race, gender, age, and other variables. This work is part of the larger field of cancer epidemiology, the study of who gets cancer in populations and why. Many cancer registries are organized through the federally funded Surveillance Epidemiology and End Results program (SEER) which began in 1973.

Data collection has grown in virtually every aspect of life. But as information design and programming guru Ben Fry describes,

"We're getting better and better at collecting data, but we lag in what we can do with it." (Fry, 2008, 2)

For cancer registry data, the gaps between what is collected, what the public understands, and how individuals behave in response, are large.

In their 2009 book *Making Data Talk*, David Nelson, Brad Hesse and Robert Croyle describe the challenges associated with lay audiences sifting through health data on and off the Internet. (Nelson, Hesse and Croyle, 2009, 4) As they explain, "Unfortunately, examples of poor communication of data abound—on Web sites, in written materials (e.g., reports, brochures), during oral presentations, and during media interviews, leaving many people awash in a morass of confusing 'data smog.'" (Ibid.) (Shenk, 1997)

The project described in this article explores the development and testing of an interactive display to inform the public about variation in colorectal cancer rates across population sub-groups, using data from the state of California. The display is a transdisciplinary synthesis of principles of data selection, visual design, user interface and communications created to understand how the impact of cancer statistics on the public can be improved through better presentation.

The project addresses an emerging challenge in public health communications:

as data and their delivery systems become ever more individualized, robust, and search-driven, can they also be used to help people see the connection between individual behavior and population health?

This question is particularly important for addressing the health needs of populations at disproportionately high risk of cancer and other diseases, shown in our project by the comparatively high rates of colorectal cancer—a cancer thought to be preventable through screening—for certain population sub-groups, like African Americans.

To that end, we tested our interactive display against two content-equivalent displays already in the marketplace with 550 users from the state of California. We measured four outcomes—user understanding to see if the information could be made more clear, ease of use to see if the information could be more easily navigated, engagement to see if people would pay attention to the experience, and relevance to see if it had personal or lasting meaning. The prototype that we developed is referred to as “Dataspark” (DS) throughout this article. Dataspark is now an online visualization tool (available at <http://www.dataspark.org>), recently released to the cancer surveillance community, whose members can use it to visualize their own data and share it with their constituencies.

THE INFORMATIONAL LANDSCAPE: CANCER SURVEILLANCE DATA

The production and distribution of information at large is at a historical high. In 2009, there were 1.5 billion Internet users on the planet and 60% of the world's population had a wireless phone subscription (Castells, 2010, xxv–xxvi). Seven years before that, Peter Lyman and Hal Varian estimated that information production had reached five exabytes, or the equivalent of 37,000 libraries the size of the Library of Congress (Lyman and Varian, 2003). Their report from 2002 suggested that digital information production was growing approximately 30% each year. (Ibid.)

But the time spent consuming information is increasing by just 1.7% annually, according to John Seely Brown and Paul Duguid, authors of *The Social Life of Information*, also published in 2002 (Brown and Duguid, 2002, xiii). Brown and Duguid characterize this oversupply and lack of demand as an urgent problem for knowledge management. They conclude that “a critical task ahead will be to stop volume from simply overwhelming value.” (Ibid.)

The gap between production and consumption is just one factor in a kind of societal angst. In his classic text *Information Anxiety*, published ten years before *The Social Life of Information*, Richard Saul Wurman writes about a variety of manifestations. These include “not understanding information, feeling overwhelmed by the amount of information to be understood, not knowing if certain information exists; not knowing where to find information; and perhaps, the most frustrating, knowing exactly where to find the information, but not having the key to access it.” (Wurman, 1989, 44-45) These issues seem particularly relevant to cancer surveillance data today. Web analytics show that of the people who visit the SEER website, one of the most common resources for cancer registry statistics, close to 50% leave within 30 seconds (AWStats, 2011). While these data do not capture why people leave, they suggest an unsatisfying data experience.

The sheer quantity of information appears to be one of the problems. In a qualitative study conducted by the authors of this article in 2011 to assess the cancer data needs of five audiences—cancer control professionals, advocates, journalists, policy makers, and the public—all described the problem of feeling overwhelmed by a “tornado of data”. Other challenges found in the study, which featured in-depth interviews with 16 people, included the need for interpretation of information over complex statistics and usability over precision (Spray, 2011, 6).

For those immediately and urgently affected by cancer and thus seeking more personalized information, population-level surveillance data may be too broad and its findings not actionable enough to feel relevant. For example, people often desire extremely localized data. They may wish to know the answers to questions such as: What is my sister’s chance of survival? Not only are some of these questions difficult to answer, as data collection across the U.S. is variable by community, region and state, but even as the cancer surveillance community attempts to provide increasingly specific answers, researchers in the field believe that the big picture remains important...

Presenting statistics that reflect population risks while maintaining relevance to individuals is key. But this is difficult to achieve.

Public access to cancer statistics is a relatively new goal. Historically, cancer surveillance data and related statistics have been developed and distributed by epidemiologists to cancer control decision makers, primarily other scientists. With the aid of technology, the end user group has grown to include some members of the cancer-affected

public; hence data translators have come to play a more important role in the information delivery system, a trend which is likely to grow over time. These “infomediaries” include local and national journalists, local, regional, and national policy makers, healthcare professionals, and community advocates. In effect, the communications system for cancer surveillance data is in the process of becoming more complex and gaining constituents. How well that system works in serving its audience and maximizing the communicative potential of cancer surveillance data is an open question.

APPROACH

The goal of this project was to understand how end users respond to a tool specifically designed for their use, and how experiences with this tool compare to experiences with existing tools.

