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PHR Revisioned – Navigating in the Personal Health Space

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Abstract. The field of health care and well-being services is changing due to economic and societal reasons. One consequence of this ongoing change is that individuals are encouraged to take an active role in their health and well-being related endeavours. The objective of our conceptual work is to support this change and identify mechanisms that can help individuals in their endeavours. Our work is based on the findings of a project that are reassembled under the metaphor of health navigator. The envisioned functions of the navigator are analysed using activity theory as the underlying framework, and as a consequence, human activity as the unit of analysis. The purpose of this integrative work is to create a concept that draws together the complex aspects that define one's position in the health space; the overarching state of health related efforts.

Keywords: eHealth · Health Care Information Systems · Electronic Health Records · Personal Health Information Management

1 Introduction

In the changing health care landscape of today, navigating through series of health related events (for example, in relation to diabetes) is a challenge to the patient. Primary reasons for this include lack of integrative solutions and fragmentation of health services. For example in Finland, the latter has led to a situation in which most providers offer similar service but the overall volume for a single service is too small [1]. Individual service providers are also disconnected from each other and from the surrounding 'wired world' as the work of standardization organizations has not been able to bring universally applicable solutions to the technical aspects of this dilemma.

On the level of an individual, the consequences of this kind of fragmentation are rather evident, for example, if we look into the U.S. national health insurance program Medicare. It is estimated that "average Medicare beneficiary sees two physicians and five specialists a year, and that those with chronic illnesses see an average of thirteen physicians a year", each focused on the particulars of their own specialty [2]. It follows from this that it is practically impossible, or at least overtly encumbering, for an individual to track one's position in the 'health space'; the overarching state of health related affairs (cf. [3]).

In this paper we define a concept that will help individuals to understand a) where they are in terms of their illness or ailment, and b) what is their current position in relation to the health service providers. Our vision is that if these two goals can be achieved, it is possible to help the willing individuals to become active and

cooperative actors in the matters of their health. The function of the concept is illustrated by comparing and contrasting the concept to an ordinary satellite navigation system (e.g. satnav).

Even though our approach is exploratory and conceptual, the underlying theoretical framework is activity theory. Our focus of investigation is on the end-user; how technology facilitates and affects attaining the user's health related aspirations, and what kind of notable transformations emerge with the employed technology. The discussed concept is also considered as a key element in avoiding and solving conflicts that may come up when personal preferences, formal processes of health care and norms of the surrounding society collide.

The findings of this project base on the national MyWellbeing project that ended in 2010. The purpose of the project was to look into the changing service landscape of the ICT-mediated health care services and define means for a citizen for coping with the services that are becoming more and more electronic by nature. In the project, a personal aid for managing individual's health related affairs called The Coper was conceptualized with industry partners on the basis of a state-of-the-art survey on solutions of personal health information management. The ideas presented in this paper are derived from the original concept of the artefact [4].

2 The Citizen as the Subject of Navigation

When using a satnav, the principal actor is the driver. There is a body of authorities (such as the government) that has created the required infrastructure (roads, bridges, etc.). They have also defined rules for using the infrastructure (traffic regulations). However, these authorities are rarely involved in planning and execution of a single trip; the driver eventually makes the decisions about the destination, route and most of the time schedule as well. The satnav is in place as a tool for supporting the decisions made by the principal actor.

Inspired by this, we suggest that even in the health space a willing patient (we prefer the term citizen) should be allowed to take this place instead of being subordinated to the health care delivery system of today. In this, our view to the relationship between the patient and the physician is close to the "informed model" presented by Scott and Lenert [5] in which the physician's role is support the patient and to ensure that he has "an adequate educational space" (*ibid.*, p. 2).

Allowing the citizen to take the 'driver's seat' gives rise to two immediate interpretations. Firstly, regardless of the recent patient-driven developments in the field (cf. [6]), the health care delivery system of today is still primarily controlled by the authorities as is the relationship between the doctor and the patient. As such, the relationship can be regarded primarily as a paternalistic one [7]. In our interpretation, the mechanisms of the health care delivery are reversed (to a reasonable degree) and the role of the patient can be seen autonomous [8; 9].

This implies that even though the patient and the physician co-operate and work towards a common goal in the benefit of the patient, the latter one has the freedom to decide her goals and act accordingly to them (in other words, define how a single trip is carried out). It must be acknowledged that this view is not without its flaws, for example in terms of equality. People who have been more fortunate in terms of

making a living are usually able to choose their route and means of travel more freely than the less-fortunate ones.

