

Contribution to:
User-Driven Healthcare and Narrative Medicine
– Utilizing collaborative social networks and technologies

Dimensions of the Patient Journey

- Charting and sharing the patient journey with long term user-driven support systems.

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ABSTRACT

The ways a person's illnesses and afflictions are socially constructed and culturally conceived amongst relatives and friends as biographically contextualized in the narratives of a known life-journey are contrasted with modern conceptions of "Patient Journey" in the digitizing of medical care in hospitals and in computerized GP Consultations. In this chapter most relevant dimensions of a personal life-journey support system – across health, handicaps and illness - are outlined. The chapter demonstrates a new road to facilitate private logging of phenomena, a coherent and sedimenting self-narrative not only in text, picture and sound, but also through user-network-developed pictographic fonts. Inclusion of biotelemetric data and virtual body imaging as part of such support systems are considered. And questions are raised concerning the future of thus skilled chronic patients' interfacing most trusted helpers, fellow-sufferers and wider shared social platforms of Patient Journey Records.

INTRODUCTION

Public and private expenses for healthcare are surging. As medical advances are made, unhealthy lifestyles are spreading in the industrialized world and people are living longer. We get more and more chronic patients. Public prophylactic measures and health-educational efforts to increase health-awareness and self-care create numerous private profitable health-enterprises. With the spread of Internet access, many offers of such services and drugs, programs and technological gadgets are advertised. The transition to digital records, and networking in professional health-related social networks, brings the medical rationalizing and formalization of descriptions to its force, with many advantages.

The only problem is that while tremendous efforts and results are obtained to digitize and train the medical establishment, exemplified in the Hospital and GP settings, the chronic patients are left at their own to learn how to handle a computer, establish e-mail contact, and to hook up to whatever the digitized medical society has to offer - options, threats and promises - concerning their management of their own health.

Therefore the digitizing of citizen health situations has to be re-examined in the light of what is for now the receiving line of citizens, presently having to cope with their own information across all dimensions of their life-space and eventual patient journey, without adequate tools. This involves life-style, economy, employment, family and home life conditions, relative medical compliance, and the "story" and "role" assumed in family, neighborhood and workplace.

To repair this gap, and truly qualify patients to join and contribute to utilizing collaborative social networks and technologies, we must strive to qualify citizens as administrators of their own health, each

developing their personal knowledge management skills, to become “life-long e-learners” (Pettenati 2008). It is proposed that personal healthcare and health-related interfaces of the future shall be considered in the full contexts of the citizens' general interfacing themselves through their everyday use of a personal notebook computer from 1st grade in school to final palliative care. We will gain by broadly conceiving of the citizens as genuine individual explorers on their own personal everyday life-trails, along their own life-trajectories. We must favor their empowerment as self documenting “Citizen Scientists” qualified to reflect and deal with own health-data, physiological data, economical data and environmental data. Therefore we must find ways to at least enable and equip the autonomous individual citizens/patients to develop and maintain their own most basic and private sedimenting digital self-narrative of what seems relevant to them: an electronic diary and time-indexed database, as an empowering empirical tool, not least in health-related, body- and domestic habit-related matters.

MEDICAL PATIENT JOURNEY CONCEPTS

Patient Journey is a pragmatic metaphor, an expression which may need some disambiguation, - especially in the context of patient narratives and experiences of illness. It can be used as referring to how patients proceed through an identified care delivery system. Seen from the angle of process mapping this refers to the total number of steps taken, as well as the total number of people involved, the total time taken to perform each process-step and all documents used.

*“When extensive process mapping for a considerable patient volume is done it is now possible to bring the data together and look at the care process from a unit/department perspective..... and perform a flow analysis (widely used in Manufacturing), and develop a current state flow analysis map: •Analyse patient flow across more complex processes •Identify whether the systems are managed and in control
*See what adds value and where waste occurs *Understand roles and responsibilities related to managing patient flows.”*

NHS Scotland (2006) Understanding the Patient Journey – Process Mapping

But with the digitizing of health information, and the adoption of electronic patient records, highly professional tools are developed not only for hospitals but also for GP's to organize and administer their patient scheduling, patient records and patient flows in complex and versatile frameworks. This means that recording of consultations, test results, medication, prescriptions and referrals can be integrated as it is approached by e.g. Microsoft Health Common User Interface (<http://www.mscai.net/>). The idea is, to formalize an interface in such ways, that an integrated patient-centric care record can transition seamlessly between care sessions and care settings. The doctor is offered to have a multidimensional “landing place” with appointment list, email-in box, reports received, repeat prescription requests, practice notice board, medical knowledge support links and health news. With a click, each individual patient record is displayed, with expandable panels of:

Most recent medical activities,

Previous consultations,- expandable and comparable as detailed for: problem, history, examinations, medication, impression, plan and comments,

Current and past medications

Patient charts, graphical and table, making it possible to examine:

o levels of medication,

o BMI

o BP

o serum e.g.: creatinine cholesterol, LDL, sodium, potassium urea,

related to long term time-lines, and visualized both in condensed and in detailed form in graphic curves.

Risks: allergies and side effects,

Lifestyle info , smoker/non smoker and calculated risks

Further linking to secondary-care examinations is also attempted, meaning that the GP may go into detail observing (and annotating) the results of patient respiratory pattern, cardiograms, angiograms, EEG etc from hospital or clinic.

Interfacing with the live patients will still be restricted to the briefest possible consultations. GPs can profitably handle more patients, appointments, referrals and prescriptions. In the prevalent concepts of the GP's digitized record keeping network, the cooperation between patient and doctor may be going to include e-mail, SMS, and, in the long run, perhaps occasional video telephone. But the role of the patient is not fundamentally reconsidered and the empowerment of citizens with personal laptops, everyday access to Internet 2.0 and global landscapes of health-related knowledge sources, has not been taken into account.

USER-DRIVEN PATIENT JOURNEY CONCEPT

Considering all the contemporary efforts of ministries of health and education – and of all kinds of professions, media, businesses and enterprises - to inform citizens of health issues and to the marketing of health related facilities, tools and measures to be taken by every citizen including the importance of self monitoring outputs of calories and intakes of vitamins, medicines and drugs, there would be a good logic in combining these with the general educational goals of **empowering citizens digital knowledge management skills** and growth into **personal lifelong learners**.

Not least is the upsurge of the potential and accelerating spread of biometric sensors for health life logging, implanted sensors, wearable strapped on sensors and in-home-sensors. The frontlines of wireless telemedical technology, as fitted in mobile and target-specific gadgets - as well as with patient notebook - are appearing and growing in many directions. “A whole new universe of **quantitative** health is dawning“ (Bell ~~G.~~ & Gemell ~~J.~~, 2009)

This must be kept in mind in electronic collaboration toward social health outcomes. Nor should we forget that personal hospital and GP records are in principle “personal health data”, which in the long run may be shareable for the patient. What we now must focus is the question whether **a whole new universe of qualitative health** also is dawning.

To the patients, new horizons are opening. Detailed medical knowledge is traceable e.g. Pubmed <http://www.ncbi.nlm.nih.gov/pubmed/> and www.wikipedia.com . New options for the patients sharing the journey with others are also emerging. With patient access to Internet, the world of “Health 2.0” also empowers the patient to dive into a wealth of information on health-economy, storing the diagnoses received, the treatments and pharmaceuticals prescribed, the side-effects met by others. Examples include, Quickenhealth (<http://healthcare.intuit.com/>), Microsoft (<http://www.healthvault.com>) and Google (www.google.com/health). And not least, to join networks, relevant for particular diagnoses, to locate other patients with comparable problems, and to exchange subjective narratives of patient journeys through personal bloggings, e.g. www.patientslikeme.com and <http://www.pdsa.org/>.

This is the new –and global - noosphere, the soil from which user-driven healthcare is going to grow, crossing the divides between the patients, and permitting them to collaborate toward goals of shared interest, including tools to solidify such cooperation.

