A Health Collaborative Network focus on Self-care Processes in Personal Assistant Practice

Mª Victoria de la Fuente[1], Lorenzo Ros[1],

[1] U.Politécnica de Cartagena, E.T.S.I.I., Campus Muralla del Mar,
30202 Cartagena, Spain
marivi.fuente@upct.es , lorenzo.ros@upct.es

Abstract. Public health is oriented to the management of an adequate health atmosphere which acts directly on health, as well as health education work and the supervision of environmental health threats. The work presented in this paper aims to reduce inequality, and give disabled people the tools to be integrated more effectively, reducing social exclusion, removing obstacles and barriers, and facilitating mobility and the use of technology. The work is planned to design a special healthcare collaborative network as the best solution for addressing the needs of the disabled self-care and health care community through the creation and implementation of an interconnected, electronic information infrastructure and adoption of open data standards.

Keywords: Self-care processes, Healthcare community, collaborative network.

1 Introduction

The European Union has recognized that particular attention needs to be focused on manifold issues concerning the disabled. Today the number of people with disabilities and chronic health conditions represents over 15% of the EU population. Article 26 of the EU Charter of Fundamental Rights, recognizes the right of disabled people to "benefit from measures designed to ensure their independence".

The increase in the life expectancy indicator shows that the EU will suffer a gradual increase in self-care necessities, either independent or with a personal assistant.

The HOMDISCARE Project approach is the implementation of self-care best practices through the establishment of a health care collaborative network (Public Health European Agency grant projects focused on Best Practices definition).

With the HOMDISCARE project and the design of the healthcare collaborative network, several EU members will be able to reduce care costs, through implementing services that are highly cost efficient and give the population the same, or better, care service as they are currently receiving.

If the quality of the service is not adequate it could increase the time that the disabled person will require support from the health care services. People feel safer when they are in a well-known area, experience services of high quality, have assistants that are close to them and have all the care system "looking after" them and their progress; goals that could be better achieved through the healthcare collaborative

network. With the collaborative network, access to long-term care and support services are high priorities; other factors to consider also include reducing the heavy burden of disease, minimizing its economic and social consequences and health inequality.

The paper is organized as follows. Section 2 presents the challenges and related work to health care systems and medical information and data exchange techniques. Section 3 discusses the objectives, the integration methodology, and the framework for the self-care collaborative network to be developed in the HOMDISCARE project. Section 4 proposes the architectural design and components of the self-care collaborative network. Section 5 presents the principal conclusions, goals, and benefits for mid- and long-term for the HOMDISCARE project.

2 Information Challenges in the Health Sector

These are exciting times in healthcare. This industry is in the midst of a dynamic era in which significant developments in technology can offer innovative opportunities for health or care improvements on a national and global level [2,14].

Current health care systems are structured and optimized to react to crisis and managing illness. However, Health Information exchange programs are in their infancy in most settings [8], and both need to be coordinated to be evolutionary in their own scope and function. In this sense, the medical community wants to develop new and intelligent medical information systems [9], alongside monitoring systems and wireless sensor networks, which permit the application of new technologies for the observation and control of not only illness, but also wellness, of diverse population group [11].

The current systems for collecting, transmitting and exchanging health care data are evolving; however interoperability across sector stakeholders does not exist [8,9,10]. Furthermore, data standards for coding, sharing and structuring health care information are neither fully developed nor implemented. The health sector professionals collect data in a variety of ways, relying on mail or fax capabilities to transmit them.

Without action, health care stakeholders will continue to struggle, with large gaps in the information that is needed at the patient's bedside, in the office, at local and national public health departments; and EU agencies are under the challenge of acting on health detection and monitoring of diseases and health conditions.

New health information systems should be designed within a framework (service-oriented architecture and web services) which allows planning, design, implementation and integration of digital healthcare applications, and these digital healthcare applications must flexible and responsive enough to be able to meet requirement and evolvement.

3   Working towards a solution for the delivery of self-care processes

In the 90's, the concept of the social model of disability was defined [12,15]. This model regards disability as resulting from the interaction between individuals and their respective environments rather than as something within the individual.

Disabled people themselves say that impairments are relevant to them and that the elimination of impairment is desirable. People with impairments recognise the barriers, however, they do not want to be classified as "the disabled". What disabled people want are their rights, their full entitlement to resources, policies ensuring that the environment facilitates their participation, their autonomy and their emotional life [15].

Alongside these wishes, and in line with the social model of disability, a health platform that offers high quality health care, medical treatment and daily care services to special needs groups (elderly, frail and disabled populations) should be established [16]. The importance of quality of life has originated from the appearance of national and international associations (e.g., the InterRAI [7]), who carry out special collaborative efforts with formal and informal professional carers and health home care users [16].

