



TUUCS

Janne Lahtiranta

New and Emerging Challenges of the ICT-Mediated Health and Well-Being Services

TURKU CENTRE *for* COMPUTER SCIENCE

TUUCS Dissertations
No 176, June 2014

New and Emerging Challenges of the ICT-Mediated Health and Well- Being Services

Janne Lahtiranta

To be presented, with the permission of the Faculty of Mathematics
and Natural Sciences, for public criticism in the Auditorium Beta on
the 12th of June, 2014 at 12:00.

University of Turku
Department of Information Technology
FI-20014 Turku
Finland

2014

Supervised by

Professor Sampsa Hyysalo
School of Arts and Design
Department of Design
Aalto University
Helsinki, Finland

Ph.D. Kai Kimppa
Turku School of Economics
Department of Management
University of Turku
Turku, Finland

Reviewed by

Dr Penny Duqueno
School Science and Technology
Middlesex University
London, UK

Dr N. Ben Fairweather
Centre for Computing and Social Responsibility
De Montfort University
Leicester, UK

Opponent

Professor Iordanis Kavathatzopoulos
Department of Information Technology
Uppsala University
Uppsala, Sweden

The originality of this thesis has been checked in accordance with the University of Turku quality assurance system using the Turnitin OriginalityCheck service.

ISBN 978-952-12-3068-4
ISSN 1239-1883
Turku 2014



"The Radio Doctor". A cover page from a popular science magazine of the mid-1920s¹.

¹ Gernsback, H. (1924), "The radio doctor - maybe", *Radio News*, April 1924, cover.

Abstract

This monograph dissertation looks into the field of ICT-mediated health and well-being services. Through six chapters that extend the work done in the reviewed and published articles, the dissertation focuses on new and emerging technologies, and to impact of their use on the beneficiary; the individual who eventually derives advantage from the services. As the field is currently going through major changes particularly in the OECD countries, the focus is on short-term developments in the field and the analysis on the long term developments is cursory by nature.

The dissertation includes theoretical and empirical elements. Most of the empirical elements are linked to product development and conceptualization performed in the national MyWellbeing project that ended in 2010. In the project, the emphasis was on conceptualization of a personal aid for the beneficiary that could be used for managing information and services in the field of health and well-being services. This work continued the theme of developing individual-centric solutions for the field; a work that started in the InnoElli Senior program in 2006.

The nature of this thesis is foremost a conceptual elaboration based on a literature review, illustrated in empirical work performed in different projects. As a theoretical contribution, this dissertation elaborates the role of a mediator, i.e. an intermediary, and it is used as an overarching theme. The role acts as a 'lens' through which a number of technology-related phenomena are looked at, pinned down and addressed to a degree. This includes introduction of solutions, ranging from anthropomorphic artefacts to decision support systems that may change the way individuals experience clinical encounters in the near-future.

Due to the complex and multiform nature of the field, it is impractical and effectively impossible to cover all aspects that are related to mediation in a single work. Issues such as legislation, financing and privacy are all of equal importance. Consideration of all these issues is beyond the scope of this dissertation and their investigation is left to other work. It follows from this that the investigation on the role is not intended as inclusive one. The role of the mediator is also used to highlight some of the ethical issues related to personal health information management, and to mediating health and well-being related issues on behalf of another individual, such as an elderly relative or a fellow member of a small unit in the armed forces.

The dissertation concludes in a summary about the use and functions of the mediator, describing some potential avenues for implementing such support mechanisms to the changing field of ICT-mediated health and well-being

services. The conclusions also describe some of the limitations of this dissertation, including remarks on methodology and content.