PATIENT AS LIFE-EXPLORER

It makes a difference to conceive of a patient journey in the sense of the journey of an individual explorer. My approach is targeting the citizen as a life-explorer whose journey through the everyday - earlier or later - turns into traveling through pains and problems, encounters with medicine men, passage through admissions, tolls to be paid - or not afforded, waiting times to be endured, encampment in more or less friendly healthcare institutions, undergoing pains and sufferings, deprivations and starvations, uncertainties of outcomes, demands of endurance, and potential return to a continuation of previous life voyage, more or less radical change of life-course, or terminal more or less affordable more or less palliative terminal care.

Genuine explorers accumulate data relating to phenomena encountered / obtained (observations, states, courses, trails) to their log-books, from which they can produce maps and reports. Many people use a calendar and write lists and letters, some maintain a handwritten diary for shorter or longer periods of their lives, accumulating/sedimenting/ accounting/ referring to what for them, at the time, seemed relevant.

With a notebook, we have to re-invent the diary, as a daily follower (Bjerg, 2008). In the present consumer situation we need a tool which can help patients to document, first and foremost to themselves, how they:

"traverse .. their unique disease and illness pathway through life stages and health systems and external social environments..... potentially numerous care relationships, predictable and unpredictable positive and negative influences, and feedback loops through which the patient must navigate.....; often with no definitive cure and demonstrate gradual changes over time with dynamic and evolving phases of being stable, complicated, complex and or chaotic with ultimate decline."(Martin, Carmel M, 2008)

To the extent we can consider citizens (including chronic patients) as equipped not only with a mobile, but also with a personal laptop computer, we must start caring about **self-narrative tools**, which ought to be close to hand, permitting the chronic patient explorer daily to accumulate the most private experiences of all kinds in an "intimate journal". And thus approach the interfacing to user-driven healthcare from a domestic bottom-up perspective .

The creation of a personal journey support system

In the industrialized world, the last several generations have seen their habitat equipped with ever new technical inventions, each, in their time, adapted, adopted and integrated in a new everyday life, at the very core of personal human existence: tap-water, cold and hot, water-closet, gas and electricity, stove and sewing machine, vacuum cleaner and electric iron, central heating, telephone and radio, camera, record player, refrigerator, TV, freezer, washing machine, dishwasher, coffee-machine, food-processor, microwave-oven, VCR, and CD-player. With the advent of answering machines, DVDs, video cameras, home-computers etc. we first experience these as "more of the same". But with cellular telephones and SMS, lap-tops, memory-sticks, powerful portable multimedia home computers, wireless access, digital cash, digital TV, two-way video telephony, access from homes to two-way traffic in new infrastructures of telecommunication, virtual reality, optical character-recognition, speech-recognition and speech-synthesis and an unexpected range of other technical inventions, previously only conceived in terms of the needs of professionals, we are forced to reconsider the role of the private household and its members, healthy or sick.

The home-consumer-market has stimulated a global competition to exploit an ever-wider range of technological advances for purposes of profitable marketing. And the health market is no exception. For the "**home-vessels**" of the citizen explorers, being grounded as they are, a navigable media-landscape

and a cyberspace are expanding in place of navigable oceans and voyageable continents. But one can say that we lack a valid paradigm for "**the personal domestic bridge**", and fitting tools for orientation and logging on the trails and through the travels of the life journey.

This new world where the personal (portable) computer, mail and the Internet eventually reaches almost everyone, makes new demands for orienting oneself, learning, keeping track of services and programs, passwords and pin codes, addresses and networks. This will easily become a separate province in our lives, with little consistency with our other everyday life other work, other media, other tasks and hobbies, reading and music, socializing, housekeeping, shopping, cleaning and waste, bodily functions and body care.

To competently manage personal knowledge, we are forced to be a new kind of explorer in a new kind of contemporarity - and need some kind of "log", where we - easily - can tell ourselves what we spent time with, whom we met, what we found, did, thought (and felt?) on each day's journey, or just in each week. It can be every day (very short, or along the day) ,or just sometimes. And it can be restricted to specified dimensions: training, weight, horticulture, nutrition, disease, education, press and TV, football or golf, reading, alcohol, cigarettes, knitting, family, job, colleagues, or it can go across all what they consider relevant. Medical data, yes, but also ongoing – evolving – biography, noting all kinds of subjectively relevant observations, interplay with others, stresses and reliefs, and existential issues, as they weave in with the daily and nightly chores of body-maintenance and domestic householdings. Aspects of sleep-diary, pain-diary, compliance-diary, as well as mobile monitoring of physiological data, including future telemedical appliances, may be built into the network interfacing of such a tool, without exposing the private text-diary.

Seen from an existential mental health viewpoint, but also from a health-educational viewpoint, it is important that the clients have means to journal – for themselves, if they wish - all kinds of experiences, thought and emotions, gratitudes, disappointments, angers and resentments, tacit resignations, etc., without necessarily sharing these with family and caretakers, not to speak of further networks. Journaling just health-related data may in itself not be very attractive. But doing this in a room of one's own, a room of private reflection, a room where memories and dreams, recollections and reflections can unfold as consciousness goes on, and the need for making meaning of one's life persists, may motivate in another way. This applies not least to the chronic patient. The popularity of the "life-long learner" paradigm should reach all the way to palliative care.

If we, for example, can promote the chronic patient to the role of expert patient, "Citizen Scientist", chief specialist in his/her own case, and supply an adequate user-adaptable (Schonewille, 2005) toolset for handling her/his own narrative, as an assembling of layered, systematically structured date/time indexed entries, a most personal evidential database, we may be on the road to empower the individual user to decide, and select, which aspects of this may be shared – with closest relatives or caretakers – with physicians – with networks, in blogging, or even in patients-like-me systems, or with a coming Patient Journey Record (PaJR) - Platform for User Driven Healthcare.

I offer a principal solution to how we can equip individuals, not least chronic patients, to exploit the opportunities that come within reach with a personal notebook computer, without losing the consistency and continuity in their personal lives,

Background history

I developed at the University of Copenhagen, Department of Psychology an experimental home (1972-1997) where I explored ways to help inhabitants represent their domestic everyday life and communication processes for themselves. This involved new options for monitoring bodily states, representing domestic space and the time geography of domestic events. Since the introduction of laptops and interactive programming, I focused on the concept of electronic diary, where time indexing of text entries could be automated. I have daily since 1997– myself – been the main experimental subject, through generations of laptops and software-programs, and I have been entangled in all possible ruses and ignorances, shortcomings and frustrations, while always trying to put myself into the seat of future users - a kind of general empathy-state based on a still updated stock of European senior knowledge. As systems and software tools were optimized I have strived to clarify how the substantial offer of interactivity from the computer can best be brought to use in a tool like the one I had in mind, a tool which in fact is no more than a further development of the traditions of logging in ships, of journaling in work-protocols for the drawers and shelves of operating rooms, and of personal diaries, in handwritten volumes.

Development of a preliminary prototype

Acknowledging the kind of basis which the domestic scene and the personal body must constitute, I present a preliminary non-proprietary prototype, an empowering innovation, which we should wish for prospective citizens to possess, and for the further development of which I invite cross-cultural, cross-platform and cross-disciplinary collaboration. The tools we have developed are tools of “citizen science”, enabling users themselves to pursue a sedimenting empirical logging of whatever they find relevant, around the clock, around the week, the month and the year. It is a diary-tool, while also being a log-book-tool.

We are so used to conceive of “the researcher” as an external observer, interviewer, questionnaire-designer and statistician, but the time has come to admit that the only investigator qualified to examine the personal information-flow and the user as strategic and tactic innovator is the user her/himself. We offer, with this method, a basic instrument with which users, for themselves, can keep track of the personal ongoing and events, not only on the computer, but also throughout the everyday life, in an ongoing diary.

I think it is important that we enable ourselves to hold on to our personal existence, whom we were, whom we are, whom we shall become, and how we are using the shorter or longer lifespan given us, to enable us, as regards matters of personal relevance, to hold onto this, in order to be enabled to reflect upon it. And thereby perhaps get a somewhat better hold of this life, and perhaps develop it in more desirable directions. The new conditions we all are submitted to pose new demands, create new routines and tear us loose from the life anchors in traditions, and the clear-cut roles, previously readymade for the individual. Young or old, rich or poor, ethnic insider or ethnic outsider, educated or uneducated, employed or unemployed, we are all forced day after day to re-orient ourselves in relation to some of the old, and in relation to all the new, ever coming our way.

