Information design to make an impact on health care quality – is a user-centred approach enough?

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Information design to make an impact on health care quality – is a user-centred approach enough?

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In three information design projects forms to support processes of different kinds were developed for health care organisations. In each case the purpose of the forms was to enable decision-making and communication between groups of people with different expertise. The paper discusses how the contexts in which the projects were carried out influenced, the outcomes developed, and their eventual uptake by the host organisations. It argues for focus both on users and the context of use in the design of even the most everyday documents, since such documents are often required support complex working practices within established organisational systems.

Introduction – user engagement in clinical forms design

Forms (either printed or electronic) serve many roles in communication, one of which is as checklists and records of procedures carried out and their outcomes, to be shared with others within organisations (Schwesinger 2010, 112). Even though their contexts of use may be highly sophisticated, for example hospitals, manufacturing plants and flight cockpits, the content and design of these relatively 'humble' documents often receive scant attention. For example, they may be developed without consultation of the people who must use them, so be based assumptions about their users' ability to understand and complete them; they may be designed by people without particular expertise in the visual design of information, or who may not be engaged with developing the best form to support communication (Wright 1981). Yet the detailed design of a form has potential to influence the effectiveness with which it can be used and, in turn, of the processes it supports (Degani and Weiner 1993).

In all the three cases of forms design discussed in this paper clinicians had identified contexts where they envisaged use of a form/checklist, either as a new intervention or to replace an existing document, would improve an aspect of clinical care:
– the identification of pain symptoms in people with dementia, so that their medication might be better attuned to their needs (see Black et al. 2013)
– the detection of and initiation of treatment for acute kidney injury (AKI) (see Black et al. in press)
– the assessment of hospital patients' mental capacity to make informed decisions (in preparation).
The clinicians' focus was on improving a clinical outcome by gathering information in a structured manner. They anticipated relatively contained interventions to create new or improved documents. The projects' development, however, demonstrated the need to take a broad view of the processes for and context in which the forms had to function. Such an approach, as Hignett et al. (2013) have pointed out, is still underused in design for medical contexts

compared to other domains, such as consumer product design and design for occupational environments. A similar conclusion, relating specifically to information design, has been drawn by Zender et al. (2017) who emphasise (amongst other things) the need for knowledge sharing between clinicians and designers working together and the need to consider factors beyond the immediate clinical interaction a designed intervention is supporting. Similar observations are made, for example, by Hignett et al. 2015, Russ et al. 2013 in human factors research and, amongst many others, by Abraham et al. 2012, Tariq et al. 2012 and Unertl et al. 2009 in medical informatics. In the development of printed documents, however, there appears to be more flexibility for the documents to be designed specifically to fit users' requirements, compared to electronic documents, where there may be a loss of design control due to the imposition of fixed formats by programmers on the individual forms systems deliver (Powsner et al. 1998).

Recent design research across contexts places much emphasis on a continuum of designing for or with users, taking various approaches to engagement with the people who will use the designed outcome in order to develop solutions that meet their needs. User involvement has become a standard tool in the suite of methods underpinning the current approach known as 'design thinking', which has roots stemming back to designers such as Dreyfuss1955, Jones 1970 and Papanek 1971, and also in ergonomics and human factors (e.g. Corlett and Wilson 1995, Karwowski and Marras 1999) and human computer interaction (e.g. Beyer and Holtsblatt 1998, Nardi 1993).

In the UK the National Health Service, the context for all three of the design projects discussed in this chapter, there has been a developing commitment to engaging service users and staff in the origination, development and implementation of research and service improvement (DH 1997, p.38). Although not without critics, both of its implementation and impact (e.g. Allcock et al. 2015, Brett et al. 2014), this emphasis on engagement has created awareness of the need for research that develops user focused solutions.

Despite the apparent consensus that user engagement leads to better design solutions some dissent has been expressed for some time among the HCI community about whether or at what stage user input contributes helpfully to design (Norman 2010), whether inclusion of users through participatory approaches can genuinely elicit or take into account the full breadth of user experience (Vines et al. 2013) and the practicality of implementing user-centred design processes in real world settings (Mulligan et al. 1991).

The forms development projects described in this paper were all carried out with user input, gathered by a range of approaches. The outcomes of the projects, however, suggest that while user engagement can produce effective design solutions, it is not always sufficient to ensure such solutions are adopted or sustained, particularly when there are wider influences on the implementation and impact of design solutions. Designers may wonder why their well-intended and well-formed design solutions fail to become part of established practice or (in many cases) they may be unaware that they have not, since they may not have access to follow up data that reveal long term uptake. This paper includes discussion of follow up to the three design exercises in order to track the actual impact of the design work undertaken, and its relationship to user-centred process.

