

Customising Pathology Report Design for Patient Use

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Abstract

This research aims to find ways to use information systems to encourage chronic disease sufferers to take action to improve their health outcomes. We propose a new way to present information to chronic disease patients where motivating them to take their medication or change their lifestyle is essential for their health. We believe this new model will have a profound impact on the patient's overall experience and therefore the likelihood that they will comply with what their doctor asks of them. It is proposed that the best place to adopt this model is in the design of pathology reports. The model is based on the idea of generating different designs of pathology report for different types of health customers. The information in the reports is customized both in content and design for different types of patients so that patient will respond to the information more effectively. This paper reports on the first stage of this design process.

Keywords: Behaviour; Behaviour Mechanisms; Health Knowledge; Attitudes; Practice; Electronic Health Records

1 Introduction

Governments and health insurers have spent the past decade pursuing policy agendas that encourage patients to self manage chronic diseases, such as diabetes. For example, a variety of countries, targeting high risk populations, have run major public education campaigns about the triggers and consequences of diabetes, and many best practice management guides are available online [1]. Yet an important tool to facilitate self-management has been missing. The average patient finds critical medical test results, such as pathology reports that reveal cholesterol levels or blood sugar results, largely incomprehensible. Understanding these test results is important because they provide vital on-going information about the status of the disease, its progression and what must be done to mitigate its effects. This paper seeks to remedy this problem by presenting a new user model for customising the presentation of electronically generated test results to patients.

1.1 Background

Westernized countries are facing an epidemic of chronic diseases such as heart disease and diabetes, in part due to lifestyle [2]. Collectively, along with cancer, thrombotic diseases have the highest mortality rate of any disease in westernized societies [3-4]. Well-known thrombotic diseases include heart disease, stroke, deep venous thrombosis, and peripheral vascular disease. The mechanism by which diabetes usually leads to death is via cardiac disease and stroke, which have thrombosis as their final common end point [5].

Many of these thrombotic diseases can be managed successfully through diet, lifestyle changes and medication. But to manage a chronic disease, both patient and the doctor must understand its status. Is it progressing or stable? Are more aggressive steps needed to manage it? Answering and acting on these vital questions requires a patient to absorb key information as thoroughly as possible, but there is evidence that for many chronic disease sufferers, this is not happening. For example, a large

representative survey of diabetics in New York that assessed knowledge of two key health indicators, the HbA1c and cholesterol levels, found that 89% did not know their HbA1c levels, and that 78% did not know their cholesterol levels [6].

Patient compliance is often problematic in managing thrombotic diseases and other chronic conditions. Health literacy is a significant predictor of compliance behaviour; conversely, lack of literacy is a major impediment to compliance. For example, among patients with Type 2 diabetes, low health literacy has been shown to be closely associated with retinoplasty and other serious complications due to poor glycemic control [7], particularly in disadvantaged populations, which tend to be less literate and are therefore less likely to understand specialized medical terminology commonly used in reports [7].

Ensuring that patients understand the status of their condition and treatment requirements is obviously necessary; indeed, a recent study of patient compliance with discharge instructions found that that patient comprehension was the only factor significantly related to compliance [8]. Vermeire's study of diabetes patients similarly concluded that 'the health beliefs, the quality of doctor/patient communication, and the quality of the information patients receive are important factors for patient adherence to treatment' (p. 209) [9]. A three-decade, comprehensive review of patient adherence, also by Vermeire, determined that information-based approaches influence the behaviour of people who have a chronic condition, particularly when the communication recognizes patient-specific information needs [10].

There is an extensive literature on topics related to patient use and comprehension of medical information. For example, better informed consumers patients have (1) more interaction with physicians during consultation [11], (2) greater engagement with the treatment, and stronger

intentions to continue the treatment regime [12], and (3) greater trust in the physician [13].

Making comprehensible patient-specific information available therefore plays a key role in helping patients to manage their disease; however, patients who lack medical training tend to find the information provided in pathology reports confusing [14]. Figure 1 shows a typical report. The main potential problem here is that although it is factually correct, it does not necessarily provide the information in a manner that motivates patient understanding, and hence compliance. At present, however, very little has been written about how to prepare information that will address the needs of medical consumers. The model proposed in this paper addresses these patient-specific information needs for pathology test results.