It is my conviction that it is of paramount importance that the single citizen in the broadband society, in the midst of and across the information bombardments from mass media, and the increasing involvement with the broadband society, gets equipped with a kind of “tool of self documentation”, so that we can hold on to at least a bit of what happens to us, what we think about it, and what is practical for us to keep track of: pin codes, passwords, usernames and –numbers, service providers, tariffs, subscriptions, accounts, internet-addresses, e-mail addresses, telephone numbers, birthdays, medical prescriptions, doctor’s appointments. And also which dreams we have, in all senses of the word, and the frustrations and

disappointments we meet and recollect.

There will be as many ways to keep an electronic diary, as there will be individuals that will do it, and with different advantages. It is evident that nobody could nor should use time to describe everything they do, are exposed to, think and feel along each and every day. This must depend upon richness or shortness of time and subjective relevancies. Some may centre upon cooking, gardening, books, news, the Internet - or worries, symptoms, cures. Or maybe keeping track of the cigarettes, cigars and pipes smoked where and when, how many holes achieved on the golf course, about the arguments one has, meetings, transportation-problems, or lawsuits against telecompanies.

I think, with Tristine Rainer (Rainer,-1979,-2004), that the most important aspect of keeping a diary is the establishment of an area/arena/platform – a breathing-hole of absolute freedom and autonomy, where one can permit oneself to be honest, where one can make room for all of one's ideas, feelings, secret thoughts and fantasies, grieves and worries, separated from or contextually anchored in the more trivial, but perhaps quite as meaningful, banal occupations and rituals filling one's life. Some keeping track of what others do for you, and keeping track of own reactions to others, may help us deal with more maturely with others. And accounting, narrating to oneself in writing may often help to clear the thinking, clarify the thoughts.

In this way, being equipped with adequate tools, the citizen is empowered for critical action on documented observations from both a consumer and a patient vantage point. If you have habits, which you hope to control-alcohol, tobacco, drugs, medicine, exercise, eating - you can journal the patterns and circumstances of your focused bad habit, in respect to advances, temptations, relapses and replacement for undesirable fix. But not least for persons, as chronic patients, hit by illnesses like cardiovascular disease, sclerosis, diabetes, Alzheimer's, kidney defects and/or submitted to stressful treatments, e.g. for cancer, or fighting physical and psychic handicaps, there should be a support in a purely personal keeping track of the progress of the battle, both at an outer and an inner level.

Writing a diary, journal or logbook by handwriting, has advantages, for which the present model of electronic diary cannot compensate. The expressivity in sizing and varying the handwriting, ornamentation, mixing written and drawn, dried flowers newspaper-cutting glued in, etc, is lost. But the advantages of the electronic diary compensate, especially as more and more of the information which reaches us, and which we can reach for, arrives to the computer in digital form. A most central aspect is the automatic time-indexing, organizing all inputs relative to the progression of the diurnal, weekly, seasons and years of personal life.

Two special, related functions have been developed: one, enabling the user to "write into" specified temporal addresses, earlier in the day or a previous day, so it gets into the correct slot in the chronology of the day; and another, making it possible to annotate to lines earlier same day, or any of previous days of current diary, keeping track of when annotation was made. The prototype permits the user to create reporting shortcuts around the diary, to whatever programs or services they utilize. And it facilitates the user's name-giving and access to presently forty thematic drawers with accumulating memo-fields for themes of personal relevance. e.g., one for each of one's children and grandchildren, parents, best friends, theatre, movies, acquisitions, subscriptions, books, music, chat-groups, sermons, medications, prayers, treatments etc. Including calendar and address book (linking to e-mail), integrated in the diary, we are providing the user with a workbench and a private scene, relative to which the events and phenomena in their home, their garden, their neighborhood and their workplace can be contextualized, represented and optionally communicated.

I have tried to develop a preliminary set of demands, to the types of information, which should be equally easy to self-document. I think this is important for an understanding of the full scope of the enterprise. We should collaborate to offer a toolbox for citizens of any culture and age, helping them to keep coherent, contextualized track of (alphabetically ordered):

- Addresses, agreements and appointments
- Childcare
- Browsing WWW
- Cleaning and laundry
- Creative ideas, dreams & fantasies
- Demands & waiting times
- Drug, alcohol, coffee & tobacco use and abuse
- Economy, fees and contributions
- Emerging problems & attempted solutions
- Fitness-measures
- Gaming & gambling
- Handicaps and their handling
- Hygiene
- Illnesses
- Meals, diets and cooking
- Memorable reading, viewing and hearing
- Plans, successes and failures
- Rituals, ceremonies & prayers
- Sex
- Shopping
- Sleep
- Sports
- Stresses and endurances
- Studies, school
- Symptoms & prescription compliance
- TV-consumption
- Usability of habitual and emergent tool

The Iconosphere

Putting words to cognitive phenomena in moments of shared or private life-space seems to be our most distinctive species-specific feature. Talking with others, and talking with ourselves. And logging. The invention and use of numbers, hieroglyphs, and later the alphabets, (separating the languages, self-fulfilling the myth of the ill planned Tower of Babel (with its left hemisphere bias) is what has brought us to the Obama-decennium and the new options for global brotherhood and outreach.

Dynamic virtual social networks (including senior and patient networks, etc.) are now growing up, and citizens with mobiles, SMS and WWW can suddenly play on our "own court," with biographical unique e-identity, and/or many pseudonyms. And writing is now embedded in – and potentially self-documenting – audiovisual time-space fields, with photos, video clips, voice recordings and conversation-records.

I have studied this frontier field from its first rudiments in the 1980s, and have reached to a new category of characters for logging of everyday life's typical acts and events. This is a principal solution that can bridge the gap between text and image universe, both for the individual and in virtual social networks. I introduce a pictorial writing, to ease our PC logging of everyday life phenomena, multimedia dialogues and correspondence for entirely private confidential personal use. But the possibility that we may also use it in our correspondence with others will also appear as soon as basic pictorial fonts are shared, e.g., in a patient network.

Practical agency in the individual life world implies categories of relevance, which can be considered as elements, molecules and strings of habits. The everyday routines in the home – often considered as trivia – are extensively describable in narrative language, there are thousands of typicality's for which the citizen has concept, and most have words in one or more languages. But referring descriptively to them by words in languages is cumbersome.

Already back in the early 80s, working with an experimental apartment, I found that a short cut to overview and understand the processes and events in a family-home was to use small pictures, fitted to represent what took place when and where for the individual inhabitant(s). There are so many typical

generally recognizable phenomena in everyday bodily life in our home, in the daily and weekly life, including the well-known bodily functions and household functions. I started then - in collaboration with students of methods of qualitative research - to construct a system of pictograms for this descriptive purpose. And then the technological development suddenly offered a new opportunity.

I found a second shortcut to the pictorial shorthand needed by avoiding the bit-mapped icon-format, and instead using the character-format, i.e. designing glyphs in a font-suite.

Now, as to general use of an electronic-bridge journaling, we have an apparent dilemma: people, who are active, engaged and involved in life and fellow humans, living under information overload, will have all too much to tell their electronic diaries. Involved with other humans and other tasks, there are only small and sparse time-windows for reporting to the diary. Describing everyday life with words is disproportionately time-consuming, and so some kind of shorthand would be convenient. The everyday stream of thought, of consciousness or of subjective life and agency is to a wide extent language-independent, and not in the form of propositional thought. But there is a division of labor between the two cerebral hemispheres, of which usually the left is handling language in words, whereas the other, so called recessive hemisphere, usually the right, is dealing in images and sensory-motor figures. (Sperry, R.W., M.S. Gazzaniga, and J.E. Bogen, 1969) (Levy, J., 1974).