Secondly, considering the on-going discussion on the ownership and use of patient data (cf. [10; 11; 12]) we suggest that the ultimate owner of the health data is the citizen, not the health service provider or the EHR vendor. In order to successfully navigate to the chosen destination, and to the desired health outcome, the citizens should have up-to-date information on 'prevailing conditions' in a format and language they are able to utilize. In this, mechanisms that a) proof-read and correct health related documents such as patient narratives, and b) translate medical jargon into the language of the citizen are of the essence.

It is also in line with this viewpoint that the governmental data (such as quality information on patient safety issues) originating from the health sector should be opened up and made accessible in the spirit of an Open Declaration on European Public Services [13] as is already happening in the U.K. If the citizen is to act as a subject of navigation in the health space, all relevant information should be made available. Without it, the navigation occurs on the basis of intuition and anecdotal knowledge.

3 The Current Health Status: Where Am I?

One of the most essential functions of a satnav is the identification of the current position. Using the simplified diagnostic-therapeutic cycle (figure 1) as a basis for analysis, this feature corresponds in health care to observation and diagnosis (acquisition of the location data and visualization of the current location on the device).

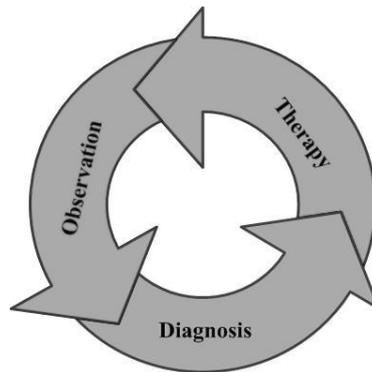


Fig. 1. Diagnostic-therapeutic cycle [14]

Whereas a satnav determines the current position on the basis of satellite signals, mobile network, etc., the closest corresponding positioning technology in the case of a health navigator comprises of health service provider's information systems (EHR, LIS, etc.), and in some cases technology acquired by the citizen (such as, blood pressure monitor). However, as it is in the nature of care, human element is an integral element in this positioning. In the health care of today, this means that the patients' preferences and actions are more and more in the crux of clinical decision making. They can be seen as key elements balancing the viewpoints of clinical state and circumstances, research evidence and clinical expertise [15].

On practical terms of navigating in the health space, we can imagine that the physician, or some other health care professional, receives on her screen one or more recommended (evidence-based) care pathways ('routes'). Taking citizen's preferences into consideration, one of them is chosen and personalized according to the situational and individual factors. The outcome of this process will be a personalized travel plan that consists of different transitions and different waypoints (such as, acquiring services from different providers). This travel plan of personalized health care is transferred to the citizen's health navigator to support her navigation through the space.

It should be kept in mind that these transitions mean changes in the state of the citizen, not moving from one physical location (or service provider) to another as is often the modus operandi, or dominant mode of operation, in the health care organizations of today. For example in the NHS (U.K.) there are approximately 37 million follow-up appointments per year and a significant portion of these visits are clinically unnecessary [16]. It is in our idealized view that data should 'move' and devices, such a medical imaging devices, arranged (when possible) within a health care organization according to the patient trajectories in the spirit of Patient Journey Modeling (cf. [17]).

The diagnosis is not always, so to speak, a 'one shot action'. Sometimes detailed investigations, such as laboratory tests are needed in order to arrive to a conclusion that leads to therapy (figure 1). In the context of the used metaphor, these investigations can be seen as a 'route' of its own. The target of such 'meta-navigation' is the correct diagnosis and the steps needed to reach this destination are taken in order to exclude inadequate alternatives. Similar investigations are needed when the progress of a therapy is evaluated. Using a metaphor has the advantage that unlike in the real life, the 'positioning technology' gives immediate analysis of the current state of affairs before, after and at the time of the therapy.

A generic feature of the concept of a route is the notion of *purposeful activity*. Purpose of a route is to reach the destination one step, or *transaction*, at a time. In terms of health care, the most obvious route is one from the state of illness or accident to the state of health the citizen had before. We call these kinds of routes *progressive*. Another type of route can be called *preserving*; the purpose of the route is not to reach a point in health space that is better than the current one. As certain illnesses are not curable and some injuries cannot be healed, it is sometimes realistic to maintain status quo, even if taking the 'route' seems counterintuitive. The progressive and preserving routes can be mixed with each other. For example, the therapy for diabetes (preserving) may have a subordinated route which aims at losing weight (progressive). It should be also noted that not all activities are active ones; they can be

passive as well (for example, through avoiding certain behaviour, e.g. smoking). In this example, the activities can be interpreted of having pre-emptive characteristics as well.