1.2 Limitations of Current Pathology Reports

Pathology results are one of the major tools used by health professionals to measure the status and progress of thrombotic diseases. Health professionals use pathology results to communicate information about chronic diseases, including severity, current status and historical data [15]. Given the importance of pathology results in ongoing management of chronic disease, it is somewhat surprisingly that only a handful of studies have looked at improving the readability of pathology reports. Some recent studies have proposed using standardized formats to improve readability for clinicians [16-17]. However, improving the patient's comprehension of health problems actually requires more fundamental redesign based on patient information needs [18]. Some exploratory work has looked at the use of patient-oriented web sites [19], and at the effectiveness of cartoons to explain wound care to patients after discharge [20]. Unfortunately, those studies are not based on any systematic theory of

CUMULATIVE GLYCATED HAEMOGLOBIN					
Date	25/01/07	10/05/07	10/08/07	22/11/07	05/05/08
Time	09:32	09:22	08:40	09:20	08:58
Lab No	7746655	1322634	2382892	2725342	5885408
HbA1c Fraction	9.6	8.1	8.1	8.3	12.2 %
Reference Ranges					
	non diabetic <6.0 %				
	good control <7.0 %				
	poor control >10.0 %				
Note:	The target for good control of diabetes mellitus remains below 7% unless episodes of hypoglycaemia supervene. In the latter situation, the lowest value which avoids these episodes would be the appropriate target.				

Figure 1: A typical pathology report. The HbA1c pathology test reveals average blood sugar levels for the previous 90 days. Diabetes patients should take this test two to four times per year because it is an essential test for gauging how well the disease is being managed in the medium term. Awareness of cholesterol levels is important because diabetics tend to have elevated levels of low-density lipoprotein (usually labelled "bad cholesterol").

consumer information needs, and so provide little guidance about how to structure reports to either improve patient comprehension of the condition or motivate the patient to manage that condition actively.

Unfortunately, the design of most pathology reports, such as in Figure 1, are limited in their usefulness because of their design. They are primarily a record of test results for the laboratory and the treating physician. Due to this technical emphasis, they are often incomprehensible to the patient, and are sometimes even confusing to physicians [21]. These interpretation difficulties are believed to underlie many cases of misdiagnosis and are a major impediment to better communication between patients and physicians [22-23]. As a result, many patients are effectively deprived of key information about their condition because the information is inaccessible.

1.3 Attitudinal Customization: A New Model for Presenting Pathology Data

The aim of this project is to apply smarter approaches driven by theories of learning and persuasion to develop new techniques for presenting pathology results, which respond to individual patient values. This will encourage patients to engage in their ongoing treatment regimes once they leave the doctor's office. The research model proposes that embedding pathology data in a report that is personalised according to the end-user's attitude will improve four types of outcome for a patient and the patient's family:

- (1) Improved comprehension of results,
- (2) Better understanding of implications,
- (3) Greater trust in the provider
- (4) Greater post-consultation compliance (e.g. taking medication, lifestyle changes)

To do this, we propose applying a theory of consumer information requirements [24] to a pathology setting, with the patient as the health information consumer. This theory focuses on designing the structure and content of health messages so that they emphasize values that are important to the individual to increase message relevance [25-26] and are structured according to that individual's preferred information processing style [27-28].

Information processing style refers to an individual's habitual mode of processing. Cognitive-experiential-self theory (CEST) [28] refers to these as the intuitive-experiential and

analytical-rational thinking styles. CEST proposes that people process information using both a rational system and an experiential system, and that each individual has a preference for relying on one system. A preference for the rational system leads to an analytical-rational processing style in which assessment is intentional, analytic, and primarily verbal, whereas a preference for the experiential system leads to an intuitive-experiential style in which assessment is holistic, associationistic, emotional, and image-based (non-verbal). Identifying an individual's preferences is important because people tend to be more receptive to messages that correspond to the preferred style [29]. Therefore, messages that are structured as a logical argument should be more effective for individuals who process information primarily in an analytical mode, whereas a storytelling approach that conveys the message through the experiences of other people should be more effective for individuals who process information primarily in an intuitive mode [30].

