Bridging the Gap
between clinical and patient-provided images

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Introduction

I will be reporting here on how a group of artists and designers and a group of patients approached the task of visualising the meaning of specific medical diagnoses without recourse to traditional medical imagery. The purpose was to investigate how people relate to images produced in healthcare and how alternative visual aids might complement printed and verbal communications between doctor and patient. One fundamental concern of this study was to evaluate the influence and effect images have on patients' experience and knowledge of their personal health. The study was carried out to collect material for further research and ultimately for the development of visualisation tools, methods and objects.¹

The overall scenario for the study was to examine the potential use of images at three different points in time: the first week after diagnosis (investigated by a group of artists), the second visit to the doctor's (represented by a group of medical students) and living with a diagnosis (the subject given to a group of patients). The interviews were carried out with medical professionals who works daily with images in a health related context, including a midwife, a radiologist and a physical therapist. In this paper I will provide examples from the artists’ and patients’ workshops and only focus on the visual material produced.

I have four simple points to make: That in the near future, the exchange of information in healthcare will take another shape; that visualisations are not only form and content, but also promote action; that the ability to produce visualisations facilitates thinking, learning and communication as well as the skill to read other images; and finally, that there is a wide gap between the clinical images commonly used in healthcare and the proposed patient-provided images, a gap which reflects the differences in interests, perspectives and means.

¹ The study was carried out with the support of the Swedish Health Council.
The gap

An immense amount of visual material on the human body is stored in the archives of hospitals around the world (at least in developed countries): photographs, videos, drawings, X-ray films, MR images, slides of pathology samples, sonographic data and several other types of images. This material is of course invaluable for diagnostic and treatment purposes, but has been little used by patients. How come? This is what initially sparked my interest in this kind of research and in a previously published article, I have provided a general discussion on this theme.²

Elsewhere in this volume there are bountiful examples of how different professionals decode and interpret images within their fields of knowledge, so I will not go into detail as to how, for example, radiologists interpret their images. Instead, I want to consider the question of how visualisations can be used by patients. The most straightforward approach to this is to let the patients see their own clinical images. Using two typical clinical images, I will try to illustrate that seeing is knowing, but in another way and that you do not have to understand the image to find it useful or meaningful.

In image 2 you see fractures on both femora. The image is easy to understand and useful in explaining what has happened. But if you were the patient, you probably would know what was wrong with your legs without having to look at a picture of it. Having such an image may not be very helpful since what happened is so obvious - you already have information about it. In other words, there is no benefit for the patient to see it.

When looking at the image 3, you may not see what it shows, but (with some help) you can see something that you might not know anything about unless you had an image of it. This image is not useful for the patient in terms of obtaining medical information but the very fact that the unknown or unclear is made more concrete and real has tremendous impact on many individuals. To see is to know more and to know in another way - even if the image is blurry and diffuse. It is not only a question of seeing more or better, but seeing anything at all. In this sense, image 3 is worth using but not image 2.

This simple example helps to illustrate that visual information has a different meaning for the patient than for the radiologist. It also shows that there are different intentions and purposes in looking at such images. Thus, there seems to be a gap between the doctor’s and the patient’s perspectives of (clinical) images and there are several dimensions to this gap. It could be a matter of information (Is more information necessarily better? Is it a question of quality or origin?); dependency and power (Who sets the agenda? Who is producing images?); competence and skill (What is...
necessary to know? What can be done?); focus and perspective (What do we look for? How do we interpret images?); or the general ‘state of things’ (i.e. as a result of tradition, division of labour, economy, etc). Naturally, this list is arbitrary, but it helps to illustrate that visiting a doctor is, in many respects, a complicated matter, and even more so if you are confronted with a clinical image. These, and many more, dimensions are present in the relationship between doctor and patient, a relationship which could act in at least two ways: send-receive, or seek-give feedback. Traditionally, the doctor and the patient have (mainly) had a send-receive relationship. I will argue that the latter state of seeking and giving feedback will necessarily prevail (or already has, in some respects) and that the key question in creating and using patient-focused images is what the individual wants to see, know and be shown. How will that be possible and what can be gained? This is part of the outset of my study.

Workshop examples

I will now turn to the visual material created by different groups of artists/designers and patients. In this section I will describe some examples of the experiences gained during the workshops, starting with the artist/designer group.