Health inequalities between regions and countries in the EU [5,16], are mainly due to great differences in national cultures, health care systems, and socio-economic disparities. It must also be taken into account that there are different welfare state regimes and different modes of proposing social inclusion for special population groups, elderly and people with chronic illness and disabilities [5,6]. To close the gap in health care between EU countries the harmonization of long-term care policies in Europe is necessary, coordinating the different Public Health Delivery Systems [10].

As such, many healthcare stakeholders have recognized the need for improved health care systems, with reductions in the cost of the way the care is provided. This is evident in the EU where the initiatives have been approved by parliament, or even the annual call of the Public Health European Agency.

3.1   Self-care processes in a personal assistant practice collaboration network project

As previously stated, the HOMDISCARE project aims to reduce inequality and give disabled people the tools to be integrated more effectively. To these means, this project starts with the analysis of self-care processes in several European countries and will develop a methodology to integrate those processes into the care system.

Disability policies are, essentially, the responsibility of the EU member states. While respecting this subsidiary principle, the European Commission does have an important role to play in the disability field, strengthening the cooperation between EU member states and other Member States [3].

Ensuring that everyone has access to high-quality health care is an essential element of the European social model. People who need medical or social care should be able to get it, regardless of their income or wealth, and the cost of such care should not cause poverty to the care recipients or their relatives [4].

On page 8 of "Enabling good health for all" [1], we can read: "European Citizens need reliable and user friendly information about how to stay in good health and the effects of lifestyle on health. When they fall ill, they need authoritative information about their condition and treatment options to help them make decisions. Enabling citizens to make the right choices is indispensable". These three principles ensure and encourage the proposal presented, and demonstrate the added value at European level.

The HOMDISCARE project makes an innovative contribution to the processes available to disabled self-care and health care community in Europe. The results of the project should improve the disabled "quality of life" through:

- Reducing the stress suffered by the Disabled and their care providers involved in home care processes.
- Providing specific tools for the care needs of citizen groups in the self care sector.

In conclusion, improving self-care practices through increasing the value of the care providers increases wealth, not only to the target groups but also to the care providers and other citizen groups.

A recent study, ADHOC-Aged in Home Care [16], carried out in a European setting has characterized home care users, and analyzed the effects of service provision. The presented conclusion is oriented to the exchange of information about users of home care services in Europe. In that sense, the HOMDISCARE project proposes the development of an innovative assessment instrument, and the wide application of the data collected from it is an indispensable tool for providing the necessary information for the move towards the harmonization of healthcare systems and policies in Europe.

The Health-Care Collaborative Network will be focused on coordinating operations (processes and services) in order to reach the target of each process: assistance and self-care practices to customers(target groups).

This Operation System model for the health-care collaborative network must be structured in several levels (Department, Organization, and Area levels) in order to enquiry react to the demand of products and services from the target groups, to achieve technical and organizational efficiency and efficient use of assigned resources and customer satisfaction, to improve business environment by means of regulation of life styles, technology, human resources and services, and financing activities and establishment of political priorities for resources allocation.

For the development of a self-care collaborative network that allows an appropriate paradigm and approach for different healthcare information systems of EU members integration and collaboration, the research team is working with the ERE-GIO methodology [13], based on Integrated Information Architectures, and the experience of the Research team in designing and managing Several Health Care Information systems.

The ERE-GIO methodology (Figure 1) presents a life cycle approach based on the "as-is" model and "to-be" model. This model will be used to develop the methodology for self-care processes in global health care. This double-model methodology will also be used to integrate the methodology and the platform that will support self-care processes, analyzing the performance and constraints of the disabled self-care prototype and further consolidation of the step-by-step HOMDISCARE methodology.
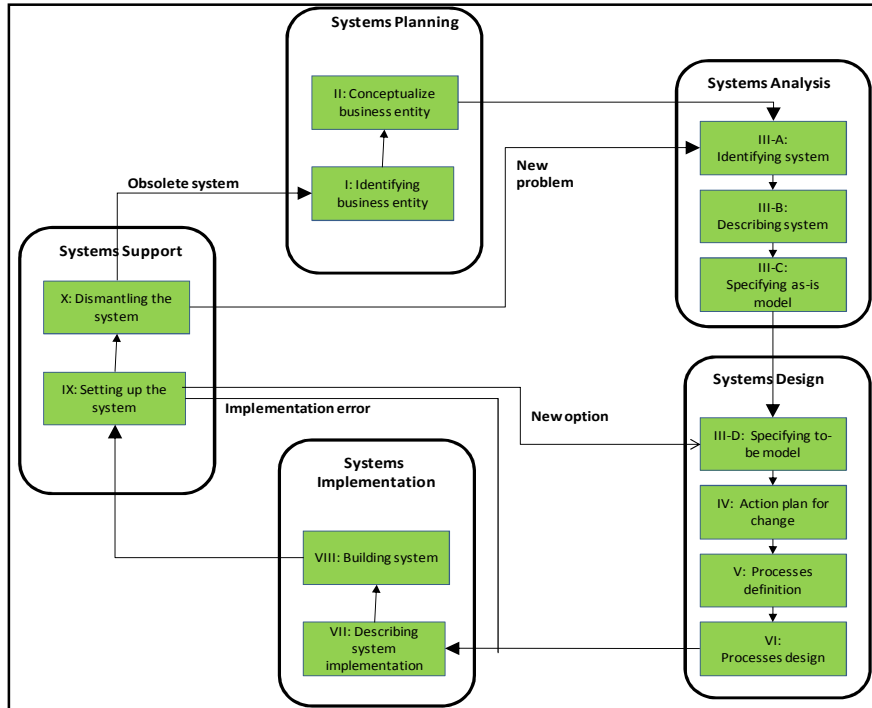
Fig. 1. Phases and stages of the ERE-GIO methodology.