The trigger for the first diagnosis can be dramatic, for example when the citizen comes to the hospital under emergency conditions. Sometimes small symptoms, or even changes in one's view on the world, can create a *fracture*, an identity disturbance affecting one's perceived mental image. In the basest form, fractures may originate from simple every day events, such as from an experienced pain or from a realization that climbing the stairs at work has become more exhausting than before and the clothes that used to fit are no longer comfortable.

We must be aware that not all citizens are able to take the responsibility of being principal actors in their health related endeavours. Children and many elderly people may need a *mediator*, a representative, for their activities. Similarly, some groups that behave destructively against other people or against themselves may need such a mediator. In these kinds of cases, the mediator may use the navigator on behalf of the actual beneficiary, providing that there are mechanisms in place that prevent misuse and identify potential health risks for the actual beneficiaries (cf. [18]).

Acknowledging personal preferences in the health care decision making, and in defining one's current position and route in the health space, borderlines a perspective described in the academic literature as empowerment [19]; giving power over one's health related decisions and actions primarily to the individuals themselves. This perspective can be seen as an extension to consumerism, a notion based on the "systematic creation and fostering of a desire to purchase goods and services in ever greater amounts" [20] as it encapsulates a notion of transformation from a passive patient to an active consumer who acquires products and services to according to one's personal preferences and needs. This notion reflects well with the individuals' instantaneous values and attitudes they express towards the (electronic) services of today.

However, in the health care context the notion encompasses some problems that stem from the knowledge base of the non-professionals. Especially when compared to health care professionals, Individuals do conscious and formal¹ health related decisions rather infrequently. When they do them, their decisions are often distorted with misconceptions and anecdotal knowledge [21]. This observation suggests that the citizen should be encouraged to externalize the diagnosis and allow the observation process to be led by a professional with a higher expertise than she has herself. There is a strong rationale and common sense behind this approach. However, it should be underlined that the overall project and the related information belong to the citizen.

A necessity to place the diagnosis to the hands of professional experts grows stronger whenever the decision leads to treatments with remarkable costs that will be, at least partly, supported by public subsidies. In this case, it is justified to require a legitimation given by an authority for allowing a patient to consume subsidized services (medical imaging, etc.). One way to implement this kind of a control

¹ We acknowledge that making a decision on what to eat is a health decision, if not necessarily a conscious or a formal one.

mechanism, that enables the function of universal health care, is to require that there is one responsible and authorized professional present throughout the personalized care plan. Not a professional who is replaced when the current provider organization or the field of medical specialty changes. This kind of an assigned professional, with a view to the overall situation from a clinical perspective, would be in a position to give the needed validation to subsidised treatments.

This kind of operation principle commonly known as case management is not new to the field of health care. For example, in the field of elderly care, case management is a common tool. It is commonly used for tailoring services in order to improve the quality of care of the elderly person [22]. To distinguish our view from the centralized coordination and leadership present in a professional setting, we acknowledge that the citizen has the overall authority and may act as a case manager even though there is a presence of a professional. With this notion, we want to acknowledge the shortcomings of a citizen in terms of health and medical expertise. The citizen is not a physician regardless of the amount and quality of personal decision support aids in her service (nor is a physician the citizen).

The role of a medical expertise is also highlighted during the journey; positioning can be seen as a feedback on the progress of the planned journey where possible deviations and delays are alerted. Since people rarely have medical devices that automatically detect and react to such deviations in the health space, this kind of feedback is often best performed by a health care professional. In this, the relationship between the citizen and the health care professional can be seen as an active partnership as described by Stevenson [23].

4 At the Intersection: Following the Route in the Health Space

Here the health navigator metaphor shows its strength. Equipped with the navigator, the citizen will see an overview of her projects. For each project, past and future transactions, and the current state are displayed. Ideally, this kind of overview will give the citizen a sense of purposefulness and meaningfulness in relation to the selected route. Some of the upcoming transactions (waypoints) may be self-services (such as taking prescribed medication), and transactions that base on professional services can be seen as ordered by the citizen who is the actual beneficiary.

As the citizen has access to the up-to-date location information (e.g. health data), she can decide the used intermediate stopping points (e.g. where health services are acquired). When health related decisions are made, open governmental data can be a valuable addition to other data sources, such as personal measurements or personal genetic data originating from biological repositories (or biobanks). For example, in the data.gov.uk project in the United Kingdoms, the open governmental data is already used in providing tools for the citizens to be used when making health related decisions. A practical example on this is the CareHomeMap application which can be used for tracking care home quality (figure 2).