Keywords: eHealth; Health Care Information Systems; Electronic Health Record; Personal Health Record; Personal Health Information Management

Tiivistelmä

Tämä monografiaväitöskirja tarkastelee sähköisiä terveys- ja hyvinvointipalveluja. Väitöskirja koostuu kuudesta luvusta, jotka laajentavat aiemmin julkaistuissa artikkeleissa raportoitua tutkimusta. Tutkimuksen keskiössä ovat uudet teknologiat ja teknologian uudenlainen käyttö, sekä näiden vaikutus palvelujen loppukäyttäjään. Koska terveys- ja hyvinvointipalvelujen kenttä on tällä hetkellä murroksen tilassa etenkin OECD-maissa, tutkimus rajoittuu lyhyen ajan mahdollisiin muutoksiin kentällä eikä pitkäaikaisia vaikutuksia tarkastella syvällisesti.

Väitöskirja sisältää teoreettisia ja empiirisiä osioita. Valtaosa empiirisistä osiosta liittyy kansallisessa OmaHyvinvointi-projektissa tehtyyn tuotekehitykseen ja konseptin muodostukseen. Vuonna 2010 päättyneessä projektissa luotiin konsepti tietotekniselle ratkaisulle, jota terveyspalvelujen loppukäyttäjän on mahdollista käyttää henkilökohtaisten terveys- ja hyvinvointitietojen hallintaan. Tämä työ oli jatkoa kansalais-keskeisten ratkaisujen kehittämiseksi terveys- ja hyvinvointipalveluissa, joka alkoi InnoElli Senior -ohjelmassa vuonna 2006.

Empiirisestä työstä johtuen, väitöskirja on luonteeltaan konseptoiva. Lähtökohtaisesti työ perustuu kirjallisuuskatsaukseen, jota on kuvattu empiirisen työn kautta erilaisissa projekteissa. Teoreettisena työnä väitöskirjassa esitelleen välittäjän rooli joka luo yhtymäkohdan eri projekteissa tehdyille työlle. Rooli toimii eräänlaisena ”linssinä”, jonka avulla erilaisia teknologiaan liittyviä ilmiöitä esitellään ja tarkastellaan. Nämä ilmiöt pitävät sisällään ihmisenkaltaiset (antropomorfiset) sovellukset, sekä erityyppiset päätöksentekoa tukevat sovellukset, joilla on mahdollisesti vaikutusta terveys- ja hyvinvointiasiointiin lähitulevaisuudessa.

Terveys- ja hyvinvointipalvelujen monimutkaisesta luonteesta johtuen, on epäkäytännöllistä ja käytännössä mahdotonta tarkastella välittäjän roolia kattavasti eri lähtökohdista yksittäisessä työssä. Tästä syystä mm. lainsäädännön, rahoitusmallien ja yksityisyyden suojan tarkastelu on rajattu tutkimuksen ulkopuolelle vaikka kaikki nämä asiat ovat merkityksellisiä välittäjän roolin tarkastelulle. Tästä rajauksesta seuraa, että välittäjän roolin tarkastelua ei ole tarkoitettu kaiken kattavaksi. Välittäjän roolia hyödynnetään kuitenkin valikoitujen eettisten haasteiden kuvaamiseen, jotka liittyvät sähköisiin terveys- ja hyvinvointipalveluihin, sekä palvelujen käyttöön toisen henkilön, kuten ikääntyneen sukulaisen tai oman sotilasyksikön toisen jäsenen puolesta.

Väitöskirja päättyy yhteenvedoon välittäjän roolista ja toiminnoista. Yhteenvedossa kuvataan joitakin mahdollisuuksia välittäjän roolin mukaisen tukimekanismin toteuttamiselle terveys- ja hyvinvointipalveluissa, esitellään

tutkimustyön rajoituksia sekä arvioidaan tutkimustyön sisältöä ja käytettyjä menetelmiä.

Avainsanat: Sähköiset terveys- ja hyvinvointipalvelut, terveyden tietojärjestelmät, henkilökohtainen terveystietojen hallinta, henkilökohtainen terveystaltio

Acknowledgements

First of all, I would like to thank my supervisors Kai Kimppa and Sampsa Hyysalo, and instructors who have changed over the years (Professor Emeritus Timo Järvi, Professor Emeritus Markku I. Nurminen and Professor Tapio Salakoski). Of these knowledgeable individuals I have worked the longest with Professor Emeritus Markku I. Nurminen who taught me critical thinking and crucial academic skills, and encouraged me to do research in the areas that are close to my heart as a practically oriented researcher and an employee in the industry. Thank you for believing in me.

