

Health information design forum **SETTING THE FUTURE AGENDA**

Location Bugatti Building, Coventry University

Host Design Institute, Coventry University

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Background

Over the last year, many of us on the organising group have met informally, usually at information design conferences. Over coffee, dinner, and drinks, sometimes late into the night, we have come to realise that we share a common cause in health information design. This forum is our first step in turning that common cause into action, and inviting others to join us.

From our experience as practitioners and researchers, we have come to realise that the design of health information has achieved some degree of maturity. Drawing on that maturity, I was able to write with confidence:

We now know enough about information design methods—the procedures, techniques and skills needed—to create documents that provide patients with the information they need and can use appropriately with ease and confidence (Sless D 2001 Usable written information for patients, Editorial, *Medical Journal of Australia* 174 (11) 557-558).

The know-how exists to help governments and industry create quality health information. Yet, as many of us at this forum know only too well, the overall quality of health information design is at present poor. There is a large gap between what is possible and practical, and what is currently available.

Let us bridge that gap.

David Sless
December 2003

Choosing the participants

The organising group canvassed widely to ensure that the participants invited were broadly representative of those organisations with an interest in health information design.

We had far more requests to attend than we could accommodate. That in itself is an indication of the great interest in this subject. But as the purpose of the day was planning, we had to decide between a large group, with many interests duplicated around the table, and a smaller gathering that was representative, but of a size that would enable everyone to participate actively and contribute to shaping the outcome. We chose the latter.

On the day we had 28 participants, a facilitator, and a reporter. Many travelled long distances specially to be with us. All delegates contributed actively and enthusiastically to the proceedings and the synopsis that follows is a tribute to their collective effort on the day. The delegates are listed in the Appendix.

To all those who could not be with us, and those who would like to join us for future occasions, we extend a warm invitation. As you will see from this report, we have laid the groundwork for many future opportunities.

Synopsis of proceedings

1 Identifying what users of health information need

Ten invited speakers provided background on challenges facing the discipline of health information design (HID), and addressed needs of users of health services and products from the perspective of their respective organizations as follows:

SPEAKER	WHAT USERS NEED	WHAT INFORMATION DESIGNERS CAN DO
Jackie Glatter Consumers Association (UK)	<ul style="list-style-type: none"> • Accessible information in understandable, trustworthy format • Consideration of special needs (e.g. visual impairment) • Assistance with self-care • Identifiable health services and providers 	<ul style="list-style-type: none"> • Design health information with all uses and users in mind
N. Lee Rucker National Council on Patient Information and Education (USA)	<ul style="list-style-type: none"> • Useful information on medicine (Goal: from only 50% of leaflets useful now in USA to 95% by 2006) • Cards for elderly to list medications being taken 	<ul style="list-style-type: none"> • Consult users face to face to judge usefulness
Dr. Jerry Reinstein Medicines Labelling Group (UK)	<ul style="list-style-type: none"> • Useful labels and leaflets • Government regulations to improve labels of prescription medicines, so latter can be used according to best practices (WHO says 50% not so used) • International harmonisation 	<ul style="list-style-type: none"> • Design health information with all uses and users in mind • Work towards national and international regulation and harmonisation
Andy Crump WHO (Switzerland)	<ul style="list-style-type: none"> • Communities empowered to care for their own needs, with sensitivity to cultural concerns 	<ul style="list-style-type: none"> • Encourage empowerment of local communities • Develop cultural understanding and sensitivity • Use images where appropriate to present information for non-literate users • Monitor and evaluate impact of health information on users
Stein Lyftingsmo Independent pharmacist (Norway)	<ul style="list-style-type: none"> • Space on medicine packages to put patient information • At minimum, need medicine's generic name, dosage, instructions for use; also ingredients and patient information 	<ul style="list-style-type: none"> • Improve information through labelling • Improve information software • Meet the challenge when medicine is imported from abroad

SPEAKER	WHAT USERS NEED	WHAT INFORMATION DESIGNERS CAN DO
David Dickinson Consumation (UK)	<ul style="list-style-type: none"> • Information that respects rather than talks down to users • Choice of extent of personal involvement 	<ul style="list-style-type: none"> • Promote education and equitable partnership rather than strictly medical agenda • Involve people in decisions on their own care to extent they wish to be involved • Account for users' reluctance to discuss personal needs • Bridge gap between users and health information providers; must speak same language
Sarah Clark WHO (Switzerland)	<ul style="list-style-type: none"> • Local needs satisfied 	<ul style="list-style-type: none"> • Find generic common guidelines adaptable to local needs (generic insufficient in itself) • Get closer to users to learn how they interact with health information (research required here) • Raise awareness of, and advocate for, benefits of HID itself on global scale • Build capacity in HID to implement high standards; share learning on it
Geoffrey Henning Roche Products Ltd. (UK)	<ul style="list-style-type: none"> • Leaflets adequately describing medicine's side effects • Information about risks that helps decision-making without creating fear 	<ul style="list-style-type: none"> • Change or overcome present regulatory environment in order to provide necessary and appropriate information • Change or overcome use of fear in marketing that may affect proper use of medicines
Jane Shaddock Centre for Health Information Quality (UK)	<ul style="list-style-type: none"> • Health information in plain language • Broader issues of accessibility than just labels 	<ul style="list-style-type: none"> • Design health information with all uses and users in mind
David Cousins National Patient Safety Agency (UK)	<ul style="list-style-type: none"> • Labelling that does not contribute to misuse 	<ul style="list-style-type: none"> • Design health information with all uses and users in mind • Set up reporting and learning systems to implement best practices in HID, including safety features for patients • Specifying design requirements should precede pricing concerns