The values used to convey the message are similarly important in influencing behaviour. Information that emphasizes values that are important to an individual should communicate more effectively and be more persuasive. Research based on the Functional Theory of Attitude [31] indicates that two general types of value-based attitude, value-expressive and utilitarian, are particularly important. An attitude is value-expressive when the object of the attitude is related to one's sense of self (self-image). People who hold this type of attitude respond to messages that emphasize self-image and social-self image related outcomes such as appearance or social interactions [32]. A utilitarian attitude, by contrast, is held when utilitarian considerations, such as money, time, or ability to perform activities, are regarded as important [33]. Consumers who have a utilitarian attitude respond more strongly to messages that emphasize functional impacts (e.g. how a disease will affect day-to-day activities) and monetary loss. The moderating effect of attitude on information fit and understanding, are individually supported by a research findings in multiple disciplines including social psychology [34], and information systems [35]

2 Approach/Method

This research project has three stages. Below, we briefly describe each stage and present findings from Stage 1.

2.1 Stage 1: Refine and Enhance

The initial model, developed by Smith, Johnston, and Howard [24], has been derived from a synthesis of relevant literature, particularly theories of product assessment drawn from the consumer behaviour literature. In this stage we will develop initial prototypes and conduct focus groups and contextual interviews to explore in detail the relationship between the variables in the model (such as attitudes toward the condition and the specific information requirements about the status and management of the condition).

2.2 Stage 2: Empirical Assessment and Refinement

In this stage, an experiment will be conducted using the prototypes developed in Stage 1 to test the model on 100 patients and assess how it can be applied to practice, particularly focusing on how to use the work in medical practice, with patient health consumers.

A second part of Stage 2 will be the development of a set of questions that can be applied by doctors to their patients to determine which type of information the patient will receive depending on their individual attitudes. A set of proposed questions, tested on a potential target population and refined through a Q-sort, is attached in Appendix 1.

The effectiveness of the approach suggested in this paper will be measured in this stage via survey and qualitative interview. The purpose will be to determine if the patients in the sample population have better outcomes in the four key areas identified previously: improved comprehension of pathology results, better understanding of implications, greater trust in health provider and greater post-consultation compliance with the patient's own agreed health management plan. Were these results to be positive, the next step envisaged would be a larger scale patient trials applied in a clinical chronic disease setting. The target group in the first instance would likely be diabetes patients, because their disease requires regular blood test monitoring and because self-management of the disease is critical to staving off the long term effects of the disease.

2.3 Stage 3: Generalizability Assessment

In this final stage, the model will be tested using a different population, support people (generally immediate family) to assess the generalizability of the findings.

3 Results: Model Development and Findings from Stage One

Subjects in our study are health consumers and so their response to information can be examined using previously established consumer models. For a consumer, success in the evaluation phase of a transaction means being sufficiently informed to make an accept/reject decision on each item under consideration. After this, consumers need to consider factors that might lead to a given product description being perceived as more or less informative because these are relevant to good website design. One might expect that this depends on the attributes of the product. However considerable research suggests that the customer's beliefs about the product are paramount [see 36]. Marketing research, elaborating on the functional theory of attitudes [31], describes how each individual may have a value-expressive or utilitarian attitude to a product [25, 37], and that, when assessing the benefits to be derived from acquiring it, each type of attitude is associated with a different value-function.

There are different value functions for different consumers. A value-function is value-expressive when the consumer believes that the product expresses information about his/her identity, values, or beliefs to other people [32], and utilitarian when the product is seen as providing only functional or performance-related benefits. Due to this difference in value attribution, each kind of attitude toward the product is also associated with a different evaluation emphasis. A value-expressive attitude will initiate a self-referential evaluation process in which the imagined stereotypical user of a product is compared with one's self-image [31], and personal value will be assessed based on extrinsic qualities of the item (what it represents). The type of self-identity involved in this assessment may be the actual self (how you see yourself), an ideal self, the actual social-self (how you think others see you), or an ideal social-self [25]. The greater the match between the imagined stereotypical product-user and the specific self-identity used, the greater the personal value attached to the item.

Conversely, when the evaluative attitude towards a product is utilitarian, evaluation involves a functional congruity process in which one's beliefs about performance-related characteristics designed into, or inherent in, an item are compared with a set of ideal attributes [31]. That is, utilitarian-oriented evaluation involves comparing beliefs about what a product can do with what it should do, with personal value derived from the item's intrinsic qualities

(inherent capabilities).

