Design to Improve the Health Education Experience:

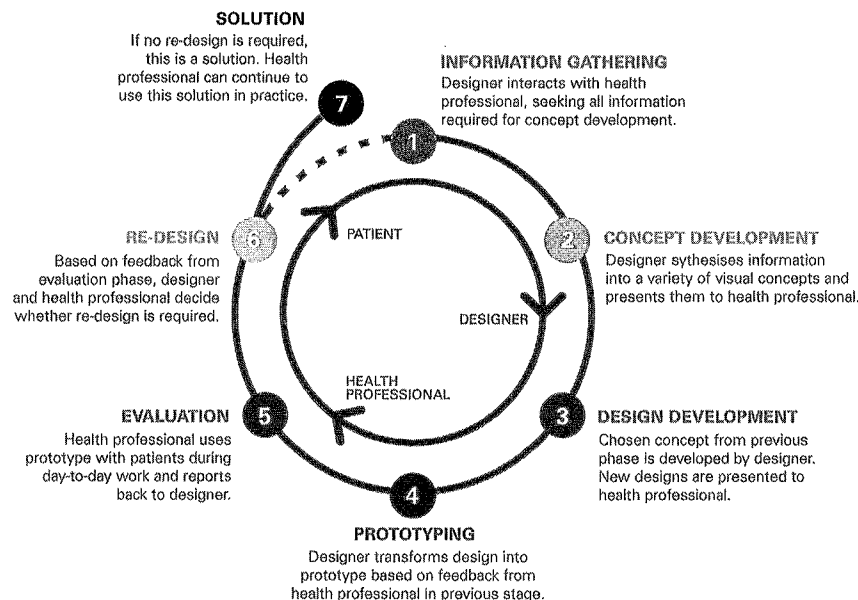## *using participatory design methods in hospitals with clinicians and patients*

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ABSTRACT

Poor communication in health is a persistent problem. Transient conversations, extreme time constraints, stress, trauma, clinical factors and the restrictive environment make effective communication between health professionals and patients difficult to achieve. Children, especially, are often positioned as passive participants in the healthcare paradigm. It is hypothesized that providing children with visual health information (well-designed, accurate, age appropriate, and presented in a way that they can understand,) can empower them to take charge of their health and well-being. For visual health education materials to be effective, accurate, and engaging, they need to be designed with input from design practitioners, health experts, and the target audience. However, constraints within the health field, such as restricted access to patients, make this difficult. Furthermore, when children are involved, ethical and practical obstacles can hinder the process. The research presented in this paper navigates the complexities of the health field and presents a realistic participatory design model that responds to the specific challenges associated with designing in a healthcare environment. The efficacy of the approach is demonstrated through successful designs and positive health professional feedback.

KEYWORDS

health communication, health education, participatory design, qualitative research, user-centered design

SOLUTION
If no re-design is required, this is a solution. Health professional can continue to use this solution in practice.

INFORMATION GATHERING
Designer interacts with health professional, seeking all information required for concept development.

RE-DESIGN
Based on feedback from evaluation phase, designer and health professional decide whether re-design is required.

CONCEPT DEVELOPMENT
Designer sythesises information into a variety of visual concepts and presents them to health professional.

PATIENT

DESIGNER

HEALTH PROFESSIONAL

EVALUATION
Health professional uses prototype with patients during day-to-day work and reports back to designer.

DESIGN DEVELOPMENT
Chosen concept from previous phase is developed by designer. New designs are presented to health professional.

PROTOTYPING
Designer transforms design into prototype based on feedback from health professional in previous stage.

INTRODUCTION

Graphics are not generally seen by health authorities as the primary way of communicating information to children (Dowse, 2004), yet it has been shown that picture-based messages are preferred by most people (the "picture superiority effect") (Dowse, 2004; Katz, Kripalani, & Weiss, 2006; Lidwell, Holden, & Butler, 2003). As well as being more accessible, visual materials that are distributed to patients are a permanent source of information (Dowse, 2004; Groves & Fitzgerald, 2010). They can be referred to in the patient's own time, making them less transient than face-to-face verbal communication. The material can be viewed and comprehended at a pace dictated by the patient (Klug Redman, 1993; Purtilo & Haddad, 2002), rather than received by verbal communication which must often be comprehended within time constraints.