My thanks go to my reviewers Dr Penny Duquenoy and Dr N. Ben Fairweather. Without you this work would have not been brought into completion. I would also like to extend my gratitude to my opponent Professor Iordanis Kavathatzopoulos. His comments on my work were insightful and helping.

I would also like to thank my colleagues in the University of Turku. First and foremost, I would like to thank lecturer Antti Tuomisto, Kimmo Tarkkanen, Jani Koskinen and Pekka Reijonen, my long-term co-workers in the University. In particular, I owe my gratitude to Antti Tuomisto who brought me to academia from the private sector. As I have worked more than a decade of work in the field of health and well-being technologies, I have learnt to appreciate the accumulated knowledge and wisdom of the experienced individuals who have worked in the field much longer than I have. Of these domain experts, I would like to thank Professor Reima Suomi and Professor Sanna Salanterä who have helped me over the years.

For their support over the years in the Turku Science Park Ltd., I would like to thank my managers and my colleagues. In particular, I would like to thank Mr. Jaakko Kuosmanen, Mrs. Sirpa Simola and N. Tapani Saarinen who enabled my dual role as a researcher, and an employee of the industry. As a related matter, I would also like to thank members of the IKITIK consortium who have helped me to understand inner workings and business logic of the health care sector.

During the course of my work, I have also received a great deal of concrete support from Turku Centre of Computer Science (TUCS) and Turku University Foundation. I would like to thank their current and previous leaders for their help. I'm also grateful for having the privilege of working with various research units, especially IISHSS and Laboris, and with the newly formed Turku Information Systems Research Alliance (TISRA).

For the last, I would like to thank my family and friends for their support. Above all, I would like to thank my wife Päivi for her support during my endeavours.

List of original publications extended in the monograph dissertation

- I. Lahtiranta, J. & Kimppa, K. (2006), "Elderly people and emerging threats of the Internet and new media", in: Suomi, R., Cabral, R., Hampe, J.F., Heikkilä, A., Järveläinen, J. & Koskivaara, E. (Eds.) *Project E-Society: Building Bricks*, 6th IFIP International Conference on e-Commerce, e-Business, and e-Government, October 11-13, 2006. Turku, Finland. Springer, 2006. pp. 13-21.
- II. Lahtiranta, J. (2008), "Emerging roles in eHealth", in: Suomi, R. & Apiainen, S. (Eds.) *Promoting Health in Urban Living*, 2nd International Conference on Well-being in the Information Society, August 19-21, 2008. Turku, Finland. TUCS General Publication No. 49, pp. 141-152.
- III. Lahtiranta, J. (2008), "Current Challenges of Personal Health Information Management", *Journal of Systems and Information Technology*, pp. 230-243.
- IV. Lahtiranta, J. (2011), "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.
- V. Lahtiranta, J. & Kimppa, K. (2006), "The Use of Extremely Anthropomorphized Artefacts in Medicine", *International Review of Information Ethics*, Vol. 5, pp. 13-18.
- VI. Lahtiranta, J. & Kimppa, K. (2005), "'Some Ethical Problems Related to the Near-Future Use of Telemedicine in the Armed Forces", in: Collste, G., Hanson, S.O., Rogerson, S. & Ward Bynum, T. (Eds.) *Ethcomp 2005: Looking Back to the Future*, September 12-15, 2005. Linköping, Sweden.