Case studies

Form to elicit patient pain symptoms from family carers of people with dementia

As reported in Black et al. (2013), people with dementia who have been hospitalised often have difficulty communicating pain symptoms to staff, with the result that they may be given inappropriate medication, in some cases antipsychotics,[1] when their response to pain is misinterpreted by clinicians. In order to improve patient care, the psychiatric and pain management teams at a large, regional hospital asked us (Centre for Information Design Research, University of Reading) to work with them to develop a pain questionnaire that could be completed by patients' carers (most typically, family) on admission of a patient with dementia. The aim of the form would be to support clinical response to patients' expressed or unexpressed pain symptoms.

An initial exercise in iterative, user-centred design, including consultation with clinicians, advocates for patients with dementia and carers themselves, and a sequence of design development, prototyping, and refinement delivered a solution of a small (A5 format) questionnaire booklet, intended to be completed by carers on patients' admission.[2] The format followed a precedent of an A5 booklet for eliciting information from carers about their relatives, which consultees regarded as successful. The questionnaire was trialled on two wards in the hospital but, against expectation, it wasn't used during the trial period. A key reason emerging from subsequent interviews with ward staff was that the format of the form, although believed to be appropriate for eliciting carer input, didn't fit with hospital clerking systems and so there wasn't an easy way of including it in routine patient documentation.

Insert Figure 1 about here

The design of the questionnaire was then revised so that it fitted a single page A4 form (see Figure 2) and, in order to ensure it was embedded in routine process, it was combined with the professional pain symptoms recording system in use in the hospital (the Abbey Pain Scale, Abbey et al. 2004). The combined approach meant that the carer questionnaire was immediately available on first administration of the professional scale. This redesign necessitated condensing the carer form into less space overall, resulting in compromises in the wording and ordering of questions, and the space available for form filling, particularly for responses to open ended questions. Such compromises are not unexpected in design solutions (Kujala 2003, Lehoux et al. 2013, Steen 2011) and were regarded as unavoidable in order to ensure uptake of the forms themselves.

Insert Figure 2 a and b about here

Despite the perceived design compromises, subsequent audit of the form after implementation (Modi et al. 2014) demonstrated that after training and a 'settling in' period of four months, use of the form led to adjustment of medication in 36% of patients, compared to baseline adjustment for fewer than 15% of patients before the form had been introduced. Interestingly, immediately after

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[1] The UK government has had a policy of reducing prescription of antipsychotics to people with dementia, set out in its dementia strategy (Banerjee and Owen 2009).

[2] This first phase of design was carried out by students in the Department of Typography & Graphic Communication, University of Reading, as a professional practice project.

introduction, adjustments to medication were observed in over 50% of patients, and the pattern of adjustment did not correlate with use of the form. In this initial evaluation phase it appears that introducing the form and accompanying training had raised awareness of pain relief prescribing, independently of the form, whereas the 36% level observed subsequently was more likely to have been indicative of the impact of the form itself. The 36% level was considered a significant enough improvement in prescribing sensitivity to support continued use of the form.

The difference in uptake of the second version of the form, compared to the initial, trialled version demonstrates the importance of fit of the form with its wider context of use, even if that involves some compromise in design for the intended end user. Carers of patients were not going to get the opportunity to use the form and give their input *unless* it also met the filing requirements of hospital systems. This is not dissimilar to the compromises in user-centred design resulting from the introduction of electronic systems, discussed above. In this case, at least, the involvement of information designers ensured careful exploitation of the space available in the standardised form.

Form to launch and record care bundle for patients with acute kidney injury

Not all design interventions, however, even those developed with the cooperation of their users, and demonstrated to have positive impact, are adopted immediately, as the following case demonstrates. We worked with the renal and care quality teams of a large, regional hospital to improve documentation for the care bundle to initiate treatment of acute kidney injury (AKI) (Black et al. 2017).[3] While there was existing care bundle documentation, most staff were unaware of it. Review of the documentation revealed that it both included redundant information and lacked information that was needed to initiate treatment, and that organisation of the document content did support treatment workflow. It also imposed a process where nursing staff, who were key to monitoring fluid intake and urine output (an indicator of kidney function), could not initiate the bundle without sign off from a doctor, potentially delaying treatment. Approaches to bundle documentation in other hospitals were also examined and found, similarly, to lack information thought to be essential for treatment, or to contain so much information they ran the risk of overloading their user. Neither of these was surprising given the potential complexity of treating AKI, often in patients with other, existing health problems.