The findings should help improve the cancer surveillance communication system as the field looks to integrate informational tools for various audiences, including infomediaries. The project assessed users on a scale from understanding at one end, to ease of use and engagement, and finally, personal relevance at the other.

RESEARCH TEAM

Given the range of stakeholders and the complexity of data to be communicated, a transdisciplinary approach was adopted. This allowed a blend of cancer surveillance data expertise, including data selection and statistical analysis; visual design, usability, and programming; and experience in health communications science, human subject testing, messaging, and data analysis. The three primary sets of researchers were cancer epidemiologists from the Cancer Prevention Institute of California, one of the oldest cancer registries in the U.S., designers from the Sam Fox School of Design & Visual Arts at Washington University in St. Louis, and specialists from the Health Communication Research Laboratory, one of five national centers of excellence in cancer communication research, also from Washington University in the Brown School of Social Work.

PROCESS

Several key parts of the project, including data selection, audience research, iterative prototype development, and planning for user testing required sustained dialogue across the larger team. This group used a reflective methodology, creating and responding to paper and screen-based prototypes to frame feedback and expertise at every stage. In the book *The Reflective Practitioner*, Donald Schön describes reflection-in-action as a productive alternative to the

traditional “technical rationality” approach prized by professions such as Law and Medicine. As he explains, this approach focuses on the tacit knowledge acquired by practice that can seem to be beyond verbal description. For Schön, doing, making, and problem-solving are ways to make that valuable tacit knowledge explicit (Schön, 1983, 21–75). For our project, the benefit of a reflective process was two-fold: not only did we find that our ideas became more clear and specific when we put them into form and reflected upon them, but the reflective process also provided a critical platform for transdisciplinary conversation.

..... *In a sense, our project was about finding the tacit
..... in our group’s knowledge.*

Our development process roughly aligns to a seven-step approach described by Ben Fry in *Visualizing Data*. Once a goal is established, these stages include acquire, parse, filter, mine, represent, refine, and interact (Fry, 2008, 5-6). Our process began with the development of a goal and was followed by acquiring and filtering data, representation, refinement, and interaction. We measured the interactions through a randomized experiment and then analyzed our results in the context of our research goals. Each stage of the project included activities that were “owned” by a particular set of expertise. For example, the designers took the lead creating representations of the data through an iterative series of paper and digital sketches. These were viewed and refined not just on visual terms, but for clarity of the data, potential for the visual structure to house variations on similar kinds of data in the future, ability to capture and hold users’ attention and interest and help them connect to cancer data, conventions of web design, emerging influences of mobile on website design, and programming implications. In the development of the format for user testing, the health communications experts took the lead. Because of their broad-minded facilitation, all other team members were able to contribute to project’s testing goals, questionnaire items, and evaluation approach and methods.

..... *What made the process different from traditional, client- driven
..... projects in the field of design, or even academic projects
..... positioned solely within design, was the range
..... of expertise synthesized into the prototype.*

PRINCIPLES AND PRECEDENTS FOR INTERVENTION

Principles of graphic display, usability and communications processing, all well documented in literature, factored into the development of our interactive display and the formation of our testing model. Key principles taken from each field are described below.

GRAPHIC DESIGN: HIERARCHY AND GROUPING

The visual principles of hierarchy and grouping, documented in a variety of texts in the canon of print graphic design literature, were critical to the success of our prototype. Hierarchy refers to the relative prominence of elements in a visual field (Lupton and Phillips, 2008, 115). That translates to a set of design decisions that cause one element to be more or less important than another. Scale, shape, and color are among the factors influencing hierarchy. For example, in this infographic spread from Al Gore's book *Our Choice*, designed by New York design firm MGMT, the darkest circles rise to the top of the hierarchy (*figure 1*).

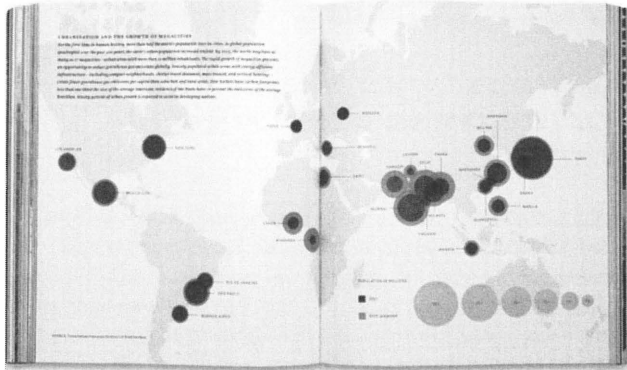


FIGURE 1 Spread from *Our Choice* by Al Gore, designed by MGMT.

Grouping refers to the way that our eyes tend to link elements in a visual field. Elements that are linked are often close in proximity, or of similar size, shape, or color. In the MGMT example, the three circles at the top of the map—in Europe—appear more visually connected than the three in North America. Their size is the same and they are closer to each other in space. Hierarchy rests on our ability to perceive difference; an element that looks different will tend to have more prominence in a hierarchy. In order to perceive difference, we must be able to group elements that are the same. These principles help to explain how we perceive visual patterns.

For decades, the principles of hierarchy and grouping have been applied successfully in areas such as business, education, and news media where customers, students, and the general public serve as primary audiences. But visual design has had a minimal role in fields that have not made systematic efforts to communicate to broad populations, such as cancer surveillance.

EASE OF USE AND GRAPHIC PRECEDENT

When information is disseminated digitally—on computer screens and mobile devices instead of paper—principles of user navigation become important. The field of usability has emerged in the last 15 years to explain the dynamics of interactive environments, in which multi-dimensional information is presented on a screen and the user makes choices to guide his or her experience. Usability.gov defines how well users can learn and use a product to achieve their goals and how satisfied they are with that process as the measures of success (Usability.gov, 2012).