To my beloved family

Contents

1. Introduction	1
1.1 Motivation for the Study.....	2
1.2 Research Questions and Objectives.....	3
1.3 The Research Domain	5
1.4 Conceptual Origins.....	6
1.5 The Research Approach	11
1.6 Structure and Background of the Thesis.....	12
2. Elderly People and Emerging Threats of the Internet and New Media	19
2.1 Macro-Level Trends and Development of Electronic Services	23
2.2 Electronic Services and Elderly People	26
2.3 Emerging Risks and Threats for the Elderly People	33
2.4 Recommendations	40
2.5 Conclusions	49
3. Emerging Roles In the ICT-mediated Health Care.....	53
3.1 The Roles.....	58
3.2 The Patient.....	64
3.3 The Citizen.....	66
3.4 The Customer	68
3.5 The Consumer	70
3.6 Interrelationships of the Roles in the ICT-Mediated Health Care.....	73
3.7 Recommendations	81
3.8 Conclusions	86
4. Current Challenges of Personal Health Information Management	91
4.1 Research Method.....	93
4.2 Personal Health Information Management Today	94
4.3 Current Challenges in PHIM	98
4.4 PHIM of Tomorrow?	104
4.5 Recommendations	113
4.6 Conclusions	117

5.	Changing Nature of Best Practices in eHealth	121
5.1	Best Practices in Health Care	123
5.2	Consumer-Centric eHealth Solutions of Today.....	127
5.3	Computerization of Best Practices in Health Care.....	129
5.4	Recommendations.....	133
5.5	Conclusions	135
6.	Anthropomorphic Artefacts of ICT in Health Care and Medicine.....	139
6.1	Anthropomorphism, the Good or the Bad?.....	140
6.2	Anthropomorphism, Ubiquitous Applications and Care.....	143
6.3	Familiarity and Anthropomorphized Artefacts.....	147
6.4	Optimal Anthropomorphism in Health Care and Medicine?.....	151
6.5	Recommendations.....	156
6.6	Conclusions	158
7.	Telemedicine and Armed Forces – Ethical Questions and Challenges	163
7.1	On Agreements of War	165
7.2	Debatable use of Drugs, Chemical Weapons and Warfare Agents in the Armed Forces.....	167
7.3	Coercion and Armed Forces.....	169
7.4	The Near Future of Telemedicine in the Armed Forces?.....	170
7.5	Potential Threats and Risks.....	174
7.6	Recommendations.....	177
7.7	Conclusions	180
8.	Conclusions	183
	References	195

Abbreviations

3-D	Three-dimensional form or appearance
ADHD	Attention deficit-hyperactivity disorder
ANT	Actor-Network Theory
AR	Augmented Reality
AT	Activity Theory
BISA	Battlefield Information System Applications
BMI	Body Mass Index
BMSIS-T	Battlefield Medical Information System – Tactical
BoK	Body of Knowledge
CCG	Current Care Guidelines
CDSS	Clinical Decision Support System
CP	Citizen Pathway
CPR	Computerized Patient Record
D³	Design for Dynamic Diversity
DARPA	Defense Advanced Research Projects Agency
DDSS	Diagnosis Decision Support System
DG Connect	European Commission Directorate General for Communications Networks, Content and Technology
DG INFSO	European Commission Directorate General Information Society and Media
DoD	Department of Defence
DSS	Decision Support System
DTC	Direct-to-Consumer
EBM	Evidence-Based Medicine
ECG	Electrocardiography
EHR	Electronic Health Record
EMR	Electronic Medical Record
ePHR	Electronic Personal Health Record
ERA	Expert Responsibility Area (Eriytisvastuualue, ERVA)
ES	Enterprise System
FFW	Future Force Warrior project
FIST	Future Infantry Soldier Technology program
FSA	Food Standards Agency
GP	General Practitioner
HIS	Hospital Information System
HL7	Health Level 7 organization
HON	Health on the Net foundation
ICT	Information and Communication Technology
IED	Improvised Explosive Device
IS	Information Systems
ISD	Information Systems Development
Kela	The Social Insurance Institution of Finland (Kansaneläkelaitos)
LOINC	Logical Observation Identifiers Names and Codes
LPR	Local Population Responsibility
LSD	Lysergic acid diethylamide
NLP	Natural Language Processing