Artists: first week after diagnosis

The session was held at the Malmö School of Arts and Communication in Sweden, and the problem at hand was to create novel visual representations of health from a patient’s perspective given certain diagnoses. Elsewhere, I have documented this workshop in detail; here I will only give a few examples.3

The participants, who acted as patients, were told that they were being hypothetically diagnosed with one of three serious illnesses: multiple sclerosis, myocardial infarction, commonly known as heart attack, and breast cancer. Some information was given concerning various symptoms and impairments, and possible treatments and prognoses. The gravity of the illnesses was stressed and the ‘patients’ were told to return for a second consultation a week later. A full week’s interval would have let them experience a state of limbo until the next time they could see the ‘doctor’. During this time the ‘patients’ were told to answer the following question individually: ‘What do I want to know about my
condition and how do I want it to be presented?' Next, the 'patients' were separated into groups of three according to diagnosis. They were told to create a concept or prototype to visualize the ideas and questions they were having in regard to their given diagnoses. Here, I will comment on the conceptualisations made by two of the groups: the multiple sclerosis and the breast cancer 'patients'.

The multiple sclerosis group came up with the idea of creating a game board for the patient's future life – a kind of existential game. The game was intended to be used ('played') by patients ('players') to provide a tool which would let them explore a multitude of possibilities and paths in their future lives. The key issue of the game was hence social and emotional, not medical.

Let's take a look at the structure of the game. First of all, the player will be asked a number of questions regarding his or her daily life and other important details, such as family, friends, work, special interests, hobbies etc. The player then uses the answers to create the game board. By breaking up the horrifying news that you have multiple sclerosis into small familiar steps, focused on your specific circumstances, the week of waiting in limbo for the second visit to the doctor's becomes more manageable. The game is based on these local and current factors and the purpose is to let the player be able to construct hypothetical future scenarios, depending on the specific mood or hope of the playing moment. With this game strategy, the group wanted to emphasise that there often are several possible options and outcomes. Another reason for choosing a game format was the tendency in modern life towards (often irrational) calculated risks such as smoking, driving cars, bad eating and exercise habits.

There would also be a manual provided with the game, explaining the rules and possibilities as well as giving specific medical, statistical, and other information such as homepage addresses of support groups and personal accounts by other patients with similar diagnoses. The manual of the game would be designed by international patient organisations and by research departments, ranging from medicine to social studies and it would be adapted for each individual player based on the answers provided during the game.

This means that the patient is continuously involved in constructing the game by creating the story to be played, guided by the provided/co-created manual. Along the process, the player is faced with a number of choices creating different paths on the game board. These paths, finally, lead to various endpoints in the game, in the extreme cases

![Image 5. Multiple sclerosis game board](image)
death or total recovery. By having a manual, the player does not have to have full knowledge of the medical and statistical facts concerning the diagnosis, nor how to continue playing the game, since the ability is part of the structure of the game and aids the patients in building their personal games. By making a choice at a crossroad, the player looks in the manual and follows the directions given. In this respect, it is an organised structure which could guide the patient through the difficult time.

This game relates to the day-to-day life of the individual, not just the medical/clinical aspects. It is possible to play ahead of time – to experience the future by trial and error without risking anything. As such, it is a visual and interactive tool, displaying present and previous choices and enabling back-tracking by tracing the steps made, showing their influence on the present (game) situation. It also allows several players to interact with each other, combining their individual game boards, facilitating learning and mutual support.

From a patient's perspective, this could be a useworthy approach to a visual/empowering tool. If we compare this to a clinical magnetic resonance (MR) image, there is not only a difference in how they look and what the two representations depict. There is also the inherent feature of interaction and choice in the game board version which is absent in the, so to speak, ready-made MR image. The game is a narrative rather than a simulacrum. It is open-ended rather than final. It is a negotiation, not a verdict. Paraphrasing Latour, this is not a matter of following a context, rather to follow the simultaneous production of a ‘text’ and a ‘context’.