The literature surrounding visual communication design for children is sparse, with the majority of studies being market-research oriented and commercially driven. While it is important to understand the target audience and their motives, greater importance should be given to children's comprehension of vital health information. It has been demonstrated that young patients are less anxious if they are told what is going to happen to them clearly and honestly. They find it useful to know the order of events (Lloyd & Bor, 2009, 112) and are more interested in concrete information on current experiences rather than possible consequences in the distant future (Rapoza, 2003, 260).

It may be argued that children lack the maturity to understand complex health information. Children may be perceived as lacking the knowledge and experience needed to make informed choices (Buckingham, 2011). Furthermore, issues such as low health literacy and age-related cognitive abilities may impact children's comprehension of presented information (Terre, 2009). There are also several psychosocial factors specific to children that may affect their healthcare experience. For instance, child patients are dependent on a parent or guardian in relation to medical care and decision making. This lack of power positions child patients as passive bystanders in the healthcare paradigm (Lambert, Glacken & McCarron, 2010). In addition, the culturally defined power dichotomy that exists between patients and health professionals adds to the passive positioning of the patient. However, by making health information available and accessible, we can empower child patients to take control of their own health, giving them a sense of independence and competence which may foster better health outcomes and psychosocial well-being. Working with children to increase their understanding positions them as active participants in the education process (Lambert, Glacken & McCarron, 2010).

Participatory and user-centered design methodologies can be implemented across health settings to generate site-specific, end-user focused, and holistically informed education materials.

User-centered design considers the subjective experience of end-users (patients and health professionals) and is able to identify a purpose for the design. Participatory design involves these end-users in the design process to create products, services, and designs that are user-friendly. The project that will be discussed in this paper straddles the boundaries of both user-centered and participatory design. It is user-centered design because it is design for child patients and health professionals as users (Ryan & LaBat, 2009), and it is participatory designed because the author works with health professionals in a collaborative manner to build a picture of the patient experience to inform design outcomes (Ryan & LaBat, 2009). It is best positioned as a participatory design approach that contributes to a user-centered outcome. This paper puts forward a participatory design model specific to pediatric health that is not currently presented in design or health literature.

RESEARCH DESIGN

A multiple case-study approach was employed to gain a comprehensive understanding of health professional and patient interaction with designed materials in a real-life context. This reflects the need to examine complex social phenomena whilst preserving the interwoven variables that arise in real life (Yin, 2009, 4). Three qualitative case studies were conducted within the pediatric areas of Rehabilitation, Gastroenterology, and Asthma, informed by the methodological principles and methods of ethnography and grounded theory. Qualitative approaches unite the research with reality (Barach & Johnson, 2008, 192), while the inclusion of multiple cases offers diversity, variation, and a number of perspectives, helping to diminish the danger of developing a biased point of view (Stern & Porr, 2011, 51).

Throughout each case study, the author collaborated with health professionals to produce design prototypes that were trialed in patient education sessions in an Australian public hospital. The goal for these prototypes was to attempt to break down the power dichotomy between patient and health professional and to move patients away from the sick role and passive bystander position by making health information available, accessible and engaging. Furthermore, we wanted to distill the most successful aspects of this process into a model that other health professionals and designers could implement in their own practices. The case studies consisted of three core phases: collaboration, prototyping, and evaluation. Collaboration involved working with health professionals and exploring ideas for design prototypes. This was a practical, collaborative, and reflexive process aiming to understand and improve collaborative design practice in the field of health (Kemmis & McTaggart, 2005, 566-567). In-depth, semi-structured interviews were conducted focusing on information that could be better communicated to patients and identifying tasks that the end-users (both health professionals and patients) were required to perform. Over the course of the case studies, 15 digitally recorded in-depth

interviews took place ranging in length from 30 to 60 minutes.

Prototyping involved the development of design concepts. The initial visual concepts were developed by the author and were reviewed at regular intervals by the health professionals involved to ensure that the concepts were appropriate, accurate and clinically relevant. During this project, prototyping was used to evaluate the developing design and to elicit health professional perspectives as the design evolved. The prototype and review cycle continued until a design prototype was resolved and produced. Visual milestones were recorded to document the prototype development journey from concept to completion. Rather than providing only a hypothetical solution, this research is translated into design practice with tangible visual results.