OECD	Organisation for Economic Cooperation and Development
PDA	Personal Digital Assistant
PDSS	Patient Decision Support System
PHIM	Personal Health Information Management
PHR	Personal Health Record
PHR-S FM	Personal Health Record System, Functional Model
PIM	Personal Information Management
PSI	Public Sector Information
SDLC	Systems Development Life Cycle
SHA	System of Health Accounts
SHAD	Shipboard Hazard and Defense project
SME	Small and Medium-Sized Enterprises
SSM	Soft Systems Methodology
SWaP	System Size, Weight and Power
WI	Work Informatics
WPSM	Warfighter Physiological Status Monitoring System

Figures

Figure 1.1. MyWellbeing project and the research groups.	14
Figure 1.2. Reworked articles and themes of the dissertation.....	16
Figure 2.1. Households with broadband access, 2006-10, percentage of all households (OECD, 2011a).	19
Figure 2.2. An example of video conferencing (from News@Cisco press release January 28, 2009, http://newsroom.cisco.com/dlls/2009/prod_012809.html).26	
Figure 2.3. The factors affecting the Internet perceived risk components: demographic traits (Liebermann & Stashevsky, 2002, p. 293, figure 1).....	28
Figure 2.4. Layers of information available for different actors (illustration). ...	46
Figure 3.1. A time line indicating the evolution of patient-physician relationship (Kaba & Sooriakumaran, 2007, p. 64).....	54
Figure 3.2. Example of a chain of service in the case of a chronically ill elderly patient (Lehto, 2000, p. 42, Finnish).	57
Figure 3.3. Different roles and ICT-mediated health care.	60
Figure 3.4. Spheres of influence (Pratt et al., 2006, p. 51).	62
Figure 3.5. Eight rungs on a Ladder of Citizen Participation (Arnstein,1969, p.217).	63
Figure 3.6. Tamilnadu advertisement (from: http://adsoftheworld.com/).....	72
Figure 3.7. Roles, influence and constitutive effect (illustration).....	75
Figure 3.8. Cyclic nature of articulation, declaration and execution.....	77
Figure 3.9. Some of the potential service providers in the case of the elderly people (example).	80
Figure 4.1. Stand-alone and networked PHR solutions.	96
Figure 4.2. Knowledge taxonomies and examples (Alavi & Leidner, 2005, p. 171).	102
Figure 4.3. The functionalities of the Coper (author).	107
Figure 4.4. Citizen Pathways, illustration (author)	113
Figure 5.1. Portion of Asbru protocol for the Management of Hyperbilirubinemia in the Healthy Term Newborn (Roomans et al., 2002).....	123
Figure 5.2. Decision rule of Orient et al. for men with abdominal pain. Copyright (c) 2010, Institute for Algorithmic Medicine, Houston, TX, USA.	124
Figure 5.3. Pathways, guidelines, protocols and algorithms (author).	125
Figure 5.4. An updated model for evidence-based clinical decisions (Haynes et al., 2002, p. 37).	130

Figure 6.1. L'Inconnue de la Seine, "the unknown woman of the Seine", picture of the dead girl used in modeling the face of Anne CPR training manikin (Wikipedia Commons).....	139
Figure 6.2. "Rabbi Loew and Golem", ink and pen illustration for Old Czech Tales by Mikoláš Aleš, 1899, (http://www.mikolasales.org , accessed: 25.2.2011).	141
Figure 6.3. Examples of the use of anthropomorphism in telemedicine.	142
Figure 6.4. The "Simroid", a robot that 'feels pain' (from: Mail Online, 2007)	146
Figure 6.5. Anthropomorphic design space for robot heads (ibid., p. 182).....	147
Figure 6.6. The Geminoid F (pictures by Osaka University).....	150
Figure 6.7. Fidelity, components and tasks (a non-mathematical illustration).	154
Figure 7.1. The HULC Exoskeleton by Lockheed Martin.	164
Figure 7.2. Complexity of military medicine, example (Lam, 2007).	173

1. Introduction

The field of health and well-being services is changing quickly and in fundamental ways. In addition to demographic changes, societal changes and economic realities have effectively forced the service providers in the field to face again the age-old dilemma of providing (better) services for a growing number of people in a more economic fashion. At least in the OECD countries there are two fundamental reasons for this. Firstly, the demographic relationship in the population is changing; the ratio between those of working age and those who are not is changing upon the side of the latter. Secondly, the economic relationship is changing; the ratio between the employed and the unemployed is also shifting to a less-fortunate direction.