Looking at the second group, the most important issue for the breast cancer ‘patients’ was how to cope emotionally during the week of waiting for the next consultation. During this period of time there will be much worry and anxiety and also confusion and possible denial. The concept of distraction or escape was chosen by this group to be a way of dealing with this. A paper toy, well-known to all the participants from childhood as a ‘Flea’, was produced and re-named ‘Move focus’. The toy works like a randomised answering device. The player picks a number between one and five and flips the sides of the toy this many times. Then, one of four questions visible on the inner side is chosen and on the flip side, there are proposals on how to act.
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<td>Do you want to win?</td>
<td>Buy a lottery ticket</td>
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<tr>
<td>Do you want to deny?</td>
<td>The diagnoses must have been mixed up</td>
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<tr>
<td>Do you want to act?</td>
<td>Gather all people with good energy</td>
</tr>
<tr>
<td>Do you want a good prognosis?</td>
<td>Buy it! (bribe the doctor to lie)</td>
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<tr>
<td>Do you want to take control?</td>
<td>Turn on the auto pilot</td>
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<tr>
<td>Do you want to hide?</td>
<td>You cannot hide from yourself</td>
</tr>
<tr>
<td>Do you want to dream?</td>
<td>Rent the video 'Total Recall' seven times</td>
</tr>
<tr>
<td>Do you want to run?</td>
<td>Travel around the world in seven days</td>
</tr>
</tbody>
</table>

This toy provides means for distraction and a more or less irrational response to the difficult diagnosis and the passive situation of one week of limbo. The hypothesis was that it would help to cope during a limited period of time when action is almost impossible. This visual tool does not deal with the disease/diagnosis itself, but is used to divert its emotional effect. This was similar to the approach of the multiple sclerosis group, which also partly focused on the effects of the disease rather than pure (medical) information.

**Patient group: living with a diagnosis**

Similar to the artist workshop, the patients were asked to provide information about their experience of the medical condition in two ways: verbally and visually. The idea behind this approach was to compare the question-answer method with the do-it-yourself method. The workshop understandably had to be relatively short due to the condition of the participants and thus had to be designed in such a way that the physical strain would be minimised. I therefore constructed a simple game of Bingo, which was called 'Reality-Bingo' and a cultural probe, described below. I chose a game of Bingo since most of the participants were used to playing Bingo every week and really enjoyed winning small prices.
In the Bingo game, I asked the participants a number of pre-defined questions concerning how their medical condition was affecting them in their everyday lives. They answered by marking a game board with different colours for ‘Yes’ and ‘No’. This part was intended to mimic the situation where the doctor is asking the patient about his or her general health status. Another intention of the Bingo session was to inspire them to partake in the second part of the workshop, using a cultural probe.

The probes

After the Bingo game, a cultural probe was handed out to the interested participants. The material provided in the probe package included a single-use camera, a diary, a large sheet of paper, a notebook, some images for inspiration, instructions, information about the study, and a short evaluation form. The instructions for the use of the probe were very simple: use the material provided to describe what is important for you and what affects you and your health in your daily life. The intention was to provide tools and options to help them express themselves. The outcome of the probe was uncertain, but the hope was that it would originate from the initiative of the participants through their individual selection of what they considered to be important.

Of the eleven probes that were distributed, ten were returned with contents and only one was empty. Taking a quick look at the returned material, it was obvious that the diary and the collage were the least used options to communicate. This could have several possible explanations. For one, the majority of the participants experienced pain in their hands and fingers while writing. The collage required them to use scissors, which also could be a problem. Many of them also reported that the diary was unimportant while they already had written short texts in the notebook provided with the camera. They said that the collage was unnecessary since they already had taken images with the camera. It was expected that they would not use all of the material in the probe and the reason that there was redundant material was to provide them with optional means of communication.
What was returned? Let’s take a look at a couple of the collages. The collage depicted in images 11 and 12 was made by a woman in her mid-forties. She considered the collage to be a very stimulating and rewarding way to express herself, which is apparent when looking at it. In a vivid and colourful way she has covered several important aspects of her everyday life. Her strategy of mixing humour and seriousness seems to be a helpful when trying to cope with a difficult situation. The way she chooses a funny picture and combines it with a serious and sometimes negative text seems to provide an opportunity to defuse a potential feeling of resignation or hopelessness. In her choice of images and the accompanying texts she also describes her situation in terms of ‘living’ rather than ‘enduring’.

The second example depicted in image 13 is different in style as well as content. It is more structured and organised and lists important events or activities. The simplicity of the drawings should not be thought of as something negative or less valuable. Instead, it should be stressed that although the person who drew this ‘storyboard’ was not used to drawing, he or she actually did it, and found it useful and inspiring. Hence, it is not the quality of the final picture which is important, rather the quality of the action of drawing and referring to it.
By combining images and cut-outs with their own texts, they succeeded in telling their story. It seemed to be easier for the participants to write smaller texts in combination with cut-out images or simple sketches than to write in the diary included in the probe. Maybe the images worked as an inspiration to write the texts, or they abbreviated what had to be written down. The collages can later be redrawn, adding new features and removing old ones, in a continuous loop.