The development of human civilizations is, as said, -intrinsicly based on development of spoken language. And the invention of writing, with its origin in images (the hieroglyphs) is a crucial turning point. But writing has, for millennia, developed in force of a minimal number of letters in alphabets, and basically tied to the sounds of spoken language. The original track of the hieroglyphs, writing with images, has been out of bounds to the handwriting-, typewriting- and printing-cultures, simply because general picture-alphabets had to include so many more characters. The international use of traffic signs was the first forceful penetration to the general public of modern hieroglyphs. And since computers entered the scene and reproduction of such pictures were facilitated, the modern world is replete with icons, pictograms, glyphs, used to identify typicality's of brand, origin, qualities, functions, actions and behaviors of goods, men and machines. We see simple non-verbal symbols heavily used, not only in traffic, but in vehicles, hospitals, newspapers and in most mechanical and electronic tools, including their manuals, toolbars and controls, and even on the child's toys, the clothes we wear and the containers of the foods we eat. Their communicative value lies partly in their at-a-glance recognizability, one-letter briefness, colourability and resizeability. But their cross-language understandability is, in force of migration and globalization of the market, a further incentive to extend their use.

Now, in the habits of everyday personal life, typicality's abound. In dealing with the communication-handicapped, programs have been developed which offer a rich variety of icons for symbol and image-based interpersonal communication about everyday life. But they are bit-mapped pictures, and mainly bound to licensed software. However, pictograms can be considered as a species of characters. Symbol fonts are in fact produced and marketed. This implies that a basic diary writing, which can report habitual situations, everyday events and activities with pictograms as single dedicated characters, understandable even to the illiterate and the child, is a logical possibility. But, the number of keys on keyboards being limited, the entry of icons must take place ~~instead otherwise than~~ the entry of words. The solution presented here is to let the user choose and distribute pictograms, stored as characters in a font suite, as screen buttons. Users can arrange and rearrange them on a principal screen-window, surrounding a central scroll field, where text is entered, and they can then, with a single mouse-click, be entered in the (time-indexed) text-lines of the diary. Actually, the day card of the diary is a potentially revolving stage-scene to the user's own body map, virtual home, virtual neighborhood, etc, where pictogram-buttons also can be placed, contextualized and grouped according to such structured topologies.

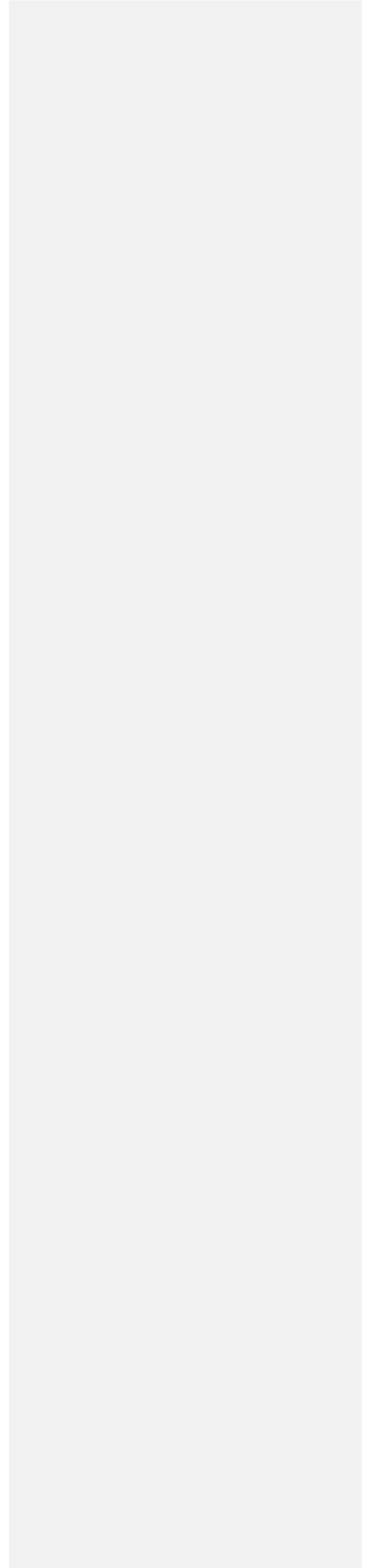
The idea of using glyphs to support the verbal journaling and reflection of personal phenomena may

sound like an attempt to square the circle. But understanding such glyphs, not as objective classifications, but as private signs of contextualized subjective phenomena points to a future of shared/folk-taxonomy alphabets for the more or less global typicality's of phenomenal event in habitats and in bodies.

The glyphs developed amount presently only to approximately 450, and many are lousy and inadequate. A series of them are not available in Windows version etc. But there are presently 12 root-stems, ready for inclusion of many, many more glyphs.

For some, the use of such glyphs in their diary may be uninviting. For others, especially individuals with limited reading writing capacities, lacking language-skills, or anybody in situations where motive for journaling is strong, but time or energy is short, glyphs may provide convenient provisional shorthand.

INSERT FIG.1 Here



BODY



CHILD



SOCIAL



HOUSEHOLD



FOOD



CULTIVATE



SMOKE



INFO



OUTSIDE



SPORT



STATE



REFLECTION

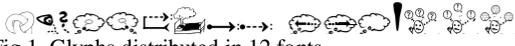


Fig.1 Glyphs distributed in 12 fonts

I am certainly not proud to present this preliminary suite of glyphs, with all its weaknesses and shortcomings. In the menus from which they can be chosen, an explanatory label is attached to each, and the ones installed by the user keeps their label as a tool-tip. The glyphs with labels can be closer inspected in www.phenomenalog.dk/glyphs.htm. The user thus has access to an extended library of pictograms, primarily referring to more or less universal all-human – or culture specific - typicality's of bodily, domestic and neighbourhood endeavours, pursuits and processes. No user will need them all. It is essential that it is the user who selects and distributes wanted icons, tries out chosen samples, and easily removes and replaces them with others. They facilitate swift logging of habits and events, intermittently with what may be typed in from the keyboard, reporting in words and sentences, names, numbers, titles of books and films, feelings, thoughts and reflections.

It is essential that the electronic diary thus can serve both cerebral hemispheres in timely ways.¹ The mere use of icons may for some contexts and purposes suffice, under time-pressure and in cases of language barriers, illiteracy or speech and language-impairment. For adults in literate culture, however, they may sooner function as occasional short hand where qualifying words and sentences (immediately or later) can be added and situated.

An important endeavor will be to organize network-based mechanisms to evolve pictogram-alphabets for subjective symptoms and treatments received, within and across major diseases and chronic conditions. This relates closely to the perspectives of tagging in networked adaptive information systems for chronic care (Biswas, Martin, Sturmberg 2009) (Martin 2009)

The Body, the Home and Cyberspace in the Diary

From a psychological viewpoint it is crucial, that by ensuring for the members of a household a permanent reference to the solid ground-level of their own particular domestic and bodily time geography, a personal grounded and rooted stem of self-reference can be grown, that can be made to function as a convenient core and anchor point for further personal orientation and reality-testing (Agre, P & Horswill, H 1997). It implies the emergence of a new, coherent potential of demonstrative identifying reference to re-identifiable individual objects, states and event-types in the private life-world, according to their personal biographical relevance and provide us new means of self-reflection, evaluation and ordination of past and possible future operations, states, informative objects and persons (Bjerg, K, 2008).

In this, one's body constitutes a necessary frame of reference, even for the healthy person. So, before focussing on any specific patient target group, we must cooperate to find general formats for personal body referring over time, in a diary. The day card must include a window to a 2-D or 3-D map of one's body. This constitutes a background scene for distribution of most health relevant glyphs already in the prototype. But it shall also permit a user to bookmark and comment (more permanent and/or on a daily base) spots and areas anywhere in one's body.