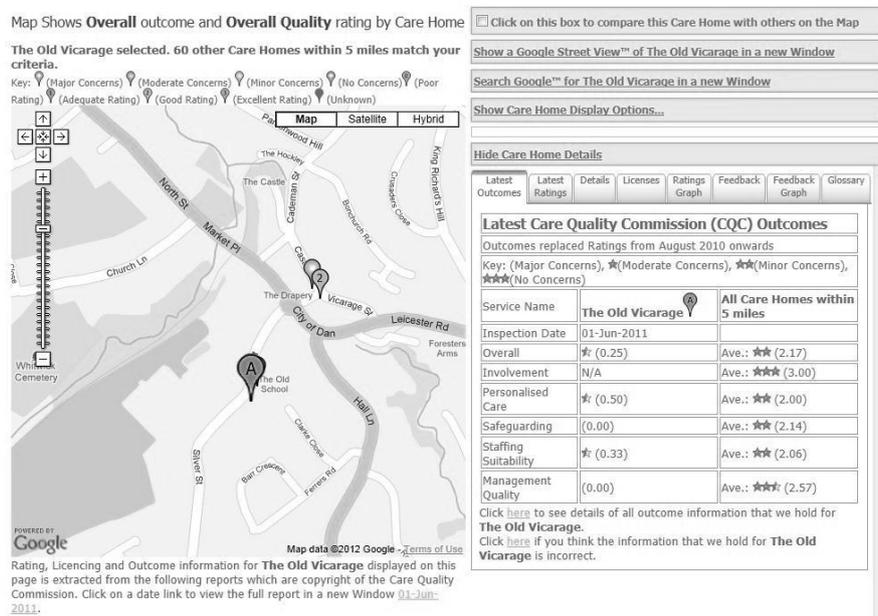


Fig.2. The CareHomeMap application (<http://carehomemap.com/> (accessed December 3rd, 2013))

One important consequence of the citizen-centric view on service acquisition and data ownership is that the citizen acts as a point of integration, supporting unification of different projects, service providers, etc. and related information sources into a single coherent collection regardless of the actual source or format of the information. And most importantly, the route is now controlled by the citizen herself rather than any single service provider (or unit).

As discussed, this approach also supports mediation such as case management [22], for example when one is unable to act due to health reasons (such as declined cognitive capabilities). In the light of the used metaphor, the individual acting in the role of a case manager can be compared to a travel agent. While the travel agency helps in planning the route (articulation), the agent acts as a tour leader taking care of practicalities (execution), such as schedule, co-travellers, etc. Naturally, in the field of health care the duties of a case manager are often more multifaceted than those of a travel agent. The role often encloses more than just coordinating services. Depending on the service provider, the role can be related to unemployment benefits, community resources and support groups (just to name few), covering a wide aspect of issues related to the health and well-being of the citizen.

According to our vision, the health navigator will structure the information according to the life cycles of the active projects, each of them having a route in the

health space. On a practical level, the route may be displayed chronologically, for example, in a timeline. If wanted, the navigator can give a reminder of upcoming transactions, and advices for preparing to them. From this perspective, the envisioned solution has properties that support health literacy and patient education, and integrate personalized care instructions into the care pathways. As a consequence, the pathways will become inherently individualistic by nature, supporting the patient choice. With this kind of functionality, it could be possible to complement (or even replace) parts of the more generic and formal guidelines that may not be fully applicable to the current health status of the citizen (for example, in the case of comorbidity).

This is in *some* contrast to the health care delivery of today; even though in the core of the health care has always been the individual, the care has been personalized only to a degree. In practice, since the introduction of scientific methods to medicine at the end of 19th century, the personal aspects of treatment have “started to become endangered” [24]. A consequence of this development is that the best practices of evidence-based medicine are flexible only from the perspective of their application via clinical freedom; the degree of freedom clinicians are permitted to employ in benefit of the patient [25].

The properties of the health navigator, that enable displaying transactions in relation to each other, also imply that each transaction has an objective. Each objective can be evaluated instantly, or as a subsequent event, thus becoming a part of the follow-up and feedback record. The parts become a whole within the context of individual's health; the individual transactions can be seen as an assemblage from the perspective of a project. The health navigator can also be used to manage the contracts with service providers: for each intended transaction, an appropriate service provider must be found and selected. Scheduling, pricing (i.e. price and reimbursements) and finally actual payments must be performed.

The concept of a route in geographical navigation conforms well to that in the health space. More so when there is a pathway of care that aims at a positive change in the current health status of the citizen, such as in, in the case of an injury or sickness (cf. *ibid*; [26]). In terms of a route, the idea of a purposeful activity is a useful metaphor as it encloses the concepts of target, activities and motivation under an umbrella. More so, if the activity is by nature progressive and active. Regardless of the nature of the activity, they must be systematically analysed in terms of the goals of the project; otherwise they cannot be regarded as truly purposeful.