3.2 Developing an interconnected self-care information infrastructure

There is an obvious necessity to analyse the existing information system in the environment where the development of the collaborative network of self-care is proposed. The fundamental characteristics that the said network proposes are:

- Data come from existing clinical systems and are not stored externally.
- The fact that data are coded and transmitted by using open standards makes critical data sets accessible, efficient and usable by various data consumers.
- Data elements are existing priorities for medical insurers, providers and others.
- Privacy, security and business rule functionality to identify key health events included in design requirements, and processed information will be passed back to the provider at the same time as it is sent to medical insurers.
- Openness to participation: any provider, medical insurer, national or local association that wishes to participate is able to, because the open standards provide a common basis for exchange of information.
- Resulting health information linkages for standards based reporting from clinical information systems is a step on the critical path toward national health information infrastructure.
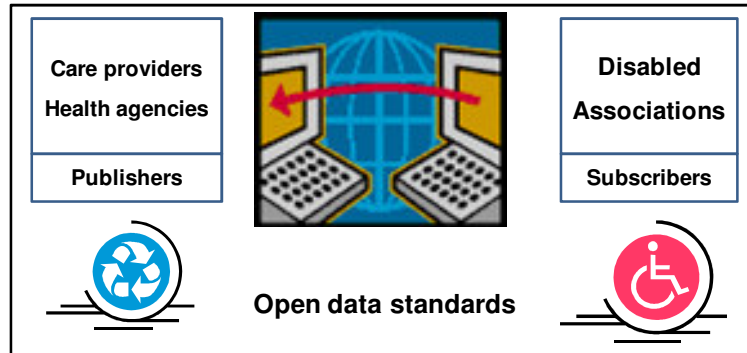
Fig. 2. Interconnected electronic information infrastructure.

To summarize, the collaborative network focuses on catalyzing specific actions of the health care organizations (including providers, payers, public health organizations, pharmaceutical companies, information technology suppliers, etc.) with the aim to accelerate the adoption of clinical data standards and to enable the development of an international, interconnected, electronic self-care information infrastructure (Figure 2).

4   The Architectural Design of the Self-care Collaboration Network

The architectural design for this collaborative network is made up of three major components for data transfer and exchange (see Figure 3):
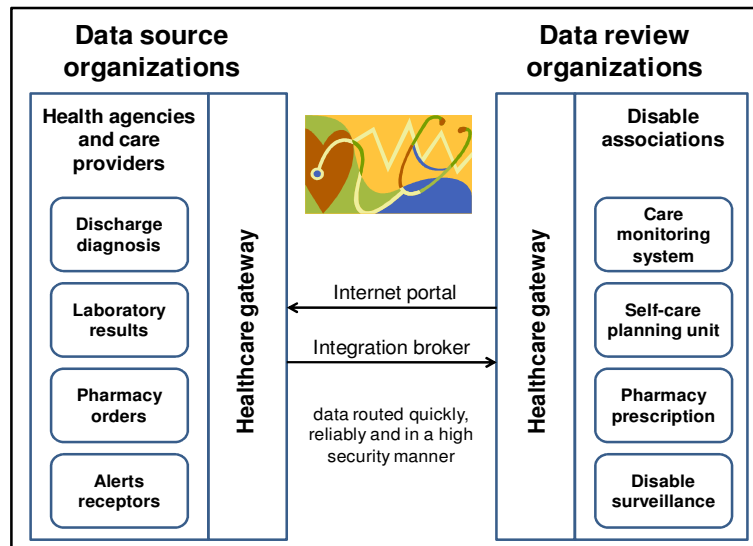

Fig. 3. Project architecture for Self-Care Collaborative Network.