Close collaboration between designers and medical and nursing staff in a series of workshops led to the re-design of the documentation. The new documentation set out a sequence of reviewing patients' symptoms, responding to indications of AKI with appropriate investigations and treatments, and referring patients to renal specialists if they did not respond to treatment within a time period. This 'three R's' approach (Review, Respond, Refer, see Figure 3a), enabled presentation of more detailed information than in the original but used spatial organisation to make this information navigable. Subsequent testing of the re-designed documentation in comparison to the original, in simulated diagnosis scenarios, suggested it was likely to lead to more rapid and effective AKI detection and treatment. A promotional leaflet was developed after testing to support

[3] Care bundles are defined as 'a collection of processes needed to effectively and safely care for patients undergoing particular treatments with inherent risks' (IHI, 2006)

introduction of the documentation to hospital staff Figure 3b. Further development was carried out to create a version of the bundle to support general practitioners in identification of AKI in patients in the community.

Insert Figure 3 a and b about here

Both the hospital care bundle and primary care identification documentation were adopted, after a time lapse, in the originating hospital and local community. The hospital care bundle was adopted, with small adaptation, by a further, large, regional hospital and the package of information now forms the basis for wider regional work. The hospital bundle documentation is also now published as an example within the NHS national recommendations for minimum requirements of a care bundle for hospitalised patients with AKI (NHS 2015). This spreading effect, much due to the energy of the clinical lead for the project, contrasts with the pattern of feedback from the pain questionnaire. In complex social systems, such as the NHS, interventions to improve service quality may take time to develop (Marshall et al. 2016).

Form to record assessment hospital patients' mental capacity to make informed decisions

The spreading uptake of applied research outputs is perhaps not surprising. Exploration of the domain is likely to have been thorough, well-reasoned responses produced, and memory of the project remains with the clinicians involved. We have seen this take place in a further project – the development of a record form for mental capacity assessments in hospital patients – where we had an initial involvement that was then taken forward by others.

The care of adults within medical and social services must be given, as far as possible, with their consent. When there is doubt that an individual has mental capacity to consent, and they reject medically recommended treatment or need to make choices between treatment options, a documented process of assessment of their mental capacity to make informed decisions is required by the UK Mental Capacity Act (2005). The law requires that a patient has to be assumed to have capacity to make their decision unless contrary evidence is gathered in an assessment. There is a specified structure for assessing and documenting whether patients can understand the information relevant to their decision, retain it in memory, weigh up the pros and cons of their decision, and communicate back the decision they have made.

Any professional in a hospital setting can make a mental capacity assessment but some are anxious about getting an assessment wrong and the legal implications of doing so. Some may also feel uncomfortable about documenting the process in patients' notes, as is required legally. So in many cases hospital psychiatrists are asked to carry out these assessments, even though other staff might have more background knowledge of the patient through day-to-day care of them. Getting the time of such a specialist psychiatrist in busy hospitals is difficult, so there is an advantage in supporting other staff to take on this task.

We worked with psychiatrists, gerontologists and social care professionals in a large, regional hospital and regional community health provider to develop a form to guide and record the assessment process. The aim was to reassure less confident staff about carrying out the process and to deliver some consistency across records of the assessment process. There were, already, published assessment forms for recording the process but these were regarded as over-structured and unwieldy by people who had used them. Indeed one informant in our research asked us to design 'a form that was not a form'. We were already

aware, from our project on pain assessment (discussed above), of the reduced likelihood of uptake of a record form that was not a single sheet of A4. Indeed another informant on this project had set out her expectations for the design of the form, 'You have to limit checklists to the important things. One side of A4 is sufficient.'

In reality, the need for a form that appears concise is not compatible with the potentially complex nature of capacity assessment and need for a detailed record of its outcomes. We developed a form that partially satisfied the single side requirement by showing the four stages of capacity assessment (demonstration of an individual's ability to understand, remember, weigh up and communicate back their decision) on one side of an A4 sheet (see Figure 4a and b) so that the form could be completed, and read back easily. The other side of the sheet was reserved for a formal declaration of the decision, and the consultees' and assessor's details. An additional training sheet (Figure 5) was produced to guide the assessment process. Setting out these instructions as a separate sheet was, we felt, the best way of providing instruction without compromising the space available for assessors to record the assessment itself. This draft form was approved by the hospital's management team for implementation, but at this point the hospital's champion for the project, with whom we were collaborating, left his post, and we lost touch with the project.