Information requirements thus vary considerably according to whether a product is evaluated using a self-referential process or a functional congruity process. In the self-referential process, information-gathering activities focus on determining the extent to which an item's symbolic qualities are compatible with one's self-image. A product representation that emphasizes symbolic qualities should meet the information needs of that process. In a functional-congruity process, on the other hand, performance attributes or utilitarian benefits will be assessed against requirements [32], with the corresponding information needs likely to be satisfied by a functionally oriented product representation, such as a description of technical specifications or how the item can be used.

Our model builds on previous research to offer a way to motivate action based on the attitudes held by health consumers. In particular, we build on the work of Smith, Johnston, and Howard [24] by describing conceptually how messages can be tailored in the health realm to appeal to specific attitudes, and also by developing specific examples of health information that should apply to each

category of patient. Because consumers are more receptive to messages that match their attitude-based information requirements, a consumer will also feel more informed when this fit occurs. More informed consumers should, in turn, have a more positive view of the provider and will be more likely to complete follow-on activities (e.g. complete a purchase transaction). Similarly, health consumers presented by messages that tap into their personal attitudes are also more likely to commit to a treatment regime.

As the first part of this stage we have so far developed some initial prototypes for the value expressive consumer. Attitudes that are value-expressive are directed towards the achievement or maintenance of personal values. People who hold this type of attitude respond to communication with an emotional element. For example, medical impacts could be described using stories that emphasize emotional outcomes that are important to the person [38]. Benevolence, defined as caring for the well-being of one's closest others [39], has been found to be an effective emotional focus in this type of context [e.g. 40]. Medical information designed to meet this value might emphasize how a failure to