¹ The maintenance of time-indexed 24-hours display of inserted icons, as separated from the text written by the user, is an important feature possibility. It means, e.g. in the present prototype, that their distribution around the clock can be inspected in a separate window, where browsing through sequences of days make changes in pattern immediately apparent. And it opens for further developments towards columnar or circular displays permitting their juxtaposition with corresponding curves of vital parameters from body sensors. Physiological curves plotted relative to pictograms referring to behavioural or ideational events may be illuminating not only to researchers and doctors, but also to potential patients. To this end we must approach the logging process from a non-symbolic angle: The more or less automatic inputs of measurements, which a laptop diary can be made to record, along the diurnal cycle

General formats are also being created for visualizing in the diary relevant physiologic parameters over time, beginning with the most obvious - accumulating tables of sleep length, number of pills, cigarettes, drinks, and manually entered blood pressure and weight - as basis for occasional reflections. but aiming toward inclusion of illness-specific monitoring, e.g., cholesterol, coagulation, glucose, etc, and zoomable curve-display. Enabling patients to monitor and keep track of bodily states and symptoms will most certainly be the call of the immediate future. The above-mentioned potentials of biotelemetry bring it, so to speak, "under our skin", and highlight the potential intimate, bodily closeness of this "personal level". Some such data might even, if desirable, be accepted for sharing with one or more helpers (Bjerg 2009b). Configuring body-state-representational tools for personal state-reflection is a little-noticed potential, mainly cultivated in circles working with the concept of biofeedback. But seen as one of many keys to a sane health-education, such tools of self-knowledge may reveal a strong prophylactic potential, and thus be worth adding to the domestic tool kit (Baskin, [S.M. et al.](#), 2004).

The thinking about social processes around the human body includes ranges of social workers, doctors, nurses, secretaries, patient groups, clinics, training facilities etc. And the thinking about technological process, around the human body, includes ranges of diagnostic, maintenance, treatment technologies, prescription and journalizing databases. But the convergence of all these social and technological processes around the human body has an internal double nucleus -the personal body and the personal home, what we term the Somasphere and the Oikosphere.

Whatever measures we take in health and medical care, social and technological, the moment we think of just one citizen we must understand that a convergence of social and technological processes around the body already exists inside the information dynamics of the home and the family. We must build a counterpoint to the systems notion of a patient or client: a view from below, a view from the vantage point of the person-number, a view from the target of the healthcare, the consumer, the citizen's own local and temporal viewpoint, as conscious phenomena in continued personal cognitive and meta-cognitive processes.

As discussed above, one's home also constitutes an essential frame of reference, even for the healthy person. The day card can include a map of the home, being a floor-plan vector graphic representation, or a richer "furnished" "doll-house" top view. This constitutes a background scene for distribution of most household-relevant glyphs already in the prototype. It shall also, in future versions, permit the user on a daily basis to mark, link and comment on spots and areas anywhere in one's home. No doubt such options can have pragmatic value in all kinds of households, not least in cases of brain damage rehabilitation and senile dementias.

As the inclusion of a representation (furnished floor plan) of the user's own home is a complicated endeavour – presently out of reach for most users - a more abstract generalized habitat topology has been designed - the OIKOS –scene.

Insert Fig. 2 here

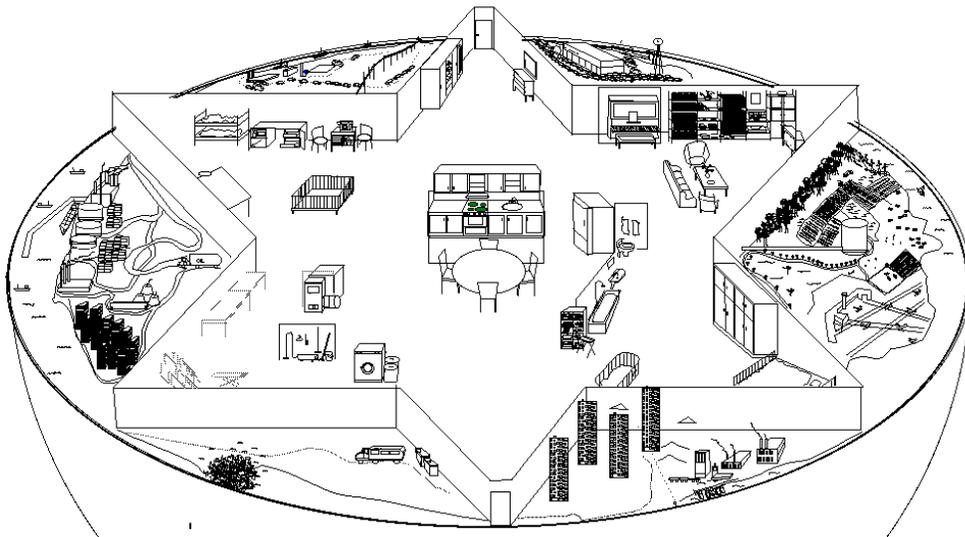
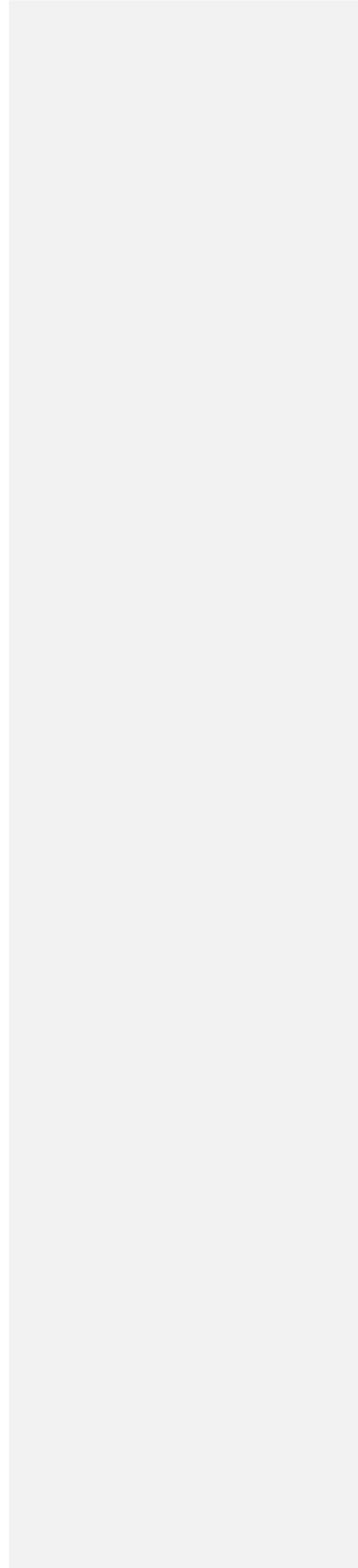


Figure 2.

This constitutes a topology, relative to which glyph-buttons can be distributed, and, not least, demands for coming glyphs arise.

But by the recent inclusion of browser functionality in the diary, the following map may also constitute one of possible backgrounds of the MYCYBERSPACE window, upon which users, here enabled to accumulate and organize Internet bookmarks, can distribute their links, relative to social-ontological contexts.

Insert fig 3 here



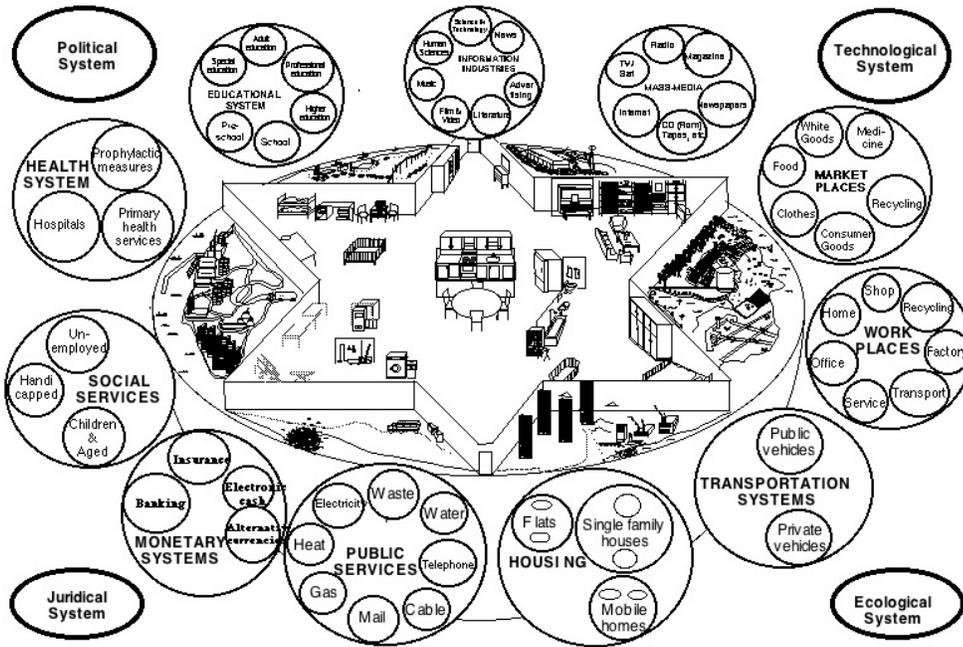


Figure 3

The Personal Interface

My method has been to develop an investigative tool, which at a minimum could satisfy the needs I met in daily use on my personal laptop(s) day in and day out, during all seasons of the year, over a period of 10+ years. The diary opens with a small window on the screen, from which a user can orient.