Good usability is about ease. If navigation is intuitive for the user, then s/he will not notice it, but will know what to do. In *Don't Make Me Think*, Steve Krug puts it this way...

..... "I should be able to 'get it'—what it is and how to use it—without expending any effort thinking about it."
..... (Krug, 2005, 18)

Part of the reason that users “get it” is that they rely on conventions, which are described by historians Charles Kostelnick and Michael Hassett as a set of social principles that we identify over time through use (Kostelnick and Hassett, 2003, 10-23). For example, we understand that when a website contains a bold shape with type on it, it is meant to be clicked, and that it will take us to a new screen. We call this shape a button, much as buttons exist on elevators or electronic equipment. Our computer interfaces have functioned under the metaphor of a desktop (files, folders, etc.) since Apple introduced it in the early 1980s. The desktop is filled with graphic user interface (GUI) conventions; in the GUI landscape, what you see is what you get. As users begin to interact with mobile devices, the power of touch is changing the way that users relate to screens—in the mobile world certainly, but increasingly on the computer as well. Mobile device expert Rachel Hinman writes that...

..... "Natural user interfaces (NUIs) rely on our innate sense of the physical world where what you do is what you get."
..... (Hinman, 2012, 21-22)

This is important for interface design because it means that the context in which interactive data or elements appear on our screens has a role in determining what we think they mean, and how we interact with them. For example, the zoom and pinch feature of the iPhone allows us to expand or contract visual information. Using our fingers, we can move up, down, or across our screens, pulling in new material from “off-screen.” This functionality makes our interaction more nuanced

and less didactic, which in turn affects the way that we expect to use the mouse to move through a map or an environment on a computer screen.

An additional consideration, as Krug describes, is that the Internet is a place for scanning, not reading. Users move at high speeds to get what they need (Ibid, 17). Information delivery gets speedier all the time, pressuring graphic conventions to be intuitive. Krug advises developers to focus on straightforward navigation, descriptive copywriting, and clear labeling. He advocates for a strong visual hierarchy focusing on grouping, with appropriate consideration of existing graphic conventions. Poor usability blocks access to meaningful content, particularly when that content is complex, as is the case with cancer surveillance data.

COMMUNICATIONS

While principles of visual design and usability guided many aspects of the development of our project prototype, the psychology of persuasion informed the framework for its evaluation. In 1968, social psychologist William McGuire proposed an input/output model of persuasive communication. This model consists of five types of "input" variables (source, message, channel, receiver and destination) that can influence the effectiveness of a communication and 12 possible "outputs," or outcomes of communication (e.g., attention, comprehension, behavior change). The outcomes are successive, from affective and cognitive, to behavioral. McGuire proposes that for a communication to achieve higher order effects such as behavior change, outputs appearing earlier in the succession have to be reached (McGuire, 1989, 43-65). The progression of communication effects can stop anywhere in this sequence (McGuire, 1976, 302-219). In our model for cancer surveillance data, understanding is followed by usability, engagement, and then personal relevance. While we were not focused on a behavior change as an outcome of this project, we see our progression as a necessary and appropriate precursor to facilitating future behavior change.

PROTOTYPE DEVELOPMENT

DATA SELECTION

Colorectal cancer incidence rates in the state of California reflect significant disparity by race. For example, African Americans are diagnosed with colorectal cancer at nearly twice the rate of Asian and Hispanic populations and at higher rates than whites. It was primarily because of these pronounced disparities that we selected colorectal cancer as the content area for our prototype.

We divided California into ten geographic regions for this project. Regional incidence rates correlate to racial compositions of the regions.

While one might argue against this redundancy, our system of geographic division was important for two reasons: statistically, it broke the data into smaller granules. It also provided a potential personal connection for users; those tested were all living in one of ten regions of California.

In addition, we selected colorectal cancer because it can be treated if detected early. Non-cancerous lesions and polyps can be removed before they become cancerous, but this requires regular screening. According to a recent report from the U.S. Centers for Disease Control and Prevention (CDC), African Americans are less likely to be current with their colorectal screenings than whites (Centers for Disease Control and Prevention, 2012).

There are also gender gaps in colorectal cancer incidence rates in California and nationally. Men get colorectal cancer more often than women. But the gap between African Americans and other races is much more substantial. Because we wanted to focus the user's attention on racial disparity, we chose not to display the gender breakdowns.

VISUAL DESIGN

The Dataspark interface was designed to be a simple, interactive snapshot in which users can see and compare a general pattern of rates by race and region and simultaneously experience the specificity of particular rates. (figure 2)

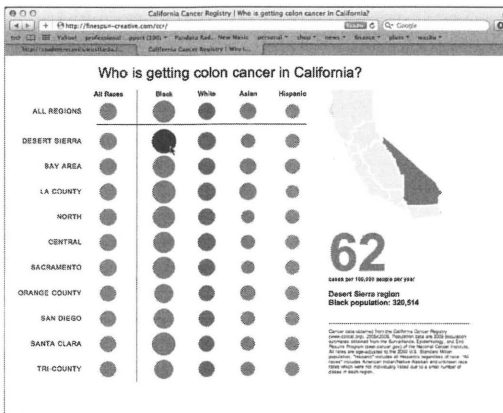


FIGURE 2
Dataspark interface,
Africans Americans
living in Desert
Sierra highlighted.

While Californians should be able to locate themselves in the data, the context that the pattern provides is an important link to the larger story.

The design is a grid of circles in which each column (and color) is a category of race/ethnicity. Each row is a region in California. Circles are sized according to colorectal cancer incidence rate, age-adjusted. The highest incidence rate appears in the upper lefthand corner, providing an immediate answer to the question posed by the headline. The user can see who gets cancer most and how big the gap is between that group and the others around it.