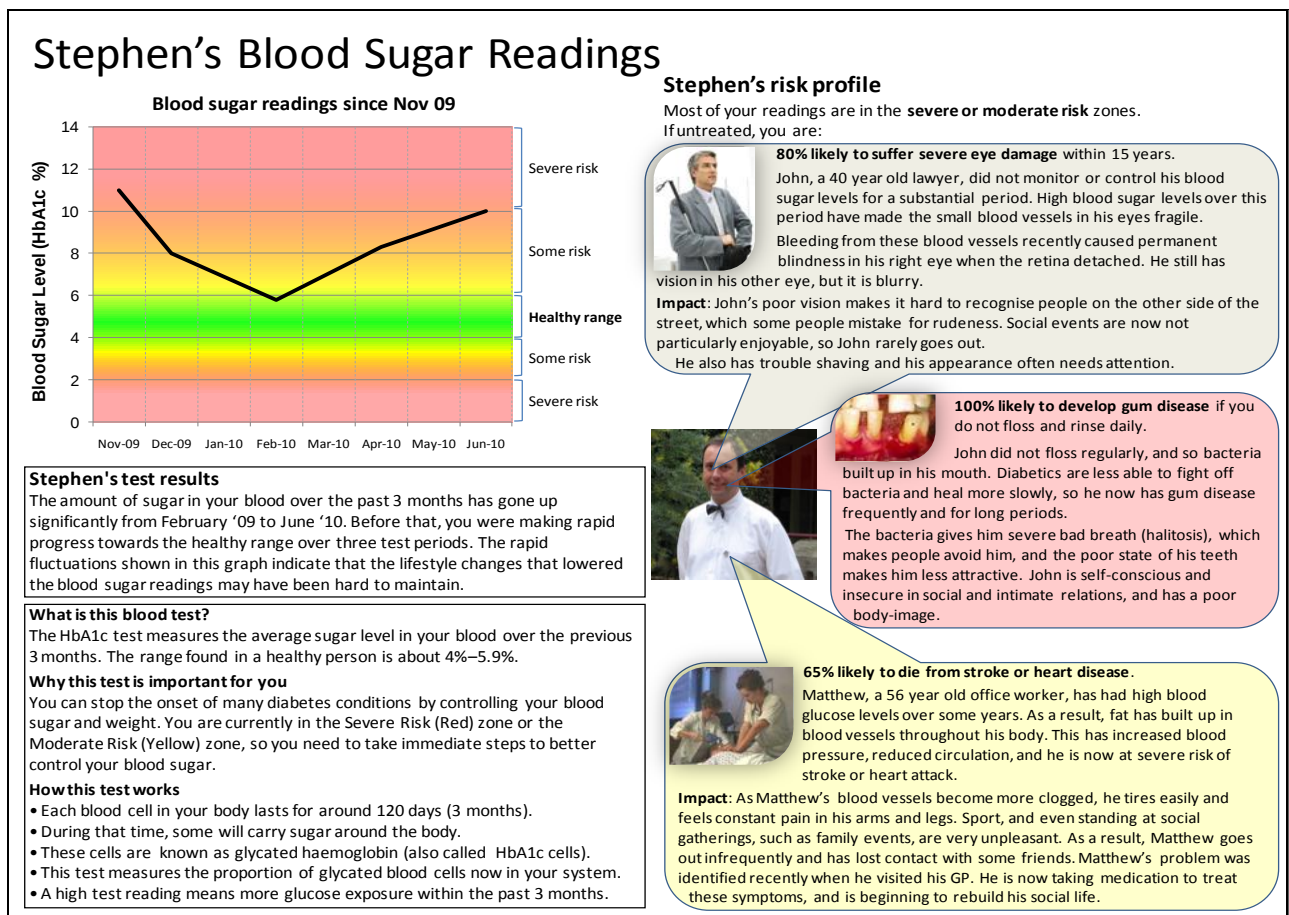


Figure 2: A status report in experiential style that frames outcomes in value-expressive terms.

treat the condition would affect the patient's family.

A sample report that presents information in an experiential style (case study) and frames outcomes in value-expressive terms is illustrated in Figure 2. As noted earlier, the experiential system helps a person to adapt by learning from either direct or vicarious experience rather than by logical inference[30]. It relies on associationistic processing of concrete examples. These examples may be obtained from direct experience or observation, or indirectly via metaphors and narratives. The report below is designed to support this processing style by describing the impacts of the disease using a story-telling approach in which the operation of a specific risk factor is personified by focusing attention on a specific protagonist. The name, age, and occupation of the protagonist are mentioned, and the text is accompanied by a photograph that shows someone who is supposedly affected by the risk factor (e.g. in Figure 2, the eye-damage scenario is accompanied by an image of "John" holding the type of white cane commonly used by people who are blind or visually impaired). The choice of image and the identity of the person are important because these elements of the story allow the reader to associate with the protagonist. How the actions (or inaction) of the protagonist

have influenced outcomes completes the story.

Although the storytelling approach makes this information concrete, the specific outcomes mentioned make the information relevant. The description in Figure 2 of the disease's impact states "John's poor vision makes it hard for him to recognize people on the other side of the street, which some people mistake for rudeness." This text is designed to appeal to someone with a value-expressive attitude towards treatment by framing the disease as a problem for one's interactions with other people (social self-image). An appeal to a utilitarian attitude, by way of contrast, would frame the disease as a threat to health, wealth, or productivity. For this attitude, the impact of the disease could be articulated through a statement such as "John is now unable to drive and has been forced to stop working".

A second report based on the same readings and disease effects but which uses a rational style and frames outcomes in utilitarian terms is shown in Figure 3. Rational processing operates according to a person's understanding of the rules of reasoning and of evidence, and is predominantly affect-free, conscious, and analytical [30]. Because rational processing is based on processing of rules and