Insert fig 4 here

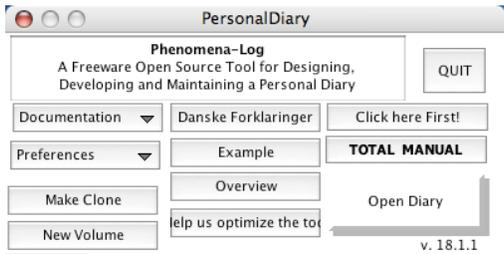


Figure 4.

The moment “Open Diary” is clicked, the full screen is taken over by a window to the last daycard

Insert Figure 5 here

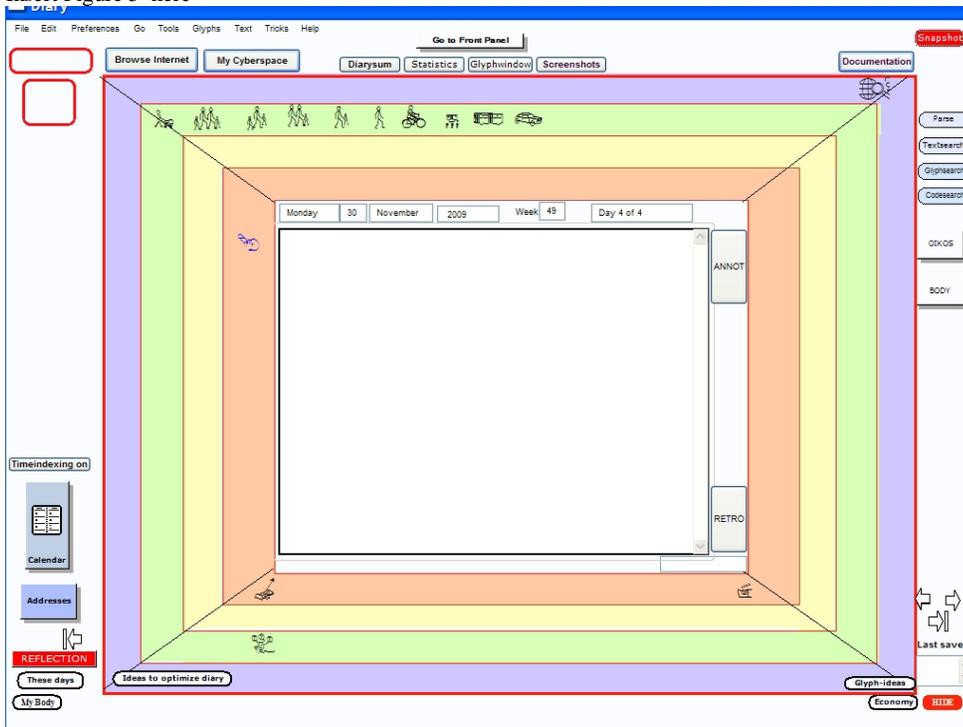


Fig.5 The immediate presentation of an interface to new users, version 18.1.1

(Colours have had to be removed in all illustrations for this publication)

But the moment the red bottom right button “Hide” is clicked, it vanishes out of sight.

Now, this interface is simplified, and users have direct access to furnish it not only with the glyph buttons they wish, but also with any of the functions shown in the next image.

Insert Figure 6 here

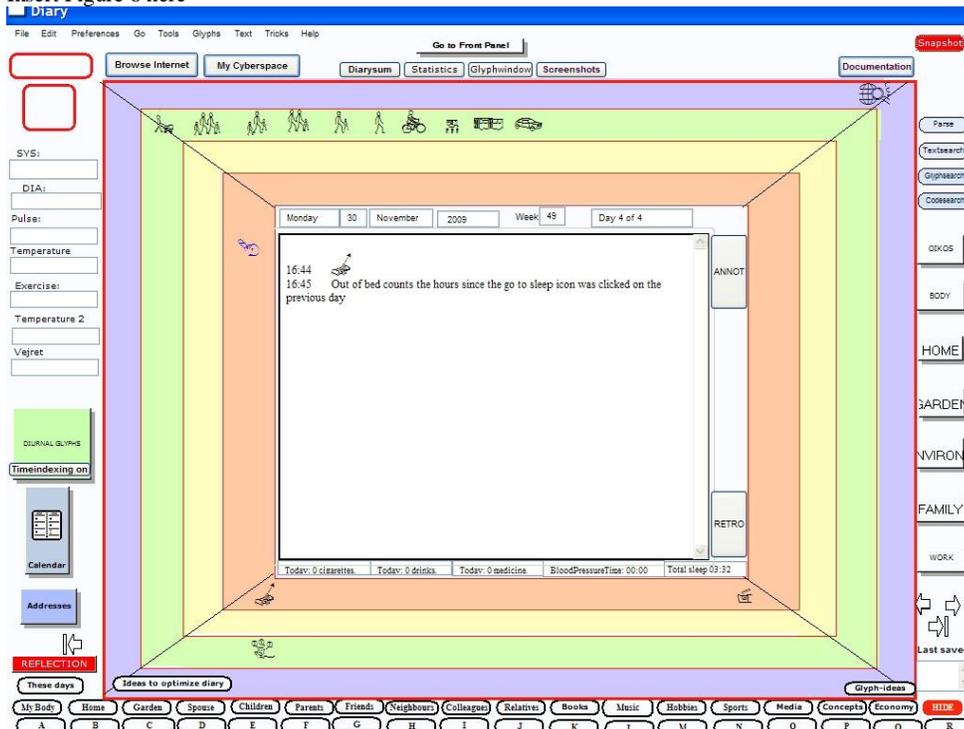


Fig.6 The full range of possible fields and functions

Shown below is a realistic impression of how a single (male) user has come to personalize his own diary:

Insert figure 7 here

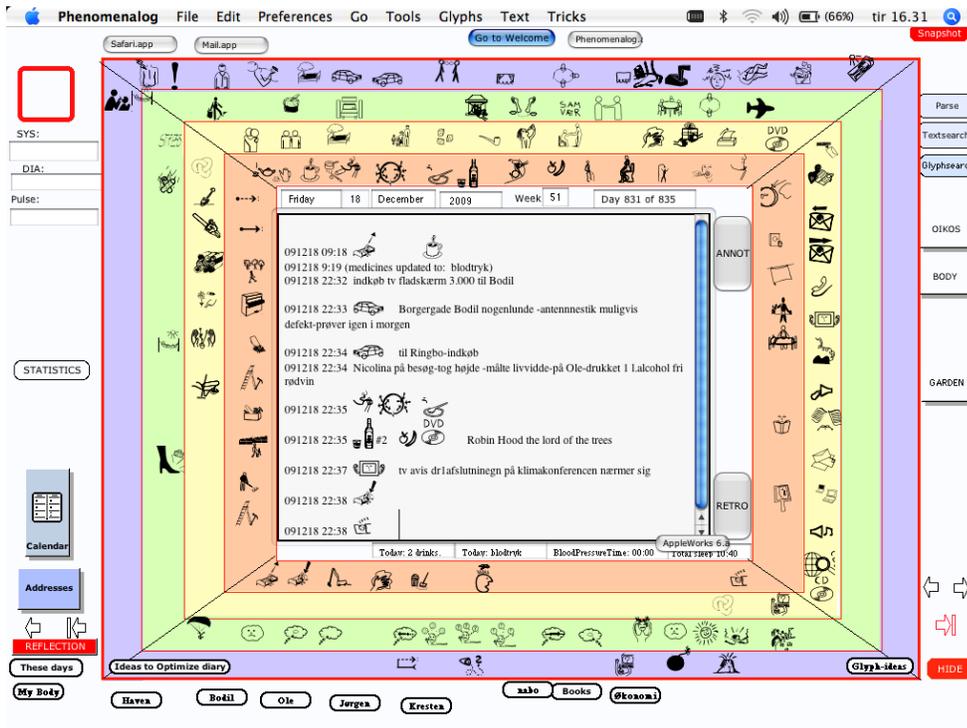


Fig.7. “Inhabited” diary

Ongoing prototyping

The latest version of the program, at the time of this writing (v. 18.1.1) has only been in use by a few relatively healthy persons. This version is now going to be tested through an appeal to the 4000+ participants in a Danish senior (age 50+) network (www.ageforce.dk) to join a shared WIKI (www.phenomenalog.wikispaces.com) and involve themselves as beta-testers, with use of the mutual support amongst beginners, empowered by this WIKI. The data from this process shall establish the basis for a thorough revision of the user-interface, beginning extension of the glyph-fonts, and a new invitation to include a larger sample of the senior network members. This second phase is scheduled to last a year, and form the background for translation of the interface to Danish and immigrant languages (Turkish and Arab), and open the questions of targeting to specific groups of chronic patients.

Anticipating the expectable

Among the assumptions about the future going into this developmental agenda are:

1. That the cores of homes and bodies will be massive informational nuclei, relative to whatever structures the broadband space will offer

2. That the (time-indexical) representational options concerning these nuclei with digital text, graphics and audio and video and more to come, inevitably will bloom, as witnessed with mobile technology, digital video-recorders, mobile monitoring, etc.

The vision of the future, in which Phenomenalog should fit best, is a global One-Laptop-Per-Child -> / One-Laptop-Per-Citizen society with free open source software (GNU etc.), and free wireless peer group and neighborhood networking, embedded in an open Wikipedia 3rd millennium Babel. To convey a coherent and sufficiently contextualised understanding of the relevant dimensions of this field, I have found it necessary in my publications to make a few conceptual extrapolations into the near future. In so doing, I have introduced three concepts: the virtual home, the virtual body and the virtual neighbourhood - as logical and necessary constructs for grounding a coherent notion of the demands to future domestic information technology (Bjerg, 2000, Bjerg, 2001). A discussion of these matters should hopefully connect the enterprise at hand with the total recall universe of Gordon Bell and Gemmel (Bell, 2009), and with the "the sixth sense technology" enterprise of Pranav Mistry (Mistry, 2009), and its promises of a wearable gestural interface, e.g. narrating gloves, 3-D pens, and establishment of shortcuts to create virtual objects distributable in virtual spaces, like the virtual home. They are thematically relevant because they can point us to the notion of a fully and coherently contextualized interface, coming to make it possible in timely ways to refer and annotate to any location/area within one's home and any bodily posture and any location/area on or inside one's body.

Interfacing the most trusted helper

Seeing client-helper as a special case of future close multimedia interfacing with trusted others points to important improvements in the long distance person-to person communicative space. Already advanced enterprises setting up frameworks for telehomecare, patients treated at home using telemedicine, are emerging in Denmark, e.g., www.virtuellehospital.dk and www.telekat.dk. To the extent our now-and-here, within-sight and within-reach info-environments (including desktop) now electronically can be made shareable, participants can point in real time to postures, spots and areas both in their own and others' bodies, paraphernalia, instruments, surroundings, practical situations, and sequences of typical events. Interfacing the chronic patient might well empower the patient to display and refer, not only to his body, but also to his room, even showing, in a conversation, by pointing and looking at things (Bjerg, 2009).

Citizens will increasingly depend upon, and anchor themselves through information in and out from their computers. Their acquired orientation, personal inputs and outputs, trails and landmarks across Internet sites and neighbourhoods will increasingly reflect and condition their thinking and problem solving. To the extent the option of showing/sharing what can be seen on one's laptop is an evidently relevant feature in future close communication between laptop users, it enables the sharing of evolving personal patterns of subjective relevance on the Internet in detail and over time - an important aspect of health-education. Citizens' dealing privately with all this - not to speak of private dealing with IT-tool use - will, also more generally, profit from being shareable in distance-conversations with close friends and trusted helpers.

"Patient literacy" and "patient education" explicitly refer to the knowledge distributed and distributable on websites and WIKI's. If patient education is an aspect of shared health-management, it should support

telecoaching within the frames of patients' further orientation on the Internet. Such added features in interfacing the lonely handicapped and chronic patients would at least compensate somewhat for the missing expensive corporeal visits of the helper.

CONCLUSION

In view of the blooming of professional medical technologies, the escalation of healthcare expenses and the spread of health threatening lifestyles in the populations, the importance of increasing health-awareness, self-care and self-monitoring is generally acknowledged, while growing number of chronic patients is escalating. Public health information is intensified. The profitable marketing of drugs, health-related facilities, training, remedies and tools is exploding. But the evolving of patient-driven networks and shared blogging gives unexpected promises of support to the individual patient.

The only problem is, that while tremendous efforts and results are obtained to digitalize and train the medical establishment, the chronic patients are left at their own to learn, how to handle a computer, establish e-mail contact, and to hook up to whatever the digitized medical society has to offer. Therefore the citizen health situation has to be re-examined in the light of the global spread of notebook computers and networks. Personal healthcare and health-related interfacing of the future shall be considered as just one dimension of the citizen's general interfacing him/herself through the everyday use of a personal notebook computer.

We must conceive of citizens as genuine individual explorers on their own personal daily life-trails, along their own life-trajectories. We must favour their empowerment as self documenting "Citizen Scientists" qualified to deal with own health-data, physiological data, economical data and environmental data. We must qualify citizens as administrators of their own health. Therefore we must motivate and equip the autonomous individual citizen/patient to develop and maintain a most basic and private sedimenting digital self-narrative, an electronic diary and time-indexed database, as an empowering empirical tool, not least in health-related, body- and domestic-habit-related matters.

The rationales behind the development of an open source freeware cross-platform tool for this purpose were explained, the dimensions it shall be fit to document were listed, the very preliminary library of pictographic short-hand presented, and the overall design of the interface of the early prototype illustrated. Long term perspectives of the project relate both to the expected spread of bio-telemetric technologies and to interfacing personal health data in the medical systems. Immediate short-term perspectives relate to preliminary testing and user-driven development in a Danish senior citizen network (www.ageforce.dk), and the collective development of a new wiki: www.phenomenalog.wikispaces.com, while developing targeting for broader and more specific chronic patient populations.

ACKNOWLEDGEMENT

The development of the concepts and the software described was based on:

- Experimental Home Project, Department of Psychology, University of Copenhagen, Denmark.
- Students involved in Course of Qualitative Research Methods
- Kim Borreby, with whom I co-edited the Proceedings of the IFIP 93 International Cross-disciplinary Conference on "Home-oriented Informatics, Telematics and automation" in Copenhagen, 1994
- A grant from Scandinavian Tobacco Company
- Early programming by Mag.art Bjørn Nake
- Extensive unpaid voluntary programming help by Steen Andersen.
- Extensive unpaid voluntary programming help by Mark Schonewille.Economy-X-talk.com
- Advice and critique from my wife Beth Bjerg
- And occasional help, over the years, from programmers in the "Revolution" developers community ; Sarah Reichelt and her DateTime.rev collection, Richmond Mathewson for his Paint widgets, Eric Chatonet, Klaus Major, Mark Talluto and others.