Continuing with the navigator metaphor, a satnav can be used with other forms of transport besides the obvious ones (by bicycle or on foot). For example, the navigator could be used in conjunction to collective transportation (train, ferry, flight, etc.). In our analysis, the driver operating in a ‘self-service mode’ becomes a consumer of external services offered by multiple providers; the citizen is expected to compose a route of feasible transactions that lead to the desired target. In order to reach the destination, the transactions must match with each other in terms of schedule, and there is a need for coordination for changing from one transaction to another.

Naturally, some transactions may require a reservation to be made in advance. Each transaction has a price and the chosen route should be economically feasible to the citizen. When applied to the health care setting, this metaphor means that when the citizen has formulated the purposeful project (i.e. set the destination), the health navigator should help in setting the ‘milestones’; when one should be at the reception,

how the ‘tickets’ are arranged (in other words, costs and reimbursement). In addition, the navigator should be able to ‘reroute the trip’ for example, if the citizen has missed an appointment.

Particularly in the health care setting, there should be a level of reflection present at all times. As discussed in the chapter 3, this implies to an involvement of a professional who supports the navigation efforts with one’s professional expertise. While each purposeful project can be seen as singular trajectory from citizen’s perspective, the projects may be linked within the level of a care pathway (such as, loss of weight, managing medication and taking care of skin problems can all be linked to the care pathway of diabetes) therefore having an impact on the actual service provisioning.

On the level of care pathways and service provisioning, two additional metaphors emerge, that further validate significance of supporting navigation in the health space; the map and the passengers. The map in an ordinary satnav is often a part of the business model of the device manufacturer. While the acquisition of the device is a singular transaction, the maps need to be updated constantly over the life cycle of the device. In terms of the health navigator, the map can be seen as a similar representation. The field of health care services changes rapidly and in order to acquire the services that meet the citizen’s preferences in terms of price or quality (etc.), an up-to-date compilation, a map, of the services is needed whenever a route in the health space is planned.

While some of this information is available from the sources of open governmental data, the information often needs visualization and refinement. In this, new business opportunities for business emerge, for example in a form of Web 2.0 mashups (cf. [27]). Mashups are web application hybrids where different service and data sources are integrated in similar fashion to the CareHomeMap application (figure 2). Creating these kinds of solutions, and distributing them via application marketplaces, is already a tested and proven distribution mechanism for different mobile health and well-being applications, such as the online dermatology application, Skin of Mine². In terms of the discussed concept, these kinds of solutions can be a way to actually realize the health navigator, or some of its functions.

The passenger metaphor broadens the discussion towards mediation and acting-on-behalf. While the number of electronic applications in the field of health and well-being increases, there will always be individuals who are not willing, or capable, of using them. In order to help these kinds of individuals to conduct their affairs online, supporting mechanisms are needed. From the perspective of navigation in the health space a passenger or in other words, a technology and health literate individual who helps in using the health navigator, can be of the essence. Especially in the today’s ‘wired world’ where ‘traditional’ services are replaced with their electronic counterparts, mediation mechanisms, that help the individuals to conduct their affairs in the way they choose to, are more than welcome.

² <https://www.skinofmine.com/> (accessed: November 19th, 2013)

5 Generalizations of the Concept

The notion of purposeful activity has proven to be a powerful generic concept. It lends itself to be applied according to the principles of S.L. Rubinstein's, L. Vygotsky's and A.N. Leontiev's activity theory, a framework explicitly formulated on the notion of human activity as a unit of analysis (cf. [28; 29]). The route can be seen as activity, whereas the transactions can be interpreted as actions through which the activity is realized. Activity also lends itself well for describing the preserving projects which need action without a visible change in order to avoid undesired changes.

Activity theory itself has been successfully used for interpreting and explaining work within the field of health care [30]. It is not, however, the only application area and the theory can be extended to many other (if not most) human activities. In the close vicinity of the health care are the social services, recreation and even everyday life. These areas that were examined in the context of the original MyWellbeing project as ones into which the generic concept of a purposeful project can be adapted.

There are other areas of life in which citizens can manage their activities with an application similar to the health navigator. One area in particular is highlighted in the context of health and well-being; supporting older people's independent living at home. While the overall objective (or goal) is to continue life at home, it can be realized in multiple concurrent projects. In order to meet the demands associated with the independent life of an elderly person, these projects can include acquiring specific living aids or renovating the house). In terms of services, the emphasis is (in all likelihood) on health care and home help services.