Turning to the other visual tool in the probe package, I found something interesting. All of the participants who returned the probe had used the camera. This was a bit of a surprise, since the single-use camera provided was rather difficult to handle, with small parts and mechanisms. Despite the problems and, in many cases, pain experienced in handling the camera, the mere use of it I take as a proof of it’s useworthiness.

All but one of the participants reported that the camera was fun to use and gave important feedback by making them think in another way; and this without even having seen the photographs they had taken. This means that it was not really the photographs as such that were so important, but rather the action of taking them. The opportunity to share important things in their lives was appreciated and meaningful and the feeling of having something meaningful to say was stimulating and thought provoking. The simple fact that someone was interested in what they had to say and was actually listening proved very significant. In the context of visual literacy, I thus think it is important to stress not only having the ability to ‘read’ images, but also having the skill to ‘write’ and share them.

A quick look at some patient-provided images reveals some common features when compared with clinical images of rheumatoid arthritis:
Building a bridge

The initial phase of this study was to examine the potential use of patient-provided images in a medical context. The experiences gained, both by me and the participants, should provide some clues as to the general direction of the next move. A brief summary of the two described workshops is as follows:

1. The themes of the three different artist groups could be condensed to: exploration (multiple sclerosis), emancipation (heart attack), and escapism (breast cancer).
2. The material provided by the patient group focused on social life and specific problematic issues in everyday situations.

These various aspects of visualising health should not be seen as oppositional, rather as complementary. One reason why the responses focus on different aspects is that they describe different points in time. Another reason is naturally that the participants in the three groups have different roles and interests.

What has been learned during the workshops? Using the four questions posed by Marshall McLuhan to describe the essence of new media, I will present one possible interpretation of the outcome of the study, and by doing so, try to clarify the four points mentioned in the introduction.10
1: What does it enhance or intensify?

Is the communication between patient and doctor really working? It is well known that there is a discrepancy between information asked for by the patient and information the doctor considers important. A case study examining this issue reports: ‘...the patients in the study want more information. Most often it is the kind of information the doctor cannot provide...The patient wants to talk about his or her fears and worries... The doctor wants to talk about tumour biology, prognoses and possible treatment options, statistical calculations of the outcome, etc. The knowledge available sometimes appears both unintelligible as well as inadequate for the patient.’

Since a specific visualisation acts as a translation of a body or diagnosis, it is by nature arbitrary and depends, among other things, on the intentions of the enunciator (producer). The language it uses to translate illness or diagnosis into image thus achieves its meaning through use. It is therefore crucial that the patient is involved in the image production, if he or she is going to be able to read it. Hence, having the tools to produce images is changing the ways they are consequently used. To put it simply, it is a matter of learning by doing, and what is gained is not only skill in image production and usage, but also knowledge of relevant medical and personal information. Paraphrasing Deleuze and Gauttari, this new situation is rhizomatic, in the sense that it is ever evolving and redefined, non-hierarchical, and acentered. It is composed of dimension, not units and always has a middle (a milieu; the patient ‘looking out’). It is a matter of negotiation rather than information or prescription. I am sure many doctors agree with this last statement when it comes to the problematic issue of compliance, the degree to which patients follow prescriptions and act according to rational information.

2: What does it render obsolete or displace?

Another aspect of using patient-provided images is empowerment. Since most of the treatment actually is performed outside medical institutions, for example in the patients’ own homes, tools for individual responsibility and initiative could be useful. It is also a matter of the direction of the flow of information and knowledge. Through visual methods, the individual patient could seek knowledge in a way which does not need interpretation or translation by a medical professional and the need of knowing the specific jargon of medicine could be decreased. The image becomes something concrete to talk about, acting as a starting point for discussion and self-reflection and reshapes the dialogue between patient and doctor from the traditional hierarchical relationship of a sender and a receiver into a seek-feedback loop.
3: What does it retrieve that was previously obsolete?