Visual principles of grouping and hierarchy play important roles. Scale, color, and proximity of circles allow rates in a given category to group together visually; in that environment of sameness, differences in the scale of the circles are easy to detect and link to comparatively lower or higher rates.

The circles in the grid are rollovers. Each rate displays numerically when the corresponding circle is rolled over. In Figure 3, the user has rolled over African Americans living in Desert Sierra, a group with an incidence rate of 62 cases of colorectal cancer per 100,000 people. In Figure 4, Hispanics in LA County have a much lower rate of 35 cases per 100,000 people. Because the circles cannot be clicked, the user has the immediacy of scanning with the mouse. Nothing moves or changes during a rollover except the appearance of the large rate number, its supporting text, and a color highlight of the relevant region on a California map.

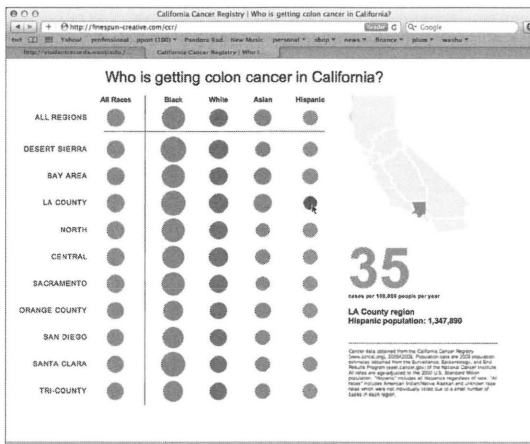


FIGURE 3 Dataspark interface, Hispanics living in LA County highlighted.

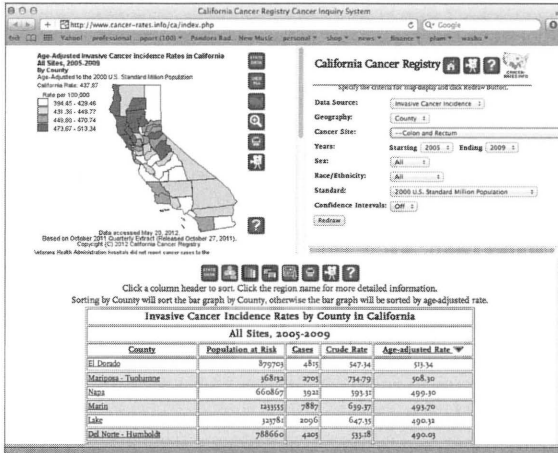


FIGURE 4 Common display of cancer registry data, California Cancer Registry display.

METHODS

We created our prototype for end users so that we could study the specific challenges associated with making the data meaningful for the lay public. We were interested in learning about their understanding, ease of use, level of engagement, and sense of personal relevance, all areas that we believed to be problematic for other interfaces containing cancer statistics.

We tested our prototype against two others produced by major sponsors of cancer registry data. Each participant was assigned randomly to one of three displays – 183 people to Dataspark, 184 to the California Cancer Registry (CCR), and 183 to the National Cancer Institute (NCI) – and asked an identical set of questions (figures 4, 5).

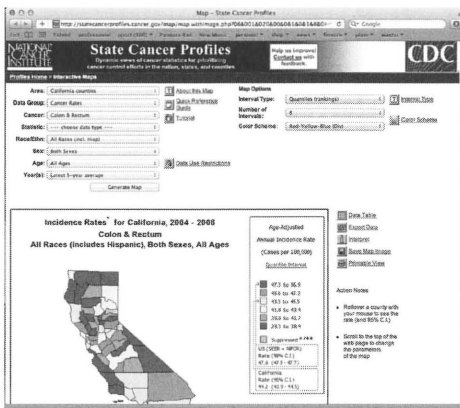


FIGURE 5 Common display of cancer registry data, State Cancer Profiles.

While created primarily for scientific and public health audiences, the CCR and NCI displays are publicly available and among the top results returned by search engines for many online cancer-related inquiries. For the experiment, each of these interfaces was set up to show California colorectal incidence data. Each of the interfaces contains data organized by race.

There were 550 participants in the experiment. Participants were registered voters in California, ages 50–79 (therefore age-eligible for colorectal cancer screening; mean age = 60.1). We did not require that participants had any experience with cancer. Each participant received a modest incentive as compensation for time spent completing the online experiment. Most participants were white (75%), had at least some education beyond high school (76%), and had an annual income of \$25,000 or more (76%).

The survey was conducted online and began with a set of questions about personal relationship to cancer and patterns of Internet use. Participants then spent 25 seconds viewing their assigned displays without interacting with them and were asked eight questions about their initial impressions, including whether the display looked intimidating, hard to use, out of date, attractive, easy to use, inviting, confusing, and overwhelming (agree/disagree). During the interactive session which followed, all participants had access to the full functionality of their assigned interface (e.g., rollovers, drop-down menus, etc). They took a short, multiple-choice quiz on the statistics to evaluate their understanding. Quiz questions asked about cancer facts available in the display (e.g., “Who gets more colorectal cancer in California, Blacks or Whites?”)

Quiz questions were followed by questions about ease of use, engagement, and personal relevance. Ease of use was measured by asking participants to respond to statements about how easy it was to use the interface (Likert Scale: 1= strongly disagree; 6=strongly agree) and find information (Likert Scale: 1=strongly disagree; 5=strongly agree). Engagement was measured by asking participants to respond to statements about how interesting the display was (Likert Scale: 1= strongly disagree; 6= strongly agree) whether they were interested in learning more about the subject (yes/no/not sure). Personal relevance was measured by asking whether participants sought information that was specific to their racial group or region (yes/no/no answer), and evaluating their connection to cancer (yes/no/not sure).