Evaluation was initially ethnographic and involved observation of health professional-patient interaction with the design prototype during an education session. An interview was conducted with the patient directly after the session. The health professional was to be interviewed upon completion of the case study, as it is important to note that usability of the design prototype applies not only to patients but to other end-users and stakeholders (Ryan & LaBat, 2009). However, after one patient observation and interview, it became clear that the research design would not work long term. The author's experience was that gaining objective information from the patient was extremely difficult and this likely would have been the case with subsequent interviews. Furthermore, recruiting suitable patients and gaining informed consent was a time-consuming process for all involved, and this may have become excessive if we were to recruit more patients. As the appearance of patients and their parents could not be predicted or managed, this process involved a level of coordination on the part of the health professionals that the author felt was unethical.

Instead of working directly with patients, the author decided that working directly with health professionals (the people who have the greatest insight into patient comprehension) was the most suitable alternative. They work with these patients over the course of days, weeks, or months. They can obtain a sense of how well the patients understand the health material presented, and they are able to keep a record of this information. While user-centred design methodologies advocate working with all user groups directly, in this case patient-designer interaction was omitted from the research design in favour of health professional-patient interaction due to the ethical and practical restrictions imposed by the field. Designer-patient interaction was not required in this instance because the information needed to generate prototype content and design could be extracted from the health professionals, the health professionals could provide in-depth insight into patient education needs, and the health professionals could evaluate the resulting designs with patients on behalf of the designer.

The amended evaluation method involved providing the health professionals with copies of the design prototypes to use as they would any other educational device in their day-to-day work. The only restriction was that they had to be used with patients rather than staff, students and the general public. The health professionals had full control over how often they used the design prototypes and which patients they used them with. A checklist was stored with the design prototypes and the health professionals were required to complete this after each use. The checklist requested the perceived level of patient understanding, as well as any comments that may have impacted the patient's comprehension ability (for example, this is the patient's first presentation, the patient has been using the design prototype at home, the patient is agitated).

The amended evaluation phase departed from ethnography but sought to maintain ethnography's methodological principle of naturalism whereby people's behavior is studied in an everyday setting rather than under experimental conditions set-up by the author. This amendment recognized that the author's presence would affect the study setting and results (Allen, 2010). Allowing the health professionals to use and evaluate the prototypes assisted in gaining a true representation of how the materials would typically be used in the field and would be more likely to elicit genuine responses from patients. Surveys, questionnaires, and the presence of an unfamiliar researcher, on the other hand, could disrupt the care paradigm and generate false data. This approach also aligned better with the case-study method where research is constructed out of naturallyoccurring situations, unlike the manipulation and control of variables that occurs in experimental research (O'Reilly, 2009).

Structuring the case studies as shown in *Figure 1* and utilizing the health professional as the evaluator solved a number of patient access issues. First the health professionals had access to patients that the author did not, such as non-English speakers, non-verbal patients, patients with guardianship issues, critical and acute patients, and inpatients and outpatients. Additionally, the health professionals did not have to organize times for the author to come in to speak to parents and times to come back to conduct the observations and interviews. The health professionals were able to implement the design prototypes at the patient's first presentation and to monitor usage at follow-up appointments, whereas the author could not due to having to gain informed consent after the patient had first presented.
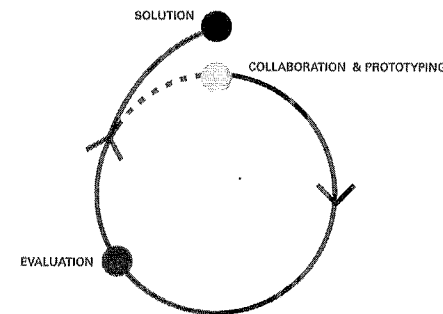

FIGURE 1:

Case Study Structure

THEORETICAL PARTICIPATORY DESIGN MODEL

Constraints within the health environment and the research experience informed the development of a participatory design model that facilitates interaction between designer, health professional, patient, designed object, and environment. The *3-Corner Collaborative Design Model (Figure 2)* was developed by the author and is a framework for creating highly effective, audience-specific, patient education materials. It is a synthesis of two different phenomena: the design process (outer circle) and designer and end-user interactions (inner circle).
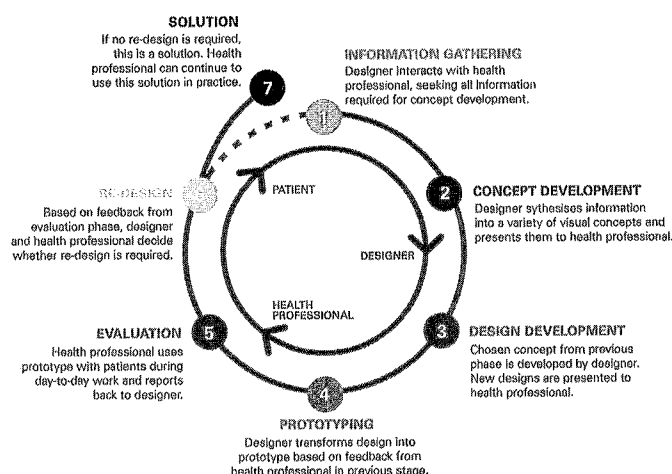
The design process is based on a synthesis of existing design models and the author's experience of designing throughout this project. It is specifically informed by the iterative nature of the *Communication Research Institute Design Process Model* developed by David Sless (Sless, 2008, 52). The research design ultimately shaped the way in which the participatory design process unfolded over the course of the three case studies, with collaboration, prototyping, and evaluation the core components (see *Figure 1*). Figure 2 breaks down the case study model stages into smaller, critical areas beginning with information gathering. While the process is presented in a cyclical form with each step progressing logically backtracking often occurs in practice. Constant self-reflection by the designer, recognizing when problems occur with the design, or revealing new information that wasn't mentioned in the earlier stages, mean that adjustments to the process are made as needed.

Figure 3 interview questions:

1. Is there a type of patient that responds particularly well / poorly to this prototype? Why do you think that is the case? Patients may be discussed in terms of age, gender, clinical background, native language, etc.

2. How do patients indicate that they have understood / not understood the material?

3. Have any patients provided feedback about the prototype? What was it?

4. What impact has the prototype has on your education technique/experience? Has the prototype had a positive/negative impact on your practice?

5. Do you think this prototype has longevity? How long do you think you will continue to use it? How can the life of the prototype be extended?

6. What were the most positive aspects of the prototype?

7. Were there any problems with the prototype? What were they? How can they be overcome? Are changes to the design required?

The evaluation stage of the model is critical as the feedback provided by patients and health professionals guides the design process. At this stage the health professionals report back to the designer about the efficacy of their education. The efficacy of the design needs to be distilled and extracted from this information. In this project the author asked the health professionals a set of interview questions about the designs as shown in Figure 3.

These questions helped extract focused, specific information from the health professionals which could be used to determine the strengths and weaknesses of the designs and to identify our next course of action.

At the re-design stage the designer and health professionals need to decide whether the design prototype can continue to be used in the health field in its current form. The critical questions are as follows: Have we arrived at a suitable solution? Can the prototype be improved? Does the prototype meet its objective of effective communication and education of the target audience? If not, what can we do to make it better? If re-design is required, then the designer and health professional restart the process at the information gathering phase. If re-design is not required, then the cycle ends at the solution stage.

Built into the earlier stages of the *3-Corner Collaborative Design Model* are ethnographic principles. During the first four stages (but especially during information gathering), the designer regularly visits the environment to observe and interact with health staff. Designers using this model in the future should adopt an ethnographic approach, regularly visiting the health field to gather information, interact with health professionals, and immerse themselves in the hospital environment. This is critical because the interactions between designer and health professional that take place over time allow an understanding of each other's culture to be developed. These ethnographic interactions create a holistic, interdependent design approach that is highly effective in generating site-specific, user-centered designs. However, during the evaluation phase, the designers should consider whether their presence in the field might alter the normal health environment, leading to inaccurate responses. If this is likely, leaving the field and allowing the health professionals to assume the evaluator role by using the design prototype in their day-to-day practice is a good compromise. This is described as an anti-interventionist approach, which minimizes disruption to the normal healthcare paradigm. The health professionals relay patient feedback, as well as their personal feedback about using the design prototype to the designer at the re-design phase. The nature of this feedback ultimately determines whether any design amendments are required.

The designer and end-user interactions that take place over the course of the design process shape the design outcomes and are an example of the interdependent nature of participatory design. The fact that the designer regularly interacts with health professionals (who are end-users in their own right) to achieve design solutions, makes this a user-centered approach. Patients remain subjects rather than a participants or collaborators, but their views as an end-users are gauged by the health professionals during practice. This is described as a 3-cornered approach where designer and health professional interact, health professional and patient interact, and patient and designer interact indirectly using the health professional as an intermediary, as shown in *Figure 2*. In this particular scenario, the designer depends on the health professional and the patients to obtain the information the designer needs to complete the project, generate meaningful data and produce the required solution. The health professional and the patients depend on the designer to deliver visual materials that facilitate effective patient education. Each party has a different motivation and a different end-goal, but the result is mutually desirable.