Especially in the public sector, a partial solution is a centralization of service provisioning that will address the economic aspects of the dilemma (c.f. the recently emerged Expert Responsibility Areas in Finland). This solution looks into the principal factors behind the cost-effectiveness in the field, namely personnel, screening and laboratory test costs. For example, in Finland the health care costs in 2005 were 8.3 % in comparison to Gross National Product, GNP and it indicates a constant increase in the costs since 1995 (Moilainen, et al., 2008, p. 5). As a more recent sample that is based on the OECD System of Health Accounts (SHA), the health care costs in Finland increased steadily over the period of 2005-2009 and the costs in relation to GNP were 9.2 % in 2009. In other words, this indicates a total expenditure of 15.7 billion euros, 2.936 € per resident (ibid.; Ministry of Social Affairs and Health, 2012). Even though the costs have increased over the time, they are still slightly below the OECD average. However, it is estimated that the health care expenditure in Finland will grow faster than GNP, for example, due to ageing population (Kuntaliitto, 2012).

In order to complement organizational changes related to the reorganization of service provisioning, and to address the wide-ranging economic, demographic and societal challenges, new approaches to service supply have been devised. As in other areas of business, a number of these rely on the use of Information and Communication Technology (ICT) as a mediating technology in service transactions (e.g. diagnosis, therapy, etc.). These kinds of approaches that are often technological innovations as well are used increasingly by the public and the private sector, influencing almost every customer of health and well-being services. Most of the new approaches are also linked to global trends in which the balance of power shifts between the service provider and the beneficiary, and which broaden the scope of the services from care to prevention (and from professional care to self-care) as delineated by Hämäläinen et al. (2011).

These trends also have a profound effect on the markets of the sector. While the health care sector in particular has operated principally on the premise of a patient-physician relationship, the new markets are more liberal, or even economically driven. In these markets the role of the beneficiary is more akin to that of a consumer or a customer. This shift in the role of the beneficiary is not just rhetorical; it has an impact on the juridical, regulatory and ethical aspects of service provisioning, even on control mechanisms that were originally put in place to protect the beneficiary. Areas in which these kinds of shifts are evident today include wellness tourism in which the service providers specialize in providing cultural and relaxation programs in addition to individualized care (c.f. Mueller & Kaufmann, 2001).

The use of ICT in the health and well-being services is a multifaceted and a complex issue that has been researched for decades, as long as ICT has been used in the field. While the most of the academic research in the 1970s revolved around the service providers (physician), the later research in the field has taken the beneficiary (patient) into focus, underlining the importance of this principal actor in health related decision making. However, there is still room for research as the use of technology in the field has expanded from hospitals to homes, from doctors to consumers, and from personal computers to pervasive and ambient solutions that constantly monitor, analyse and report the health status of the individual. The use of technology in different walks of life and in different contexts has opened rich avenues for research. The one taken in this dissertation focuses on the new and emerging technologies, and on their use from the perspective of the beneficiary.

The use of technology, and particularly its area of applicability, gives some ground to the investigation on emerging technologies, which in itself is a somewhat contradicting term. As described in (Stahl, et al., 2010), the term 'emergence' can be defined as a "counterpoint to linear and predictable developments" (p. 22) and is by nature a fickle focus for investigation. With a fixed domain, health and well-being, this dissertation attempts to approach the concept with a two-pronged approach. First, the dissertation attempts to shed some light to the use of existing technologies in a new setting, and secondly, it attempts to investigate the use of completely new technologies in a familiar setting.