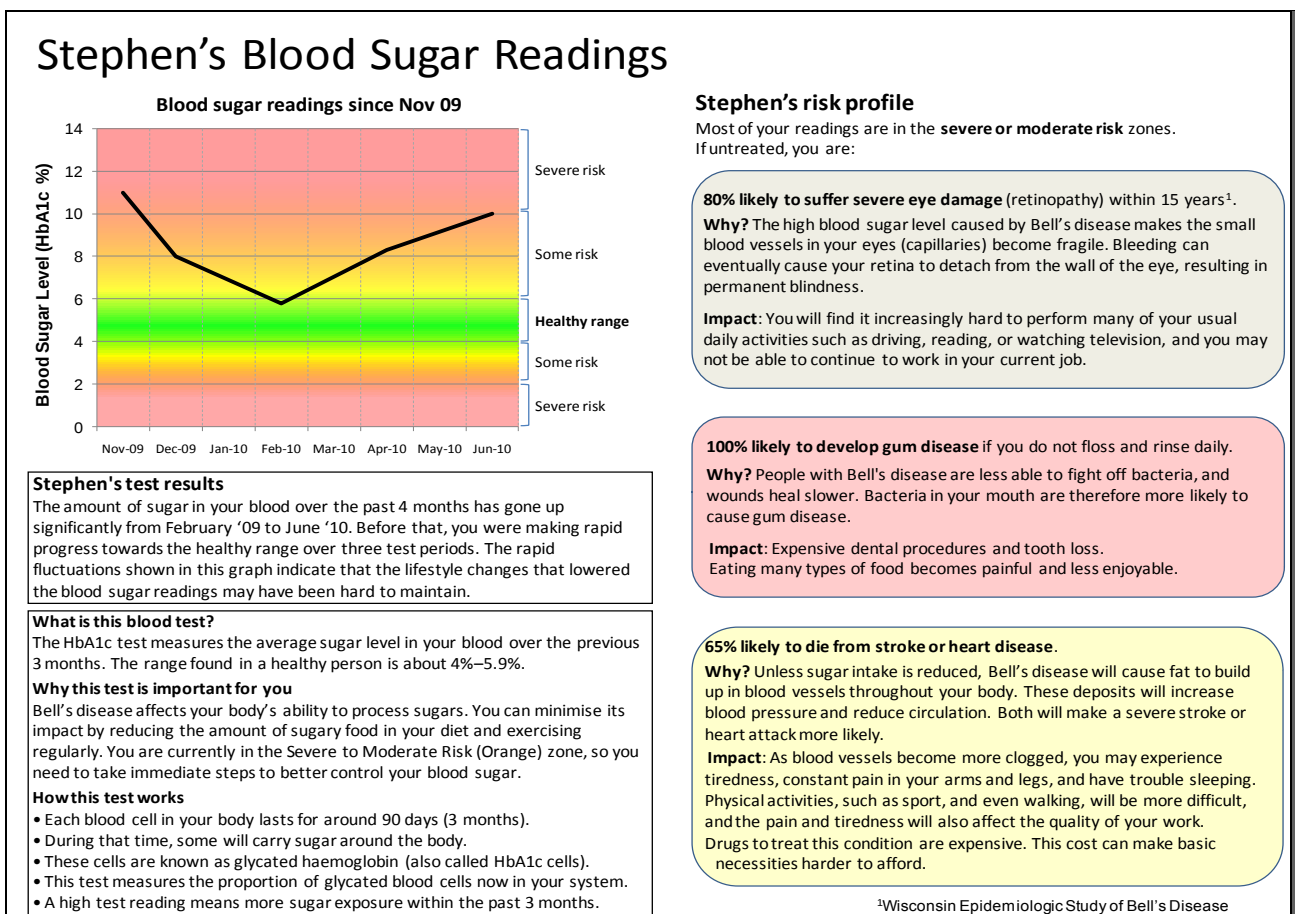


Figure 3: A status report in rational style that frames outcomes in utilitarian terms

evidence as opposed to emotional connection and experience, Figure 3 presents the risk information in a more scientific cause-effect style and refers the reader to an expert assessment to justify the claims made:

This prototype, and others representing a range of patient attitudes, will be tested in focus groups.

4 Conclusion

We have begun Stage 1 and have produced prototype report templates derived from our theory which will be assessed empirically and further refined. Our intension is to create a well-defined and proven procedure for producing a report that meets the individual needs of each patient, and thereby improves the patient's understanding of the condition and ownership of the disease management/treatment plan. Using such a tool we envisage a scenario such as the following as the end result of our research:

Miranda arrives at the doctor's surgery for her first appointment. The secretary at the front desk of the doctor's office hands Miranda an iPad and asks her to complete a brief preliminary questionnaire using that device while she is waiting. The questionnaire confirms her name, address, and other standard personal details, but also asks about her attitude to

treatment, and how she likes to read information. Based on these responses, the software quickly determines how Miranda responds to different types of information, determines she is 'value-expressive and notes this on Miranda's file. When her doctor orders the first blood test, he ticks a box online requesting that all her disease management data be presented in a design and with explanatory content that matches her particular values. The information that comes in over her treatment period is automatically customized for her based on this. The lab results and her disease management information will be presented from this first visit forward in this values-based format. It will come in using the customized design both on the doctor's desktop (possibly using Web 2.0 technology) and in a paper or printable format (for the patient to take home with her in hard copy, and possibly to show to her family to gain support for her health plan from loved ones).