The *3-Corner Collaborative Design Model* is beneficial in the development of patient education materials and has demonstrated engagement of staff and patients by taking a participatory design approach. The model is multi-layered, offering both a way to design and a way to source, understand, and integrate the perspectives of end-users. This way of working (participating, designing, evaluating, and re-developing the designs based on feedback) is not always used in the development of patient education materials. While ethnography is a common approach to gaining qualitative data in the health field, and participatory design is becoming more widely accepted in health, there is little documentation of a combined approach for the development of site-specific health education materials. Certainly, the health professionals involved in this study had not encountered this approach. They were working with patient education materials that were generic, text heavy, not always appropriate for their patients, and poorly designed. They were able to see the benefits of the participatory design process in the form of tangible design outcomes that met their needs (as shown in *Figure 4*), demonstrating the validity and value of the *3-Corner Collaborative Design Model*. Furthermore, involving the health professionals in the design process ensured that they were familiar, comfortable, and confident with the content and form of the design prototypes and were able to use them to enhance the way they deliver information to patients.

FIGURE 4

Design prototypes (Gastroenterology, Rehabilitation and Asthma)
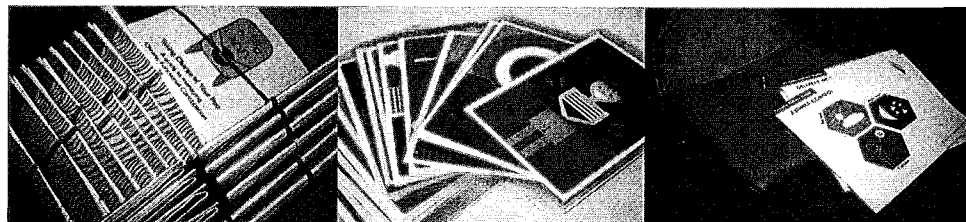
In terms of education practice, all of the health professionals found that using the design prototypes assisted several aspects of their education process. Some said that the design prototypes produced these positive outcomes:

.... Streamlined the education process

.... Allowed them to follow or go through a process (systematisation)

.... Acted as an insurance policy by making sure that all of the critical information was covered

.... Acted as a prompt (helped them remember the more intricate aspects of their education topic)

.... Enabled education to be delivered in layers (if education was interrupted, the design prototype served as a good indicator of where to resume the education session).

Furthermore, the *3-Corner Collaborative Design Model* provided a brief but structured way for the health professionals to think about the way in which they were delivering patient education and sparked reflective practice. One health professional noted that "it has been an interesting exercise actually ... [because] it does make [me] think a bit more about [the information] I'm giving them" (Gastroenterology CPC 2013, 30 September). Participating in design activities encouraged the health professionals to question the impact they were having on patient education. Self-reflection most often occurred at the information gathering phase and during reviews of designs at the concept development and design development phases. The *3-Corner Collaborative Design Model* provides an excellent framework within which health professionals can reflect upon and evaluate their educational practices. This shows that the model has major practical benefits beyond the design outcomes.

Levels of patient understanding were gauged by the health professionals and documented on a checklist. Of the 65 patients who interacted with the various prototypes, 37 showed a high level of understanding, 20 showed a mid level, 6 showed a low level and 2 were unable to be classified. While there are some reliability limitations associated with self-reported data, the fact that the majority of patients were positioned in the mid to high level of understanding was encouraging.

DISCUSSION

The *3-Corner Collaborative Design Model* has been created by the author from an ethnographic understanding of healthcare and health education and has been developed in response to the particular limitations of the field. After exploring the potential of including patients as participants in the

design process, we decided against this due to the problems associated with engaging vulnerable and traumatized children in research activities, and the excessive level of coordination required.

The *3-Corner Collaborative Design Model* involves no disruption to patients. However, it does integrate the perspectives of patients indirectly, using the health professional as an evaluator. This model is suitable in situations where accessibility to patient groups is limited and problematic. The evaluation approach is non-invasive and ethically sound which is important in scenarios that involve vulnerable people.