2 Finding common ground to address the challenges

Facilitator Dr. Ruth Shrensky distilled nine challenges in HID that emerged from the above discussion. Delegates worked in pairs, discussing these challenges and presenting the results to the full group. The primary points presented under each challenge are as follows:

Improving government regulations

- Following the current regulations, as they are, won't solve usability challenges
- Insufficient information on labels for patients and physicians: who takes responsibility at a global level?
- Information requirements can also be legal, to protect manufacturers
- Labelling also for computer coding
- Must get government to improve health information (monitor "Ask about Medicines" conference next October; Gates Fund, Howard Hughes Medical Institute, British government and others may be interested in supporting efforts to do this)
- Need to determine what regulations exist around the world
- Need to coordinate delegates' international contacts

Coordinating and harmonising different stakeholders, localities and knowledge-sharing from users' perspective

- Need to determine why coordination is needed and whether harmonisation means same standards for all
- What are best practices? Is there common ground on which we can build?
- Users different everywhere, so must relate information to different contexts (including visual language); need more dialogue among different users
- Patients' interests must come first, so stakeholders not all equal here
- Much medicine unused and wasted
- Global solutions for Europe by EU may not be appropriate for everyone
- Involving certain groups in this dialogue (e.g. EU) will be a challenge
- In Canada, propose to integrate scholarly training to bridge information gaps among interested parties

- In Australia, collaboration and dialogue among stakeholders rather than unilateral decisions; actions flow from advisory group
- Seek letters of support from organizations such as MRC and WHO to fund applications for further research into HID

Adapting information to meet local needs

- Need to provide guidance on international standards; extent to which use can be evaluated; and how to get it down to local level
- ISO's graphic standards set general criteria; WHO has template for local adaptation
- How local do you get? Some national and international bodies are focused on their own areas
- Global perspective and coordination required; for example, WHO asking pharmaceutical companies to donate drugs and to observe certain guidelines
- Empowering patients is broader issue, as is accounting for culturally diverse backgrounds and diverse levels of literacy
- World Information Processing Society targets world online by 2009 (most of developed world there now)
- Ask what media most suitable: print, radio, video, mobile phone, etc.; needs research
- Information campaign needed, for example, in public health

Identifying what kind of health info, when, given by whom, how and from whose perspective

- Behavioural change towards medical outcomes required on international scale, so must identify barriers to action (e.g. social, economic, psychological)
- Pharmaceutical industry insufficiently informs patients and citizens
- Must show that HID benefits bottom line for pharmaceutical industry as well as users
- Need education through outreach and certification to ensure products as per specification (risk management)
- Pharmaceutical and hospital information technology systems can do much pre-thinking for physicians; new paradigm for labelling required
- Insufficient attention paid to what happens after information is given to users; must understand users' contexts and barriers to their use of medicines
- Better usability tests for products needed before they go to market
- Questions such as where research is published and who is funding it affect access to and receipt of health information

- Need to make many lists to identify issues (e.g. list of kinds of health domains where information would be useful)

Respecting users (equity and trust)

- Users have right to information that's evidence-based, not just opinion
- HID process should be in collaboration and consultation with users
- Concern with online information: plethora of sources and not all credible

Determining where to balance information and users' involvement

- Need incentives to add evaluation and monitoring into HID processes (probably no money available for this; with decentralisation, no central funds)
- Problem for designers who want evaluation and monitoring, but get it removed from tenders or otherwise not pursued by clients
- Problem: no way for granters to find out what happens to money after funding
- Problem: no one has found a single system of evaluation and monitoring that works

Establishing criteria and standards for HID

- Need to determine what research exists from which to work
- Need international standards and generic template that are evidence-based; Coventry University seeks a lead role here
- Stein Lyftingsmo's website (www.lyftingsmo.no) has links to guidelines relevant to regulations governing labels
- Institute for Safe Medical Practices (www.ISMP.org) also has information

Improving research and training in HID

- Existing research is scattered and inaccessible; much reinventing of wheels
- Need specialists in HID, trained technical writers and designers, and updated materials to supply to health care providers
- Need also to train the staff who deliver health information, to communicate well with their patients
- To what extent is there training in more than written communication of health information? Illustrations helpful as well, especially where users' level of literacy is low.