The needs of an elderly person are subject to change. Particularly in terms of services that help in coping with everyday life will probably change over time. The need of services is relative and subject to change; most of us perform daily tasks and maintenance of our homes independently during our working life. Someday our abilities to take care of these mundane tasks are reduced and the tasks become services provided by other parties. Most areas in which help is needed can be conceptualized as purposeful projects. These are operationalized as routes and managed with a solution that is domain-independent and more generic than the health navigator.

Regardless of the field of operation in which the concept is employed, the core functions of the health navigator are still in place. The contracts with the providers must be arranged (incl. financial aspects). The contracts include articulation and execution stages, similar to the diagnostic-therapeutic cycle in the figure 1. The cycle can be reduced to a more generic plan-do-check-act stages already present in the Shewhart Cycle originally defined as a tool for statistical analysis [31]. Even though the life situation of the citizen is an intangible whole, the contracts and the overall service portfolio should be analysed and operated as a coherent assemblage.

This kind of integration is often expressed as a need to manage the number of service providers, for example according to the principles of case management. This notion can also be seen as a function of trust. It is often easier to build the trust with a few than with a troop of miscellaneous service providers. In addition, creating a route

with only few stop points is easier to create and usually more economical to travel (especially in terms of time and effort).

The navigator metaphor and the examples above, demonstrate the integrative power of the original Coper concept. The original concept, and its derivative the health navigator, integrate consistently all episodes of a care pathway, combining the both services and self-services to transactions of equal weight. The concept also integrates multiple parallel routes with each other, for example by making the laboratory results available to all relevant service providers. In this lies another viewpoint to the business logic of the concept; it uses the citizen as a point of integration, complementing the endeavours of the standardizing organizations. The concept also enables building protective privacy mechanisms on the level of the citizen who controls and owns the patient data.

If the needed mechanisms of trust are in place, this function has a potential of lowering the costs born from reorder of laboratory tests and other examinations. This saving can be significant since even though the situation has improved since the 1990's, it is estimated that in 2005 even 30% of tests were reordered in the United States because the result data could not be found [32]. Even though the amount of reorders is decreasing as integration capabilities of health care information systems is in general improving, there are still significant savings to be found [33]. The integrative capabilities have unique take on the partnerships as well since it is effectively a service provider neutral solution, integrating the public, private and the third sector service providers into a collage that is truly personalized health care.

6 Discussion

Similarly to the original concept of The Coper, the circumpunct of the health navigator is the citizen. This fundamental displacement of physician, or some other service provider from the focal point of health service industry, is of the essence when navigation in the health space is depicted. It supports individual's aspirations of becoming empowered in more concrete terms than just ideological assumption. Analysing the empowerment in the context of navigating in the health space, brings up the work by Aaron Antonovsky [34] on salutogenesis; an approach which challenges pathogenesis, taking the health rather than the illness (lack or reduced health) as a cornerstone to one's health and well-being.

Antonovsky also presented a concept of "Sense of Coherence" (SoC) in his works on the role of stress [35] which portrays the situation when one has certain clarity of life and believes that the world is under control. The three main components of the concept are:

- **Comprehensibility.** A belief that things happen in an orderly and predictable fashion, and a sense that one can understand events in life and reasonably predict what will happen in the future;
- **Manageability.** A belief that one has the skills or the ability, the support, the help, or the resources necessary to take care of things, and a sense that things are manageable and within control;

- **Meaningfulness.** A belief that things in life are interesting and a source of satisfaction, and a sense that things are really worth the effort and there is a good reason or purpose to care about what happens.

The health navigator supports comprehensibility by having the citizen's health information available and providing access to general information, such as Current Care Guidelines (CCGs). The proposed chronological properties of arranging transactions in a relationship with each other can also be seen as a factor donating to this component. These properties also support manageability since it is possible to formulate a predefined route through the health space towards a desired destination. In addition, the proposed characteristics in terms of managing contracts with the providers (including the financial arrangements) potentially increase the sense of control. In terms of meaningfulness, the donating factor emerges from the purposefulness and meaningfulness of the selected route. As the health navigator supports systemic evaluation of the goals of the project, and as the citizen is the one formulating (possibly assisted) the goals from her individual(istic) perspective, it is possible to provide a comprehensive picture to the citizen on her current health status and on her current endeavours; to help her in determining her position in relation to the pre-set goal.