Following the interactive session, participants were asked a set of questions about the general usability of the interface, the believability of the presentation, and effort expended using the display. They also

provided further demographic information. Topics discussed are summarized in Figure 6. All data were analyzed using SAS v.9.2.

QUESTIONS ASKED WHEN?	TOPICS COVERED
Before viewing display (baseline)	Interest in topic Health information seeking and personal relevance Subjective numeracy Geographic literacy Duration of residence Objective regional knowledge Regional self-identification Internet usage patterns
After viewing display for 25 seconds: no interaction	Perceived ease of interpretation Engagement Basic understanding of idea
While interacting with display	Quiz on statistics Ease in Interpretation Learning / understanding Understanding gist Perceived personal risk
After interacting with display	Usability Believability Effort Cancer experience and perceptions Demographics

FIGURE 6 (TABLE 1) Survey topics for experiment

RESULTS AND ANALYSIS OF USER TESTING

UNDERSTANDING OF DISPLAY

After interacting with their assigned display (determined at random), participants were asked four fact-based questions about the data presented (figure 7). The Dataspark design produced significantly more correct answers than the other two designs for each of the questions. For example, when asked which racial group gets colorectal cancer the least, participants who viewed the Dataspark design answered correctly in 75% of cases; participants who viewed the California Cancer Registry rates answered correctly in 18% of cases. This result in particular and the outcomes in this category generally suggest that...

..... the visual design of Dataspark was effective for communicating statistics and ensuring understanding.

QUIZ QUESTIONS		DS	CCR	NCI
Who gets more colorectal cancer in California, people living in Orange County or in LA Country?	Correct answer	78%	53%	62%
	Wrong answer	7%	26%	11%
	Not sure	15%	21%	26%
Who gets more colorectal cancer in California, Blacks or Whites?	Correct answer	91%	36%	61%
	Wrong answer	4%	40%	22%
	Not sure	5%	24%	16%
Who gets more colorectal cancer the least in California?	Correct answer	75%	18%	16%
	Wrong answer	19%	55%	48%
	Not sure	7%	26%	35%
What best explains who gets colorectal cancer in California?	Correct answer	73%	33%	66%
	Wrong answer	8%	29%	12%
	Not sure	19%	38%	22%
PARTICIPANT REFLECTION				
How much, if at all, did your understanding of who gets colorectal cancer in California improve after exploring this webpage?	A lot	18%	9%	21%
	Some	46%	35%	34%
	Very little	21%	26%	20%
	None	14%	30%	25%

FIGURE 7 (TABLE 2) Results for Understanding

One of the features that differentiates Dataspark from the other two interfaces is simplification of data. This was achieved in part by showing one set of comparable rates instead of presenting crude rates and case number totals, rounding numbers to the nearest whole. A second important difference is that Dataspark's grid of circles allows for visual comparisons among races and regions and a macro view of the data upon entry. Additional differentiating features are the labels and copywriting which were written to be straightforward and minimal. Further testing could isolate these variables to assess their impact more precisely. We note that several of these design features grew out of transdisciplinary discussion, including the presentation of the visual grid.

Participants' observations about their general understanding were also positive. 64% of Dataspark participants reported that their understanding improved "a lot" or "some" compared to 44% of participants who viewed the CCR tool and 55% of participants who viewed the NCI tool ($p < .001$). For each of the four factual quiz items, participants who used Dataspark answered correctly significantly more often

than those assigned to CCR or NCI. Across the four items, Dataspark participants were correct 73-91% of the time, compared to lower rates of correctness for CCR (18-53%) and NCI (16-66%) participants (all $p < .0001$ for comparisons between tools).

Overall, Dataspark participants scored an average of 79% correct on the set of four quiz questions and 64% of Dataspark participants believed that their understanding improved. What we learn about understanding from this set of results is that data selection and visual design can aid the clarity with which material is understood, a key component of improving the impact of cancer surveillance data on the public.

EASE OF USE

Survey participants were asked about ease of use before and after interacting with the displays. (figure 8) For all three displays, there was significant contrast between perception and experience. For those randomized to the Dataspark design, the experience was much more positive than the first impression. For those randomized to CCR and NCI, the reverse was true.

SEEING, NOT INTERACTING		DS	CCR	NCI
Looks intimidating	Agree	55%	58%	49%
	Disagree	45%	42%	51%
Looks confusing	Agree	63%	59%	49%
	Disagree	37%	41%	51%
Looks easy to use	Agree	37%	36%	47%
	Disagree	63%	64%	53%
AFTER INTERACTING				
Easy to explore the webpage	1 strongly disagree	6.5%	23%	23%
	2	6.5%	25%	19%
	3	27%	19%	17%
	4	33%	16%	25%
	5 strongly agree	27%	16%	15%
Easy to figure out where to find information	1 strongly disagree	7%	20%	19%
	2	6%	15%	14%
	3	22%	21%	14%
	4	19%	16%	17%
	5	21%	17%	20%
	6 strongly agree	26%	11%	15%

FIGURE 8 (TABLE 3) Results for Ease of Use

When asked initially if they thought their assigned display looked easy to use, most participants responded that it did not (53-64% across all three designs). Approximately half of the participants responded that their interface looked intimidating and even higher percentages of people reported that the displays looked confusing. NCI's was seen as the least intimidating of the three, by a margin of 6%.

The 25-second preview session in the experiment setting created a false break in what the user's experience would have been otherwise. It is possible that users' initial impressions would have been more positive had they been able to interact with the interfaces before responding.