The model can be integrated into everyday health-care practice which is critical in the health environment as there is often a sense of urgency in terms of time. Health professionals must balance their duty to patients with administrative tasks, staff meetings, and other scheduled events. While participatory design sessions do need to be scheduled with the health professionals involved, these take up relatively little time. In each of these case studies, five formal sessions ranging in length from 30 minutes to one hour were scheduled over the entire process. This approach was designed to cause minimal disruption to the working life of health professionals. Likewise, the process of using health professionals in the evaluation phase to assess patient understanding of the design prototypes has been designed to be convenient. Evaluation was integrated into the health professionals' day-to-day work meaning that there was no additional time outside of working hours required to evaluate the design prototype. The fact that the design prototypes are able to be completed in a short amount of time, and consume very little of the health professionals work time, urges us to explore the impact that this might have on future health education development and practice.

The model helps facilitate a blending of skill sets that are essential to a good design outcome. The ethnographic nature of the model, combined with formal participatory design sessions, allows for exchange and synthesis of both health specific knowledge and design specific skills. The model incorporates designer and health professional input at every stage. Having health professionals review and comment on the designs regularly (at the concept development, design development, prototyping, and re-design phases) is crucial in facilitating this exchange. While the approach taken in this project was to work with a key individual on a one-on-one basis, the model may also work in group situations, though this has yet to be trialed. The merging of health and design knowledge bases is essential in producing design prototypes that are clinically accurate, well-designed, and empowering to patients and health professionals as end-users.

During the course of the case studies, the health professionals explained that the design prototypes allowed them to develop their own education process or system. While it is difficult to quantify, the design prototypes appear to be efficient ways of communicating with patients. Furthermore, the systematic approach to education facilitated by

these design prototypes can be incorporated into existing hospital practices, such as criteria-led discharge. This is a process through which patients can be discharged by a nurse (rather than a doctor) if they meet certain criteria. One component of this is that patients have to receive targeted education. This is where the design prototypes have the potential to be extremely useful. Following the design prototypes ensures that each patient has a consistent quality of education and receives the full breadth of information. So whilst having the ability to streamline the education process, the design prototypes could also assist in facilitating timely patient discharge.

While the *3-Corner Collaborative Design Model* is broadly applicable, it is important to note the limitations of the approach. Most significantly, the lack of direct designer-patient interaction limits the weight of the claim to a user-centered approach. While there were valid reasons for omitting patient-designer interaction from the research design, the approach cannot be defined purely as user-centered in the strictest sense of the term. This research was limited to child and adolescent audiences and to specific health conditions. While we can hypothesize that the design model would work just as well in the production of materials for adult patients and for different health topics, we do not have any data to support this. In many instances, the design prototypes were used to effectively educate parents, which is encouraging. However, further evaluation would need to be conducted with adult patients to confirm this hypothesis. Data collection was conducted solely in South Australia, limiting observation geographically and culturally. While a broad demographic was studied, the design model needs to be trialed more broadly (in other countries, for example) to assess its functionality among a wider socio-geographical audience and to validate the approach.

CONCLUSION

There is a need for health education materials that engage child patients. The literature shows that there are challenges associated with communicating with young people; however, it also demonstrates that children are capable of understanding complex health information if it is presented in an appropriate manner.

This paper has demonstrated that an opportunity exists for communication strategies to be improved within health and medicine which may benefit the wider community by enhancing the delivery of health information. Potential exists to streamline and enrich the way that health education materials are designed. There is capacity for both hospital-employed designers and external designers to work together with health professionals using the theoretical model outlined in this paper. This is a crucial way forward for design and health collaboration which will save time and mistakes. This paper suggests that user-centered and participatory design approaches are appropriate as they consider audience factors such

as poor health literacy, comprehension ability, cultural norms, and age-related cognitive abilities, and they involve end-users in the design process to ensure a relevant result.

Due to limited access to children in health settings, the *3-Corner Collaborative Design Model* employed in these case studies sought information about the needs of child patients from key informants – the professionals who deliver health information to these patients on a day-to-day basis. As well as detailing a participatory design approach to the design of user-centered health education materials, this paper also offers a method for evaluating the impact of such designs. By allowing health professionals to use and evaluate these materials, we are able to gain insight into how they function in the real-world. By evaluating the results we have determined that this is a worthwhile approach to be adopted by others. The next step is to disseminate the model more widely to encourage and facilitate positive change and development through multi-disciplinary design and health collaboration.

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Belinda Paulovich holds a PhD in Visual Communication and a Master of Visual Art and Design from the University of South Australia. Her research has explored ways in which designers can collaborate with professionals in health, medical, and scientific domains to produce communication solutions that are visually appealing, functional, accurate, and user-centred. Her current research interests include collaborative practice, self-reflective practice, power dichotomies in the health field, and the challenges associated with conducting qualitative research in medical and scientific domains.