7 Conclusions

In today's changing health and well-being landscape, the citizen may face challenges that leave her powerless and lost. To support one's health related endeavours in the world that is becoming more and more 'wired' by nature, and in which the services providers are multiform and often disconnected, a truly personal aid that acts as a point of integration is needed. To depict properties of such a solution, and to highlight the role of the principal actor, the health navigator metaphor was described.

The metaphor was founded on a satnav, a mundane technological innovation that helped in defining what navigation in health space, an over-arching state of health related affairs could entail. The discussed issues included those of a route and a destination, concepts lending a hand to individual-centric data and service integration that is in the core of the health navigator concept. In the surrounding discussion, the role of the citizen as an active subject was touched upon in the context of purposeful activity; an individually driven endeavour, that encapsulates the individual's preferences, values and motivation under an umbrella.

The generic character of health navigator, and the navigation metaphor behind it, addresses some of the current challenges related to the fragmented health care landscape. It seems that the prevalent approach to addressing (technical) challenges associated with the fragmentation is to create centralized data repositories for limited use (such as, for a hospital district). A problem with this kind of monolith health repositories is that there is no connection to everyday life of the citizens; to the expanding sphere of well-being that overlaps with that of health care and is often associated to aspects such as prevention and proactivity. The citizen-centric view built on the navigator metaphor transcends this boundary and is open to everyday life, activities outside the trajectory set by a health care professional that principally bases

on the clinical evidence and set guidelines. While this is, without doubt, a valid point of view, there is more to health than just medicine.

As a conclusion, it must be stated that a solution, even one that is close to the *idealized* model described here, is not on its own enough. There are already interesting solutions³ in the market that give room to individual-centric management of health-related efforts, while leaving much to be desired in terms of privacy, trust and completeness; issues that are in the core of enabling navigation in the health space. In order to promote the citizen into the position of a subject in navigation, a systemic reform that would challenge the existing business models, service provisioning mechanisms and attitudes of individuals regardless of their role, is needed. With the conceptual work performed above, we hope to open up discussion that could lead to changes in the field that would really give the citizens a possibility of being the ones truly in charge of their health and well-being; to be truly empowered.

³ cf. <http://thecarrot.com>; <https://www.healthvault.com>; <http://myphr.com/resources/choose.aspx>
(accessed: December 4th, 2013)

References

1. Teperi, J., Porter, M.E., Vuorenkoski, L., Baron, J.F.: The Finnish health care system: a value-based perspective, Sitra Reports, Vol. 82. (2009)
2. Elhauge, E.: The Fragmentation of U.S. Health Care: Causes and Solutions”, Oxford University Press, U.S. (2010)
3. Pratt, W., Unruh, K., Civan, A., Skeels, M.: Personal Health Information Management, Communications of the ACM, Vol. 49(1) (2006)
4. Lahtiranta, J., Nurminen, M.I.: Pärjäimen toiminnot ja ominaisuudet, In Meristö, T., Muukkonen, P., Nurminen, M.I., Tuohimaa, H. (Eds.), Pärjäin, Omahyvinvointi-hankkeen loppuraportti (Finnish) (2010)
5. Scott, G.C., Lenert, L.A.: What is the next step in patient decision support, Proceedings of the AMIA Symposium 2000, pp. 784–788 (2000)
6. Swan, M.: Emerging patient-driven health care models: an examination of health social networks, consumer personalized medicine and quantified self-tracking, International Journal of Environmental Research and Public Health, Vol. 6, pp. 492-525 (2009)
7. Charles, C., Gafni, A., Whelan, T.: Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model, Social Science, Medicine, Vol. 49, pp. 651-661 (1999)
8. Hogg, C.: Patients, Power, Politics, From Patients to Citizens, SAGE Publications, London (1999)
9. Torkkola S.: Media sairastaa, Tiedepolitiikka, Vol. 2001 (3), pp. 31-40 (2001)
10. Rodwin, M.: The case for public ownership of patient data, Journal of the American Medical Association, Vol. 302(1), pp. 86-88 (2009)
11. Lee, L.M.: Ethical collection, storage, and use of public health data, Journal of the American Medical Association, Vol. 302(1), pp. 82-84 (2009)
12. Rodwin, M.: Patient data: property, privacy, the public interest, American Journal of Law, Medicine, Vol. 36, pp. 586-618 (2010)
13. Eups20: An Open Declaration on European Public Services, <http://eups20.wordpress.com/the-open-declaration/> (accessed: 2.2.2012) (2010)
14. Bommel van, J.H.: Introduction and Overview, In: Bommel van, J.H., Musen, M.A. (Eds.), Handbook of Medical Informatics, Springer, pp. 3-17 (1997)
15. Haynes, R.B., Deveraux, P.J., Guyatt, G.H.: Clinical expertise in the era of evidence-based medicine and patient choice, Evidence-Based Medicine, Vol. 7(2), pp. 28-36 (2002)
16. NHS: Outpatients: One Stop Models of Care, http://www.improvement.nhs.uk/heart/sustainability/outpatients/one_stop.html (accessed: 3.12.2013) (2013)
17. Curry, J.M., McGregor, C., Tracy, S.: A Systems Development Life Cycle Approach to Patient Journey Modeling Projects, In: Kuhn, K.A., Warren, J.R., Leong, T. (eds.) MEDINFO 2007: Proceedings of the 12th World Congress on Health (Medical) Informatics: Building Sustainable Health Systems, IOS Press (2007)
18. Lahtiranta, J.: Changing Nature of Best Practices in eHealth, in: Salmela, H., Sell, A. (Eds.), “Nordic Contributions in IS Research”, Second Scandinavian