On the other hand, the result suggests the importance of the entry way into each of the three designs. This is perhaps most relevant for Dataspark which likely looked the most unfamiliar to its assigned users and did not have the benefit of an organizational brand identity. CCR and NCI, though less usable in the end, have well known, credible brand identities that participants may have recognized. Whether recognized or not, the CCR and NCI interfaces are designed using drop-down menus and other common conventions, so it seems possible that they would have been perceived as more familiar.

We propose two ideas that might address this entry way problem for Dataspark:

- 1 Provide data gradually. During the initial loading, material could appear on the screen in steps, instead of all at once. For example, in the Dataspark design, it might have been valuable to show the state totals without the regional breakdowns first. (figure 9) Perhaps clicking on each circle would cause the regional dots to drop down.

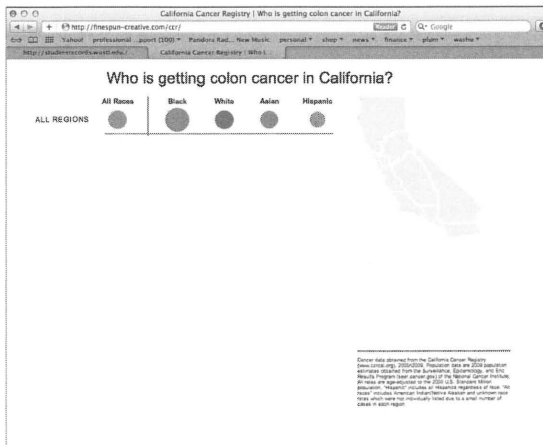


FIGURE 9 Manipulation of Dataspark design

2 Embed inside existing websites. If we had placed the display inside of an existing website with an established brand identity, providing related content and reinforcing the rollover approach to navigation, the user might have felt more comfortable at the outset.

After interacting with the displays and answering the quiz questions, all participants were again questioned about ease of use. On a scale of 1–5 (where 5 is easiest to use), 87% of those randomized to Dataspark responded with a score of 3, 4, or 5, compared to 53% of those randomized to CCR, and 58% of those randomized to NCI. For the authors, this result was the most important. The Dataspark approach was considered easy to use. Features of the design discussed above were likely important factors in that result.

In the larger conversation about engagement with cancer surveillance data, it seems critical that new approaches to usability that span computer screen and mobile device contexts be adopted.

ENGAGEMENT IN THE DISPLAY

The results suggest only modest participant engagement in all three of the displays (*figure 10*). There is some variability in the numbers that tends to skew positively toward Dataspark, but the differences are slight. Given that most Dataspark participants were successful in answering fact-based questions and found the interface usable, as described above, a lack of personal interest in the subject may be the culprit.

On the one hand, we might hope to test the display with participants personally affected by colon cancer. We believe that audience would find the Dataspark display more engaging than our convenience sample from the general public.

But the rationale for our experiment was that it allowed us to isolate best practices in data presentation, design, and usability. As we describe at the outset of this article, cancer rates and their disparities are social problems that affect us all. They are partially an outcome of individual and cultural behaviors; changing these would lower individual risk and collective rates over time, with significant implications for public health and healthcare costs. What we learn from this result is that the Dataspark display isolated and presented rates in a clear and usable way. For future work, we may want to design tools that address the content challenge more directly: people are unlikely to seek out this information in the absence of some personal connection. How can we build that personal connection?

PERSONAL RELEVANCE

Not surprisingly, given the results on engagement, the survey results also indicate modest levels of personal relevance of the interface (*figure 11*). This is likely because very few participants (<5%) across all three groups had been diagnosed with cancer in the past two years and over half of participants had no friends or relatives diagnosed with cancer in the same time period. Accordingly, only a small proportion of our participants reported having sought cancer information in the previous month.

DEMOGRAPHICS ON CANCER AND RACE		DS	CCR	NCI
In the last two years, have you been diagnosed with cancer?	yes	4%	7%	4%
	no	96%	93%	95%
	not sure	0%	0%	0%
In the last two years, have you had a close friend or relative who has been diagnosed with cancer?	yes	36%	38%	46%
	no	61%	58%	52%
	not sure	3%	4%	2%
In the past 30 days have you looked for information on cancer?	yes	14%	11%	17%
	no	85%	88%	82%
	not sure	3%	1%	3%
Please select one or more racial categories to describe yourself.	American Indian*	3%	3%	2%
	Asian	9%	8%	4%
	African American/Black	7%	8%	10%
	Native Hawaiian**	1%	0%	1%
	Caucasian/White	74%	76%	76%
	Other	6%	5%	7%
REFLECTIONS ON BEHAVIOR				
Did you look for information about how cancer affects the region where you live?	yes	56%	66%	53%
	no	41%	33%	44%
	refused/no answer	3%	1%	3%
Did you look for information about people in the same racial group as you?	yes	56%	19%	31%
	no	43%	80%	67%
	refused/no answer	1%	1%	2%

FIGURE 11 (TABLE 4)

Results for Personal Relevance

At the same time, more than half of all participants sought out information in the display about their own racial group; and more than half sought out information about the geographic region in which they live. This suggests some attempt to connect to the data through a personal lens. While that alone does not produce engagement or relevance, it does provide an insight about the importance of personal connection. If someone living in Los Angeles who is African-American reviews the display and notes that s/he is part of the group at highest

risk, is there an opportunity to introduce a story about community action that is specific to African-Americans in Los Angeles? One might imagine using such a tool on a smartphone and pulling open the big blue dot to get a deeper story. Results related to personal relevance did not differ significantly across the three different displays. From the authors' perspective, this highlights the importance of developing and framing the data and content in a way that is socially and then personally relevant, in addition to considerations of design and usability.