1.1 Motivation for the Study

As a rule, the academic research on the beneficiary of the health and well-being services has been founded on the patient-physician relationship, a cornerstone in all health related affairs. However, this relationship which started as a priest-

supplicant relationship in ancient Egypt has changed over the time, and it changes still. To capture nuances of this change, the more recent interpretations on the relationship have emphasized equality between the related actors, or even autonomy of the patient (c.f. Childress & Siegler, 1984; Kaba & Sooriakumaran, 2007). It can be argued that this change is linked to global megatrends, such as personalized medicine, shortfall of primary care physicians, payer's influence over treatment decisions, medical tourism, and increased emphasis on prevention (Harvard Business Review, 2012) and to the changes in the attitudes and values of the patients. In addition, the significance of technology, and the recent advances in it (especially in ICT) should be taken into account as well.

Technology is an enabler for new health and well-being markets, and for new approaches to the service supply. It is a common belief, and a generalization, that the new generations are competent and comfortable in the use of technology, and cope well with the changes it brings (c.f. evolution of banking; from tellers to technology). However, these new approaches and markets are rarely universal and they fail to take the users as a whole into account. Even though certain generalizations about the users can be made, for example in terms of technology literacy and associated skills, there will always be groups of people who are not able or willing to adhere to the principles and practices of the often fast-moving technology-enabled service supply. In order to a) better understand these kinds of minority groups on the fringe of the primary audience of the ICT-mediated health and well-being services, and b) to highlight the legal, ethical and societal challenges related to the services as a whole, a research based on the notion of the beneficiary as the primary unit of analysis was conducted.

1.2 Research Questions and Objectives

Investigation into existing health and well-being services from the perspective of the beneficiary highlights some of the key characteristics of today's service provisioning. Firstly, regardless of the on-going centralization efforts, the service provisioning is still fragmented amongst different service providers and service provider units (c.f. Elhauge, 2010). Secondly, especially in the public sector, the beneficiary has limited control (if any) over the way the services are arranged. Even though the technology in the field has matured and offers a multitude of options for service provisioning, it is still the beneficiary who moves from one provider to another, whereas the data often does not. The current situation contradicts global trends at least on two levels.

One: it is often in the interests of the service providers, and the society as a whole, to place the individuals in charge of their health (and in some cases, also in charge of the health of their family members). This change is not only

administrative by nature, but it has proactive elements as well; in the case of a change in the health status, the individuals could (and should), at least in theory, seek professional help beforehand, not when the situation had degraded to a degree of an ailment or disease. With the current fragmented situation, the individuals may be unable to operate within the confines of the mandate placed on their shoulders by the service providers and the society. Simply put, they become “lost in the system”.

Two: there are an increasing number of individuals who are willing to take a more active role in managing their health and well-being. This phenomenon is commonly referred to as “empowerment” and it differs fundamentally from placing the onus of responsibility on the individual (item one above) in terms of motivation and voluntariness. While the consequences of the current situation are similar, leaving individuals unable to cope with the current model of service provisioning, there is another dimension that should be taken into account in the case of empowerment. Active and willing individuals often produce current data on their health and well-being, for example via personal sports computers and similar devices. With the fragmented situation of today, this information rarely reaches the service providers and is therefore effectively excluded from the service provider’s health related (clinical) decision making.

In order to look into this mismatch between the current situation, desired outcomes and current trends, the following research questions are addressed.

1. *How to support aspirations of a willing individual to become an active subject and a principal actor in terms of their health and well-being, and that of their close ones?*
 - a. *Would mediation support these aspirations (when present) in the context of ICT-mediated health and well-being services?*
 - b. *How could that mediation, if desirable, itself be supported?*
2. *What kind of challenges and opportunities emerging technologies bring to the contemporary health and well-being services (especially in the OECD countries)?*

It must be clarified, that even though mediation is an integral part of this dissertation, the primary focus of the research is on the beneficiary. The dissertation looks into the changing field of the ICT-mediated health and well-being solutions of the near future and presents solutions that help the beneficiary to cope with the field. The examination draws strength from challenges the beneficiary may encounter, and introduces solutions that support health and well-being related aspirations of personal nature in the field. The introduced solutions include mediation and the role of the mediator, and other more technologically-oriented ones.