- Conference on Information Systems, SCIS 2011, Lecture Notes in Business Information Processing, Vol. 86, Springer-Verlag GmbH Berlin Heidelberg, pp. 84-97 (2011)
19. Aujoulat, A., d'Hoore, W., Deccache, A.: Patient empowerment in theory and practice: polysemy or cacophony?, *Patient Education and Counseling*, Vol. 66, pp. 13-20 (2007)
 20. Davidko, N.: The concept of DEBT in collective consciousness (a socio-historical analysis of institutional discourse, *Studies About Languages*, Vol. 19, pp. 78-88 (2011)
 21. Ubel, P.A., Loewenstein, G., Jepson, C.: Whose quality of life? A commentary exploring discrepancies between health state evaluations of patients and the general public, *Quality of Life Research*, Vol. 12, pp. 599-607 (2003)
 22. Banks, P.: Case management, In: Nies, H., Berman, P.C. (Eds.), *Integrating Services for Older People, A Resource Book for Managers*, European Health Management Association (EHMA), Ireland, pp. 101-112 (2004)
 23. Stevenson, F.A.: General practitioners' views on shared decision making: a qualitative analysis, *Patient Education and Counseling*, Vol. 50, pp. 291-293 (2003)
 24. Fierz, W.: Challenge of personalized health care: To what extent is medicine already individualized and what are the future trends?, *Medical Science Monitor*, Vol. 10(5), pp. 111-123 (2004)
 25. Middleton, S., Barnett, J., Reeves, D.: What is an integrated care pathway, What is...? Series, Vol. 3(3). Hayward Group Plc., U.K. (2001)
 26. Coiera, E.: *Guide to Health Informatics*, 2nd Edition, Arnold, U.K. (2003)
 27. Laudon, K.C., Traver, C.G.: *E-Commerce: Business, Technology, Society*, 5th Edition, Prentice Hall, New Jersey (2009)
 28. Sobkin, V.S., Leontiev, D.A.: The beginning of a new psychology: Vygotsky's psychology of art, In: Cupchik, G.C., László, J. (Eds.), *Emerging Visions of the Aesthetic Process: Psychology, Semiology and Philosophy*, Cambridge University Press, Australia, pp. 185-193 (1992)
 29. Kaptelinin, V., Kuutti, K., Bannon, L.: Activity theory: Basic concepts and applications. A summary of a tutorial given at the east west HCI95 conference, *Lecture Notes in Computer Science*, Vol. 1015/1995, pp. 189-201 (1995)
 30. Engeström, Y.: Activity theory as a framework for analyzing and redesigning work, *Ergonomics*, Vol. 43(7), pp. 960-974 (2000)
 31. Best, M., Neuhauser, D.: Walter A Shewhart, 1924 and the Hawthorne factory, *Quality and Safety in Health Care*, Vol. 15, pp. 142-143 (2006)
 32. Gerntholtz, T., Heerden van, M.V., Vine, D.G.: Electronic medical records – why should you consider implementing an EMR, *Continuing Medical Education*, Vol.25(2), pp. 24-28 (2007)
 33. Hebel, E., Middleton, B., Shubina, M., Turchin, A.: Bridging the Chasm: Effect of Health Information Exchange on Volume of Laboratory Testing, *Archives of Internal Medicine*, Vol.172(6), pp. 517-519 (2012)
 34. Antonovsky, A.: *Health, Stress and Coping*, Jossey-Bass Publishers, San Francisco (1979)
 35. Antonovsky, A.: *Unraveling The Mystery of Health - How People Manage Stress and Stay Well*, Jossey-Bass Publishers, San Francisco (1987)