GENERAL ANALYSIS

Of the four questions posed initially, the results fell into two groups. The Dataspark design was successful in the categories of understanding and usability. Engagement and personal relevance ranked relatively low across the set of interfaces; the design and usability principles applied to the Dataspark interface did not make a significant impact in those outcome categories. We introduced our four categories as a range, in which understanding sits on one end and personal relevance on the other, with ease of use and engagement in the middle. We did this because we wanted to test whether baseline expectations of understanding and ease of use could be met. Our results validate this and we conclude that...

⋮ *data selection, design, and usability are critical and*
⋮ *important factors in the display of cancer surveillance data.*

The Dataspark interface is significantly different from the other two interfaces—in data selection, usability, and visual design. Given that our goal was to translate data for the public, Dataspark has a more targeted communication goal—to show differences among rates according to race. Dataspark presents a smaller, more simplified dataset than CCR or NCI. This choice was made in direct response to general concerns about health information overload and a desire to cut through the clutter.

The user's access to that smaller dataset is controlled entirely by moving the mouse on the screen, not by making multiple-choice decisions.

⋮ *With Dataspark, users explore more than they decide.*

This is unlike CCR and NCI which require users to make choices about what they want to see, before they see it. For lay-people, these choices may be daunting or suggest a level of commitment that goes beyond their interest. We believe that Dataspark's rollover approach is appropriate for the general public. In addition, upon entry to the interface, the Dataspark user is presented with overview

data, organized by race and region. With CCR and NCI, the user is asked to make data selections from eight drop-down menus, and then to click “redraw” or “generate map” which generates a map. We believe that that initial presentation of data is important for the general public.

Dataspark’s data are displayed as a grid of circles, color-coded according to race, whereas the other displays plot the rates onto maps of California. With CCR and NCI, the user can select whether to show “all races” or individual races, but the interface does not generate a comparison between two groups with a single view. The purpose of the map in the Dataspark display is to reinforce where each region is located, not to show numerical data. Interestingly, the NCI site also allows the user to make map design selections, including interval, interval type, and color. This adds to the visual and textual complexity of the interface, perhaps making it even more daunting for the user. In both maps, color is used to represent a numerical range (darker colors representing higher rates), but hue shifts occur within ranges in some color iterations, which may obscure numerical clarity.

Dataspark attempts to assign specific visual properties to the communications challenges of rate (scale), race (color), and region (shapes within the map) in a clear and direct way. These individual elements are combined in the interface design according to principles of visual arrangement and hierarchy. Arrangement includes the matrix of dots grouped for visual viewing by race or region as well as the design of the interface itself which prioritizes the pattern of dots over components such as the map and supporting numerical data. Dataspark uses four different hues to represent race differences; scale shift describes numerical difference. The experiment did not ask participants to address these aspects of the visual design specifically, as it was thought that the synthetic nature of the design would make isolating particular elements challenging. But the differences in understanding and ease of use (after interacting) are dramatically in Dataspark’s favor—87% of Dataspark users responded with a 3, 4, or 5 to the prompt “It is easy to explore the webpage” whereas 51% of CCR users and 57% of NCI users did. The authors believe that the Dataspark display could now be refined further by testing variations with a set of users.

In spite of the impact of differences among the interfaces on understanding and ease of use, the categories of engagement and personal relevance appear to be unaffected. Engagement and personal relevance represent additional levels of effectiveness that we believe should be achieved through the development of digital tools such as Dataspark. Given the results of our experiment, we believe that we are now well positioned to focus attention on both of these areas. We are of two minds about this. On the one hand, cancer statistics

and surveillance information could be directed to people affected by cancer, or even a smaller subset such as people affected by cancer who wish to understand differentiated risks. Some of the people in the latter category might include policy makers and health professionals whose basic decision-making could be affected by tools such as these. If this is our audience, then we have made a good start in developing a tool that they are likely to find useful and relevant.

On the other hand, if we view the problem as causing cancer surveillance data to have impact for the population as a whole, then we have challenges in engagement and personal relevance that will require significant work. Improving communications to the public is already a priority in many corners of public health. For cancer surveillance data, we envision connecting rates to health and wellbeing opportunities in a given community defined along geographic, racial/ethnic, gender, age, or other lines. Technological innovation and social media have fueled our ability to design tools for users to navigate interfaces in nuanced, exploratory ways which we believe makes this more possible than ever.

Even in the face of the challenges of building engagement and relevance, our clear finding that design aids understanding remains important for communicating to the public.

It also has application for categories of health data far beyond cancer surveillance, many of which have been largely untouched by experienced designers.

These include research and experiments in disease risk and prevention, doctor and healthcare provider communication with patients, training materials for new doctors, and public or semi-public reporting of other systematically collected, government data. Large, national media outlets such as The New York Times have led the way in creating higher standards for communicating health data. But information production continues to swell. There are and will continue to be opportunities on local, regional and state levels that require urgent attention in order to improve health overall and reduce health disparities.

Our team's initial charge was to find ways of making cancer registry data more accessible and meaningful for the non-scientific public. We have since built a tool that empowers cancer registry scientists to do this themselves. The tool is an information graphics "generator" (dataspark.org) which allows scientists to upload spreadsheets of registry data and translate them into a designed, interactive output, with a dedicated url. The project is a direct outcome of the positive response of the Dataspark designs in the categories of understanding and usability. Scientists who use the tool are able to target

their audiences more specifically than our experiment did, which we believe will address some of the challenges of engagement and personal relevance, though perhaps not for the general public.

The transdisciplinary nature of this project allowed us to work with significant depth in the fields of epidemiology, health communication, design, and usability, while simultaneously working across them. We believe that fusions of disciplines such as this one will be critical in moving forward on the complex problems embedded in public health and policy.