- An internet portal, which allows participants to identify and configure the type of clinical information they wish to receive (subscribe) or are willing to provide (publish).
- An integration broker, which transfers messages between publishers to authorized subscribers.
- A gateway, which connects the participant's systems to the network.
- At the participant's site the gateway filters, links, and maps data elements are based on business rules that they establish.

Data are transferred between participants (Publishers and Subscribers) via secure communications channels, with firewall rules at all end points that disallow unrecognized traffic trying to traverse the participant's system infrastructure.

5 Conclusions

Alongside the principal objective of the HOMDISCARE project, design and the start of work of the Healthcare Collaborative Network, the research team is pursuing a longer-term goal that is focused on a wide implementation of the Collaborative Network within the EU countries' healthcare systems. This current initiative focuses on a set of goals that:

- Creates an internet-based information network that enables private and safeguard transmission of healthcare data.
- Deploys, on a European level, the Self-care Collaborative Network (SCN) methodology to a larger healthcare community.
- Changes the way in which the healthcare system collects, disseminates and analyzes care data.
- Provides a foundation for a rapid response to bio-surveillance, adverse care events and inappropriate care.
- Enables advanced and more efficient interaction between care professionals and self-care patients.

As the Self-care Collaborative Network project finishes, it will hopefully accomplish the following benefits:

- Improve response time for bio-surveillance
- Reduce administration
- Enable rapid ability to aggregate and share data
- Submit clinical data
- Provide a secure environment
- Improve existing applications

If successful, the healthcare industry will have a network that enables not only interoperability, but more importantly, professional collaboration. This, in turn, will allow stakeholders to achieve the goals of reducing costs and response time to adverse events, of patients located in their own homes, and providing caregivers with the information they need to have a positive impact on the care of individual patients.

References

1. Byrne, D.: Enabling good health for all. A reflection process for a new EU Health Strategy (2004), http://ec.europa.eu/health/ph_overview/strategy/health_strategy_en.htm
2. CCBH Community Profile – Health Collaborative Network (HCN), http://ccbh.ehealthinitiative.org
3. Commission of the European Communities. Situation of disabled people in the European Union: the European Action Plan 2008-2009. Brussels (2007), http://ec.europa.eu/social/main.
4. Council of the European Union. Joint Report on Social Protection and Social Inclusion 2008. Brussels (2008), http://ec.europa.eu/employment_social/spsi/health_and_lt_care_en.htm.
5. Eikemo, T., Bambra, C., Judge, K., Ringdal, K.: Welfare state regimes and differences in self-perceived health in Europe: multilevel analysis. Social Science & Medicine 66, 2281--2295 (2008)
6. Gannon, B., Nolan, B.: The impact of disability transitions on social inclusion. Social Science & Medicine 64, 1425--1437 (2007)
7. InterRAI Collaborative network, http://www.interrai.org
8. Johnson, K., Gadd, C.: Playing smallball: Approaches to evaluating pilot health information exchange systems. Journal of Biomedical Informatics 40, S21--S26 (2007)
9. Kwon, P., Kim, H., Kim, U.: A study on the web-based intelligent self-diagnosis medical system. Advances in Engineering Software 40, 402--06 (2009)
10. Mays, G., Smith, S., Ingram, R., Racster, L., Lambert, C., Lovely, E. Public Health Delivery Systems: Evidence, Uncertainty, and Emerging Research Needs. American Journal of Preventive Medicine 36, 256--265 (2009)
11. Milenkovic, A., Otto, C., Jovanov, E.: Wireless sensor networks for personal health monitoring: Issues and implementation. Computer Communications 29, 2521--2533 (2006)
12. Oliver, M.: The politics of disablement. Macmillan, London (1990)
13. Ros, L., de la Fuente, M.V., Ortiz, A.: Enterprise Engineering versus Cyclic Re-engineering Methods. In: Proceedings of the 13th IFAC Symposium on Information Control Problems in Manufacturing (INCOM '09), (2009).
14. Samaras, G., Horst, R.: A systems engineering perspective on the human-centered design of health information systems. Journal of Biomedical Informatics 38, 61--74 (2005)
15. Shakespeare, T., Watson, N.: The social model of disability: an outdated ideology? Research in Social Science and Disability 2, 9--28 (2001)
16. Sørbye, L., Garms-Homolová, V., Henrard, J., Jónsson, P., Fialová, D., Topinková, E., Gambassi, G.: Shaping home care in Europe: The contribution of the Aged in Home Care project. Maturitas doi:10.1016/j.maturitas.2008.12.016 (2009)