- Workshops on design fundamentals are well received by non-designers
- Issue not only to make information available, but to provide specific types of basic training to make useful difference
- Ground-level view required; personalisation of information is important
- Sources of training on writing good health information exist, but how to find and recognise them?
- How-to solutions to be gathered by group in central database to be created by Stan Ruecker and Bonnie Sadler Takach
- Need paper on what HID is and how it informs communication of health information, because many organisations don't yet understand its importance
- Public relations important: need to show that HID saves money, but PR costs money and needs to be done professionally (including linking with university PR functions)

Clarifying terminology

- Must define what we mean by terms like "public health" and whether "labels" includes "leaflets"
- Need consistent vocabulary: culture clashes among designers, health care providers and others—not issues of translation
- Big job to adopt new vocabulary; note danger of divining different meanings from same term; perhaps need not so much an agreed vocabulary, but narrowed-down use of what we have
- Need awareness of complexities of language
- When we talk of personalizing information, we mean empathy for users
- Agree on English for this forum for now, with group policing its own terminology

3 Setting the agenda

Delegates reiterated the importance of further research and training in HID, and discussed the need to publish in the field. Rather than setting specific, overarching priorities for the group at this time, delegates discussed the need to continue their dialogue through a listserv or posting system. Four key issues to bear in mind were raised:

1. Users of health information may not recognise problems with the quality of what they get.
2. Global issues inform HID.
3. It is worth raising awareness of the importance of HID, and quantifying the benefits.
4. What ties it all together is an underlying respect for the intelligence of consumers.

In moving forward as a group, delegates suggested that the group should address the following questions:

1. How does HID improve health communications?
2. What processes already exist for HID?
3. What models of communication, information, patient models, etc. exist?
4. Where are good practices to be found?
5. Where is research needed?
6. Why is there a need to coordinate?
7. Who should talk to whom?
8. Does this group need a manifesto?

The group informally dubbed itself the Health Information Design Network. Its work is expected to bridge multiple disciplines, have an international scope, and precipitate new research in the field.

4 Assigning tasks

Delegates discussed specific actions to take, aimed at answering the questions and addressing the issues raised above. A list of 18 initial tasks and the parties who graciously agreed to undertake them is listed below.

	TASK	RESPONSIBLE PEOPLE
1	Identify and notify research funding possibilities with MRC and other agencies	Raouf Naguib
2	Solicit support from WHO	Sarah Clark
3	Identify and notify research funding possibilities with NIH and other agencies	Zoe Strickler
4	Develop evidence-based guidelines for health product information for specific regulatory zones	Leander Fontaine David Dickinson David Sless
5	Build case for quantifiable benefits of better health information	Jane Teather Brian Parkinson Karel van der Waarde
6	Develop a clearing house of cases (idea bank) and a template to ensure evidence-based	Rob Waller Mark Barrett Jane Shaddock Zoe Strickler
7	List practice domains where health information design would be useful	Mark Barrett Judith Moldenhauer
8	Build case for why coordination of stakeholders required	All
9	Identify sources of training on creating useful health information	Leander Fontaine Anyone else who can
10	Develop training programs in health information design	David Sless
11	Maintain central data base of information and establish forum for on-line communication among group	Stan Ruecker Bonnie Sadler Takach
12	Maintain Web site links to web sites providing design guidelines	Stein Lyftingsmo
13	Collect guidelines for designing health information worldwide	Karel van der Waarde All to provide information
14	Monitor <i>Ask About Medicines</i> conference for opportunities to encourage governments to act on improving health information	David Dickinson Geoffrey Henning
15	Coordinate and undertake lobbying of regulators to improve health information	Jerry Reinstein
16	Identify existing regulations for health product information in EU	Leander Fontaine
17	Identify people to represent regions as yet unrepresented in group	Jerry Reinstein All to provide information
18	Coordinate progress reports and meeting within next year	David Sless

The group agreed to meet again within a year, at a gathering to be convened by David Sless. Coventry University expressed its support for future events like this and has agreed to be an active node in the international development of HID into the future. Participation from developing countries, perhaps by videoconference for convenience, was seen as particularly important. This effort might be supported by organisations such as the World Bank Institute or John Hopkins. Future research could be published in journals such as the *Journal of Health Communication*.

In the meantime, delegates may meet with people from their respective domains in parallel to their efforts on behalf of this forum. Delegates will keep in touch and report their progress through an electronic forum to be established by Stan Ruecker and Bonnie Sadler Takach.

The delegates thanked Ruth Shrensky for facilitating the forum, Geo Takach for his reporting, David Sless for organising the event, and Coventry University for hosting this inaugural meeting of the Health Information Design Network.

APPENDIX: List of delegates

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