At her later appointment, Miranda sits down with her doctor who walks her through a screen showing her disease status. The report on screen is made for both patient and doctor. It includes her most recent blood test result, but compares it to all her previous sugar levels in a graph that quickly reveals a downward slide of her health maintenance. It includes future targets points on the graph to give her something to aim for. There are also pictures of

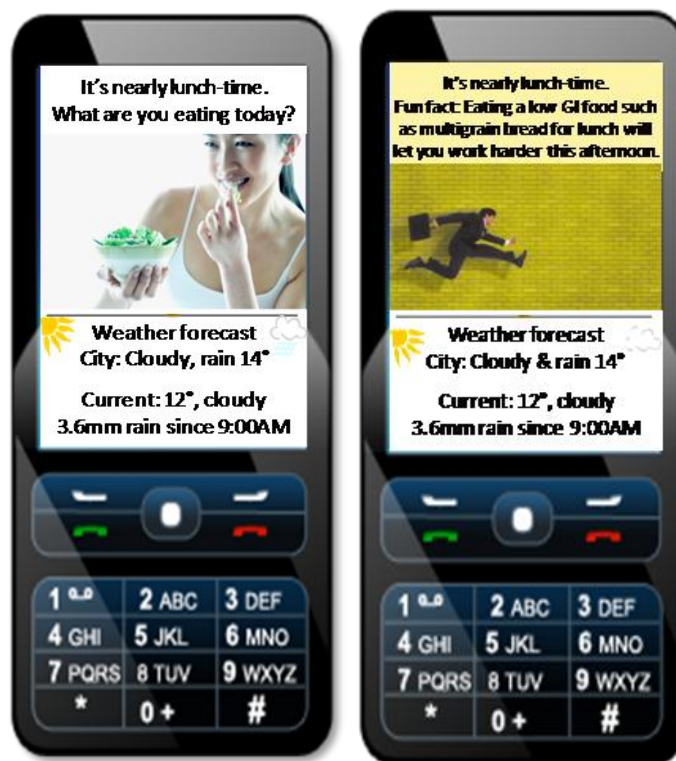


Figure 4: Healthy-eating mobile messages: value-expressive (left) and utilitarian (right)

healthy foods and stories of what happens to patients like her who don't follow treatment plans. These pictures, along with the stories of how the disease affects sufferer's families if not managed are the types of information a 'value-expressive' patient respond to best. The patient leaves the meeting understanding how her actions have advanced her disease. The next day, at 11:45 AM – Miranda's danger time zone - a photo appears on her mobile via MMS showing a tantalizing healthy fruit salad along with suggestive text (see Figure 4, which also shows an alternative, utilitarian version of the message) both designed to elicit a healthy eating decision. The message contains an up-to-the-minute weather forecast to encourage Miranda to open it. She reads the message and selects a healthier food for lunch. By her next doctor's appointment, her Diabetes management is back on track.

The above scenario is entirely possible to construct. The data collection technology (an iPad or similar portable device) is affordable, plain language descriptions diseases are already available in multiple languages, case studies of patients are easy to gather, and suitable software is not difficult to design. The challenging element of the system is to describe the consequences of both the disease and the proposed treatment in ways that relate to the attitudes held by patients. The model proposed here describes only two attitudes, value-expressive and utilitarian, but additional generic attitude types exist, and within each attitude type, variation is probably required to account for differences in age, sex, and locality. Stage 2 in particular provides a practical method of developing and refining this challenging element further in a real world setting.

The ultimate aim of this project, which we have begun with this initial consumer values analysis and prototype development is to produce a technique for tailoring test results for individual patients. This will improve comprehension and help the patient to manage their chronic condition more effectively.

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Appendix

Stem: I will manage the condition if that helps me to...

Dimension	Item
Utilitarian	do more things in life
Utilitarian	be productive
Utilitarian	cope better with the demands of everyday life
Utilitarian	avoid or reduce disease complications
Utilitarian	improve my health
Utilitarian	improve my quality of life
Utilitarian	save money
Utilitarian	avoid buying costly medications or other treatments
Value-expressive	maintain an image I have of myself
Value-expressive	feel better about myself
Value-expressive	maintain or increase my self-esteem
Value-expressive	achieve an image I have of my ideal self
Value-expressive	manage what others think about me
Value-expressive	fit in with how other people expect me to be
Value-expressive	maintain a good relationship with family and friends
Value-expressive	look after other people who are important to me
Value-expressive	avoid or reduce disease complications
Value-expressive	improve my health
Value-expressive	improve my quality of life
Value-expressive	save money
Value-expressive	avoid buying costly medications or other treatments