Insert Figure 4 a and b about here

Insert Figure 5 about here

Subsequently we contacted the hospital to enquire whether the form we designed had been implemented. We received a copy of the form currently in use with a comment from a hospital consultant that it '…is being widely used. It has been particularly useful for decisions regarding discharge destination. The juniors like it as it helps them through the process. I definitely think this has made a difference.' The effectiveness of the form had been audited independently after implementation, showing that it was completed adequately in over 70% of cases where it was used. The form that was sent is an adaptation of our original in which the need for a single sheet has taken precedence over the need to present a unified view of the decision-making process. The form and training sheet had been combined, imposing space and organizational constraints on the documentation. We cannot know how the original would have fared, given its reliance on guidance on a supplementary sheet of paper. However, as we have found, the need to choose document formats that encourage uptake is essential for their successful implementation; the combined form and instruction sheet may, in the end, be more effective than the supplementary instructions we proposed.

Lessons learned

A limited reading of this paper could be that, in order to have an impact on service quality in the NHS, documents need to be designed to fit a single sheet A4 format.[4] While there certainly seems to be some truth in that currently I hope to use these cases studies for a discussion that extends a little further into how research studies in information design can have positive impact in complex contexts,

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[4] It is worth noting, however, that when anxieties are raised about the systems constraints of electronic documentation, the current constraints imposed by paper document formats may not have been considered fully.

exemplified here by the UK NHS, and in so doing contribute to the developing field of visual communication design.

In all three studies documents were designed to fit the immediate requirements of their end users. The design outcomes were intrinsically effective in capturing required information, but the pain questionnaire and mental capacity form needed further adaptation to be effective extrinsically. Information designers have always considered the significance of the systems and context of delivery but in some cases this cannot be gauged until an intervention is implemented. As Frascara describes (Storkerson 2008) a design intervention is a working hypothesis which may need further development after trialling. Because designers are often invited to develop concepts in the early stage of a project, particularly in 'formative' studies, such as the ones reported here, they may neither see, nor be able to see through, implementation and post implementation development of interventions. In answer to the question set in the title of this paper, it seems that a user-centred approach to information design is a valuable start to improving care quality, but it needs to be bolstered by wider and continuing engagement with those implementing interventions in order to ensure design outputs can respond to a range or changing contexts of use.

There is a further reason, particularly as researchers, to stay engaged, wherever possible, with the progress of design interventions, as initial outcomes may not reflect the eventual impact that design has had. This shift in impact was demonstrated in the pain questionnaire audit where an initial, 'halo' effect suggested greater impact than the eventual, sustained data. The halo effect may explain why some interventions that are positively reported, subsequently do not appear to have much traction. Awareness of the possibility of such distortions should be factored in to concept development projects. Some effective information design interventions may also, as they become embedded in practice, be used less than on introduction, as the practices they support become routine, although the intention in all the projects describe here is that the documentation *is part of* the process.

Even outside research projects, in large organisations, simple factors such as changes of personnel (in the case of the capacity assessment project) may remove the designer from the project, possibly, although not necessarily, resulting in design changes. Application of the design work to new contexts (as in the AKI care bundle) may also necessitate changes the designer could not anticipate. It is not unusual for users to adapt products from their original, intended use (Fulton Suri 2005) and this process is, in software development, often built in to design process (see, for example, Maclean et al. 1990). Giving clients and users the means and support to make adaptations following implementation seems to be an essential part of user-centred design (it is of course, up to them, whether they draw on the support that could be provided – this may depend on whether they have funding to do so, and whether, if not, the designer is prepared to waive charging for further development work).

In the cases reported here we were only aware of the impact of the interventions by keeping contact with the host organisation, in some cases rather to their surprise. This surprise may have been partly due to the fact that implementing new ways of working in large organisations is a complex social process, requiring planning, funding, advocacy and training. Forms, such as the examples in this paper, are one of a range of means to improving service – the 'humble' documents described in the introduction to this paper. There are also likely to have been tacit views of the status of designers in relation to the clinicians commissioning the projects (as Zender, 2017, discusses, there needs to be mutual respect for the

expertise both parties bring to a project). In published, clinical accounts of healthcare service interventions, even where documentation may be focal to the intervention, it is unusual to see examples of the documentation used. This omission means that the formative impact of designers' work with stakeholders and users to develop documentation, and the reflection it enables on processes and priorities, is rarely reported outside design literature itself. It therefore seems important, where possible, to co-publish (designers and clinicians) this process so that memory for it, and the decisions it precipitated, is retained.

Where design solutions have been changed since the designers' initial proposals (as in the capacity assessment form) it may be tempting to step aside from the project, as something that 'didn't work' rather than publish its outcomes (known as the 'file drawer' problem in science research, Rosenthal 1979). But acknowledging wider influences on design solutions helps ground a user-centred approach as a practical tool, and set clinicians' and designers' expectations for future projects. The rationale for the initial design proposals and the subsequent changes are likely to be new knowledge that could influence the development of future projects by others. If the field of visual communication design is to be taken seriously within contexts such as the NHS, there needs to be documented evidence to support it.

Acknowledgement

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