Appendix A. Implemented features in the diary

Features included in the electronic diary (numbered to facilitate further discussion): ▲

- ▲ 1) Freeware
- ▲ 2) Cross-platform for Windows, Mac and Linux
- ▲ 3) Automation of time indexing.
- ▲ 4) Feature of searching , backwards and forwards
- ▲ 5) Feature of parsing, -producing a file of all time indexed lines (with n lines before n lines after) where a word or a glyph appeared in the accumulated diary
- ▲ 6) Integration with calendar (for fast access to previous days in accumulated day-cards – for swift brief quoting to calendar –and for reminders, to be quoted on opening a specific later day)
- ▲ 7) Integration with address book, (with search function)
- ▲ 8) Options for quoting to and from the diary
- ▲ 9) Options for easy assembling time-stamped notes/quotes in a large number of separate accumulating thematic fields - be it symptoms, promises, books read, films seen, passwords and pin-codes to be remembered, relatives, collaborators etc
- ▲ 10) Option for printing text of any accumulated thematic field
- ▲ 11) Options to print full diary text from single day or span of days
- ▲ 12) Option to supplement text-entries with entries of pictograms (Glyphs) for recurrent typicality's of situations, actions and events in everyday life, as a kind of shorthand.
- ▲ 13) Option for personally selecting which pictograms from an expanding library of glyphs user finds it worth to use screen space for on his/her intra-personal dialogue –scene.
- ▲ 14) Options for user to alter and redesign the interface
- ▲ 15) That diary automatically - for each day - accumulates a row in a table of data from
 - a) daily counts of use of selected glyphs (e.g. medicine, alcohol, cigarette.)
 - b) typed physiological data (e.g. blood pressure, weight, temperature)
 - c) typed word-described symptoms or other cue words: e.g. weather.
- ▲ 16) The option for user to create links (for single days- or permanently) to any file, folder or program/application in the laptop. (Use of such links automatically to be indicated in the diary to make the personal information-handling more transparent in its time-perspectives).
- ▲ 17) Functionalities for email by clicking e-mail address and for visiting homepages by clicking it, on name cards within ones own virtual address book
- ▲ 18) Inclusion of browser functionality enabling user to accumulate and organize Internet bookmarks in 2D and 2 ½ D cognitive maps. (Use of such links also automatically to be indicated in the diary)
- ▲ 19) Accumulation of a single, daily growing, Journal htm.file, containing the content of diary text of consecutive days
- ▲ 20) A superordinate metacognitive field/file, permitting time indexed quotes from any previous daycard and reflective comments
- ▲ 21) An option for any user to publish a clone of the program as designed for a chosen target-group, e.g. pre-distribution of most relevant glyph-buttons, hiding unnecessary features for that group and naming thematic fields for the expected needs of that group.
- ▲ 22) An option for any user to offer and cooperate on developing a translation of the user-interface to other languages.

Formateret: Skrifttype: 6 pkt, Ikke Fed

Formateret: Punkttopstilling

Formateret: Skrifttype: Ikke Fed

Formateret: Indrykning: Venstre: 0 cm, Hængende: 1,27 cm

Formateret: Skrifttype: Ikke Fed

- * 23) An option for any user to suggest/co-design new glyphs, found to be missing
- * 24) A forum, accessible to all users, to discuss their experience, problems met, and ideas for improvement.
- * 25) A "Hide-button" which immediately empties the screen for any trace of the diary, except its shortcut on the bottom panel, meaning that its use can alternate with all other uses of the computer, while quickly hidden, if others approach to inspect the laptop screen.
- * 26) A retro option to insert text&glyphs to earlier times same day, - to the extent user cares to detail the chronology of the day
- * 27) An annotation option , enabling time-indexed reflection/commentary to be inserted after any line in the diary (I don't know, whether this can be considered as the tagging Janice Ropers suggests, - else quoting to the superordinate metacognitive field (20) is another tagging-option
- * 28) Supplementary backgrounds, one click away, for logical distribution of glyph buttons on backgrounds like: virtual body, virtual home, virtual garden, virtual neighborhood, virtual workplace etc.---
- * 29) One thematic field is constructed as a (resort able) table: The personal treasure of usernames, account numbers, access codes, passwords & pin codes
- * 30): Options for updating the count of cigarettes, drinks & medicine
- * 31) Option for suspending the time-indexing, - useful when user wants to compose a letter, a poem, a response to a discussion etc
- * 32) Automatic saving at user defined intervals
- * 33) Option for extensive hiding unwanted fields and functions
- * 34) Automatic backups for last three complete diary savings
- * 35) Installer for windows

Formateret: Skrifttype: Ikke Fed

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Appendix B: Desired further features of the diary

- * 50) Programming the installer download process, so the number of downloads can be counted, and e-mail address of downloader's are obtained
- * 51) Installer for Macintosh
- * 52) Installer for Linux
- * 53) Option to view the accumulated data-table (15 a+b) as differently colored curves in weekly, monthly and annual perspectives
- * 54) Expansion and design-improvements of the glyph-library of typicality's from the present app. 450 to at least a couple of thousands. If we could find some designer educations , where such a project could fit in, one or two class - semesters should easily reach that goal, and be a nice way to combine teachers professionalism with student work, - and copy free product.
- * 55) Mind mapping options (I am personally using the proprietary program "Inspiration" and looking for a freeware solution to include something like it in the electronic diary)
- * 56) Translation of user-interface to other languages: Arabic, Danish, French, German, Spanish, Japanese, Chinese.
- * 57) Adaptation of the address-book to report and enable Skype calls directly from telephone numbers in address-book
- * 58) Optional time-indexed sound recording of vocal remarks and conversation storage
- * 59) Optional time-indexed phone-dialogue storage.
- * 60) Prototyping a cigarette lighter, for wireless triggering of time indexed input of numbered cigaretyglyphs
- * 61) Option for telemedical input
- * 62) Option for synchronizing diary on laptop with mobile extension-e.g. iPhone 3GS
- * 63) Option for time indexed glyph and text annotation to zoomable virtual home (2D→3D→ QTVR)
- * 64) Option for time indexed glyph and text annotation to zoomable virtual body (2D→3D→ QTVR)
- * 65) Optional time-indexed links to personal photos automatically retroactively inserted in the diary for the day, when photo was taken

Formateret: Skrifttype: 6 pkt

Formateret: Punkttopstilling

Formateret: Skrifttype: 12 pkt, Skriftfarve: Automatisk

Formateret: Brødtekst, Flere niveauer + Niveau: 1 + Nummereringstypografi: Punkttegn + Justeret: 0,63 cm + Tabulator efter: 1,27 cm + Indrykning: 1,27 cm, Mønster: Ingen

Formateret: Skrifttype: 6 pkt

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KEY TERMS & DEFINITIONS

Biotelemetry: Digital monitoring of various vital signs of ambulatory patients (or healthy persons)

Citizen Science: a term used for projects or ongoing program of scientific work in which individual volunteers or networks of volunteers, many of whom may have no specific scientific training, perform or manage research-related tasks such as observation, measurement or computation.

Cyberspace: The electronic medium of computer-networks in which online communication takes place. The expression "MyCyberspace" designates a mapping of personally most relevant sites on the Internet.

Glyph : Graphic signs of writing. Letters are glyphs, but so are also hieroglyphs, pictograms, ikons, smileys etc. The term is here used to refer to pictograms which – like alphabetic characters- are encoded in fonts

Iconosphere: A sphere of pictorial signs, e.g. glyphs.

Noosphere: (From greek nous (knowledge) The sphere of human thought

Oikosphere: (From greek oikos (home) The sphere of a home and its processes of householding.

Formateret: Skriftype: (Standard)
Arial, Fed

Formateret: Skriftype: (Standard)
Arial, Fed

Formateret: Skriftype: Fed

Phenomenology: in philosophy and psychology referring to the subjective experience of a person. Experience (or being, or existence itself) is an "in-relation-to" phenomenon, and it is defined by qualities of directedness, embodiment and worldliness which are evoked by the term "Being-in-the-World". This is the background for the term "Phenomenalog".

Formateret: Skriftype: Fed

Propositional thought: Thoughts in words or sentences, as opposed to non-verbal thoughts in images and gestures.

Formateret: Skriftype: Fed

Somasphere : The sphere of a living human body and its processes

Formateret: Skriftype: Fed

Typicality : referring to a subjective situated category of behaviour or event, which may vary in detail, but function as recognizable token and construct in a persons mental space and metacognition.

Formateret: Skriftype: Fed

Virtual Body: A 3D representation of a body

Formateret: Skriftype: Fed

Virtual Home: A 3D representation of a home

Formateret: Skriftype: Fed

Please provide 7-10 key terms related to the topic of your chapter and clear, concise definitions (in your own words) for each term. Place your terms and definitions after the references section of your chapter.