The patient-provided image displaces the focus from the pure clinical ‘problem’ to the abilities of the person. It takes into account the dimension of the ‘lived’ disease/disability and the knowledge of the specific everyday life, factors important for the wellbeing which in some cases would not be mentioned in a clinical setting. From a patient’s perspective, it is a question of creating meaning. Through the construction of meaning, the experience of a medical condition can be altered, and it is even possible to influence the actual healing progress itself. The term meaning response in relation to medical conditions is discussed in Daniel Moerman’s *Meaning, Medicine and The ‘Placebo Effect*; he notes that ‘meaning can make your immune system work better, and it can make your aspirin work better too.’ Images used to create a meaning response could be useful in healthcare, not only as ‘placebos’ but also as emancipatory and participatory tools.

4: What does it produce or become when taken to its limits?

Visual artefacts, including both clinical as well as patient-provided images, are part of the construction of a narrative of health. They function as interacting actors (actants) and as such they contribute in ways that are complementary to speech and text. In other words, images are actively a part of a complex interaction that is at once social, political, and personal. Hence, visual artefacts could prove useful as self-reflective, generative and proactive tools as well as providing a common and non-hierarchical ground for dialogue and discussion as a writing space, a common domain of control and exchange which bridges the gap between clinical and patient-provided images. Visualisations, as loaded artefacts, could function as social objects in various relationships.

Visual studies classes in a medical curriculum (and others) would help students and future professionals to understand the potential of visualisations. Such classes should also include the active use of images as carriers of
meaning from a patient’s perspective—that is, not only as means of extracting medical information (as in the protocols of reading X-rays), but also as ways of creating images that are meaningful for the patient as well as letting the patients produce their own images. A strategy based on meaning and participation could then be regarded as an addition to medical and clinical practice in the medical and rehabilitation fields. Well-designed patient focused images stimulate self-reflection and participation, and as such epistemological agents, they act as impulses for change and learning.

**Endnotes**

1 Prior to the study, I distributed a questionnaire among a group of patients in order to test the general interest in alternative visualisations in healthcare and rehabilitation. Naturally, there was a problem with this kind of voluntary questionnaire in the sense that only people interested in the kind of questions I asked were responding, a fact which was equally true for the workshops. On the other hand, the purpose of the questionnaire was to see if anyone at all was interested. A limited response was therefore considered sufficient to pursue the project.


4 The participants had backgrounds in visual arts, design, creative production, film making, and other related fields.


7 Top right: ‘I like hands, even have learned to like my own hands despite the marks of my illness. Visit to the Universum in Gothenburg gave a strong feeling of happiness by having the energy to do it despite the pain in the toe.’

Middle left: ‘Exercise is important. Affects the health in a positive way.’

Bottom left: ‘Medication is almost always present in my life. Sometimes I want to take holiday from medication and health care. To have some time off.’

Bottom right: ‘Sometimes I’m washed out. When I tidy up for example, get tired. It is difficult to learn to do things little by little. Get impatient. Want to do everything at once.’

8 Top right: ‘Go to the store and do some shopping + the post office, where the social life is. Stay and chat a while with people (we live 300 people on the island, in the summer appr. 2000). Positive.’

Middle right: ‘Vacuume cleaning. Exhausting (negative).’

Bottom right: ‘Cycling for 10 minutes. Finished appr 11.00 Press the lower back down appr 40 times

Lift up and tighten the cheeks appr 40 times

Lift legs, right and left appr 30 times’
This participant thought that using a camera in 'medical' research was silly and unserious. This particular response is important to remember, since it reminds me of the (obvious) fact that people are different and have different views on how they want to be treated, both as patients as well as human beings. There is no ‘one size fits all’ solution to the issue of accessing patients’ experiences. It is possible to ask the wrong questions, or to ask the rights ones but in a way which doesn’t correspond to the patient’s expectations of correct behaviour.


Top right: To wring out a cloth is impossible. The strength in the hands is too poor.

Bottom right: Here I spend appr half an hour each morning. Directly from the bed into a hot bath to get started.


Bruno Latour talks about human and non-human involved in an chain of events as actants. The central issue is the relationship between the actors, not their individual existence. See note 5.
**Biography**

Henrik Enquist holds a Master of Science degree from Lund University, Sweden, with a focus on medical optics and laser physics and a Bachelor of Fine Arts degree from Bergen Art Academy, Norway. Currently he is working on his PhD at the Division of Rehabilitation Engineering Research in the Department of Design Sciences at Lund University. The current research focuses on such topics as visual representations of experiences of health and images as language. (henrik.enquist@certec.lth.se)

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