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Call for Papers:
Environmental Communication
A SPECIAL ISSUE OF VISIBLE LANGUAGE FOR 2014

Visible Language is devoted to enhancing human experience through the advancement of research and practice of visual communication. A significant part of that experience occurs within the three-dimensional built environment—physical and virtual.

People navigating the dynamic seamless environment have at their fingertips ability to retrieve information instantly. Whether to play, purchase, socially interact, learn, or (yes) wayfind, environmental communication serves all. The immersive and customizing technologies available today are affecting the human experience in most profound and accelerated ways.

This special issue of *Visible Language* will examine the present state of environmental communication and its implications for the future. How are today's design curriculums shifting (if at all) to accommodate and prepare students to this unprecedented access to information and technological fluidity available to people? How shall we develop a necessary knowledge base, new pedagogical methods, and a more inclusive design process? Planning for environmental communication has brought about convergence of several related fields: architecture, landscape architecture, graphic design, industrial design, interaction design, anthropology, and cognitive science. By its very nature, this environmental communication issue may challenge, provoke and question long held precepts. It may also reassure.

Scope of environmental communication research may include, but is not limited to :

- user interaction and testing with new technologies in the built environment
- narrative development using multiple sensory channels (vision and sound)
- search strategies and their display in databases or websites
- navigation strategies and user preferences
- typographic presentation with outdoor screens
- relationships between physical and interactive screen wayfinding
- innovative teaching methods
- ethical & cultural dimensions in wayfinding innovation
- environmental communication history & criticism

This call fulfills *Visible Language's* research mission. The papers this issue wishes to include go beyond assertion based on experience or intuition and focus on empirical evidence whether gathered and analyzed through a quantitative, qualitative, exploratory, or comparative methods. The goal of this research is to improve practical performance in design while ultimately enhancing people experience.

Visible Language is interdisciplinary — it publishes scientific research and poetry — historical research and design process research — language analyses and pedagogical demonstrations and more. In this special issue it seeks to provide some exemplary research as it relates to environmental communication and the visible language challenges in the forefront of our attention.

ABSTRACT SUBMISSION

Abstracts are limited to 500 words and should include a topic description (with apt citing), research question, methods description, and conclusion. Abstracts should be submitted via email to guest co-editor Oscar Fernández – oscar.fernandez@uc.edu, by November 15, 2013. Include separately a brief biography of the author(s) not exceeding 100 words. The guest editor and journal editor will review abstracts and notify authors of selection decision by November 30.

Information on preparing a manuscript can be found at:
<http://visiblelanguagejournal.com/web/contribute>

FINAL PAPER SELECTION

Full manuscripts for review are due by January 15, 2014. The editorial board consisting of the co-editors and two other reviewers skilled in the subject area will blind review the full manuscripts and make a final selection of papers. Reviewer comments with final decision on acceptance will be returned to authors by January 30, 2014. Final, revised manuscripts are due by February 14, 2014

SPECIAL ISSUE RELEASE

The special issue will be 48.1 for a May 2014 release.

Reliable + Relevant Research

MIKE ZENDER

Visible Language seeks to publish reliable and relevant research in visual communication.

As a new Editor steering toward this goal, I've been awed by the privilege of reviewing so many interesting and different manuscripts, some great and some not so. Before my fresh experience fades into routine I want to share with you the most common failings of manuscripts submitted for publication.

We're a research journal, so it's from research parameters that I'll illustrate the two of the three most common failings I find in design research manuscripts. Quality research is Valid and Reliable. Validity or relevance is the degree to which something is worth measuring; Reliability is the degree to which the thing being measured is consistent or reproducible.

A small but significant number of manuscripts we get are well done in every detail but meaningless: they're Reliable but not relevant (Valid). They measure some small feature well but without a view of how the thing that has been so faithfully measured has any significance to anyone else. Such papers may help advance a career or tenure argument, but they don't advance design.

A large number of manuscripts we get are Valid or Relevant but not Reliable. These papers often offer significant insights and great ideas but with nothing like fact to back them up. The author often bases their considered opinion on ample personal experiences, but without a careful record of specific experiences to support their case. In such manuscripts there is no methodical study, so there is no way these ideas or opinions can be affirmed or questioned by others. Such papers may make the author feel good at having shared their mind, but they don't build design knowledge that others can use.

A third failing not directly related to research parameters is writing quality. This is almost certainly a problem shared by every journal that disseminates writing crafted by people for whom writing is a sideline. Being a common problem, it is both the easiest to address and the hardest to correct. There are many excellent sources for help with writing. The book *Guide to Publishing in Psychology Journals* edited by Robert J. Sternberg, written by journal editors, is an excellent readable source for sound advice. The last chapter, Article Writing 101, is a summary of 50 key tips for successful journal writing. I highly recommend it!

I highly recommend considering *Visible Language* for sharing visual communication research from you or your colleagues. We're committed to rigorous quality – Reliability, high impact on the discipline – Relevance, and excellent writing.

Mike Zender, Editor *Visible Language*

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Visible Language is an academic journal focused on research in visual communication. We invite articles from all disciplines that concern visual communication that would be of interest to visual communication designers.

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Visible Language, an academic journal focused on research in visual communication, seeks to advance research and scholarship for two types of readers: academics and professionals. The academic is motivated to consume knowledge in order to advance knowledge thorough research and teaching. The professional is motivated to consume and apply knowledge to improve practice. *Visible Language* seeks to be highly academic without being inaccessible. To the extent possible given your topic, *Visible Language* seeks articles written to be accessible to both our reader types. Anyone interested may request a copy of our editorial guidelines for authors.

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