Over the course of six chapters, different aspects of mediation are investigated and different interpretations on the role of the mediator are introduced. Even though the role of the mediator is not principally related to any specific profession, it should be regarded as a position that connects different actors. This calls for investigation of interrelationships between the role, the technology and business. This includes, introduction of new business models and potential avenues for implementing a service that is based on the notion of mediation. However, considering the focus of this dissertation, this examination is intended purely as an overview to provide examples.

Taking the multidisciplinary nature of the domain (e.g. health, well-being and ICT) into consideration, the academic field of information systems (IS) offers a rich variety of different conceptualizations to the research questions when compared to other, more technologically oriented fields, such as software engineering and computer science.

1.3 The Research Domain

The field of information systems has evolved for more than four decades. Over time, different schools of thought have emerged and it is even argued that the field itself has undergone “an identity crisis” during which the nature of the discipline as a distinct field study was questioned (Khazanchi & Munkvold, 2000; 2003). Regardless of the certain turmoil, the field of information systems is an established academic discipline with a well-defined Body of Knowledge (BoK). The BoK of the field today comprises of five knowledge areas (from IS expert’s viewpoint): technical knowledge, application domain knowledge, organizational knowledge, IS application knowledge, and information systems development (ISD) process knowledge (Iivari, et al., 2004). From this perspective, the definition for the field of IS by Khazanchi & Munkvold (2000) is a comprehensive one; it brings aspects of human, organization, social and technology together as a single domain:

“The study of the effective use of information and the potential impact of software systems and enabling information technologies on the human, organizational, and social world”.

Emphasizing the role of the application domain knowledge, contextualized by the organizational knowledge, a highly operational field of work informatics (WI) has emerged (Nurminen, 2006). The field, pioneered by Nurminen addresses the challenges of today’s work that is becoming more and more computerized and dependent on ICT. In the core of WI is the notion of inseparability of computers, people and today’s work. WI uses the basic concepts of knowledge and change; knowledge embedded in ICT-artefacts and

in their skilful use, and change in the work and its organization with their tools and infrastructures (ibid., p. 415). These concepts are used in analysing the processes of the problem domain and the impact of the technology. Even though WI is individual-centric, work is conceptualized in three modalities: individual work, collective work and services. In comparison to a more generic field of IS, this three-tiered view on work provides new avenues to capture different roles individuals potentially have in the context of ICT-mediated services.

The work in this dissertation falls to the field of IS, and more specifically to the field of WI. In addition, it borrows elements from different academic disciplines, such as economics, psychology and social sciences. The underlying approach focuses on the beneficiary and it is coupled with theories of sociotechnical systems and human action therein, including actor-network theory (ANT) and activity theory (AT). While these theories are not promoted in the bulk of the dissertation, their influence is visible when the contribution is evaluated as a whole and the concept of beneficiary-centricity is taken into scrutiny. In this, the basic concepts of activity theory (instruments, subjects and objects) complemented with the mediational role of technology (c.f. Kaptelinin et al., 1995), find a match in the different roles of the beneficiary, the mediator, and technology-enabled activities that revolve around health and well-being.

1.4 Conceptual Origins

Beneficiary-centric approach is not an outcome of this dissertation or a novel approach to organizing health and well-being services. It is an on-going global trend that highlights transitions from one end of a scale to another; from care to prevention, liability to responsibility and health centres to homes. Basically, the trend is all about re-delegation of the field that defines health and well-being, and services that promote them. In relation to this dissertation, the beneficiary-centric approach came to life during the national MyWellbeing² project in which the bulk of the empirical research on the background of this dissertation was conducted (see chapter 1.6. for a description on empirical work).

The goal of the project was to define means and practices for managing individual's health and well-being services, and related information. In the core of the project was the conceptualization of the next generation Personal Health Information Management (PHIM) solution called "The Coper"; an aid that would help individuals to cope with their everyday lives to manage their health related efforts. For inspiration, the project team looked into different individual-centric theories employed in the field of IS. The most influential ones included AT and ANT, theories used in innovation studies, and more generally, in

² <http://omahyvinvointi.utu.fi/index.php?id=70> (accessed: 10.10.2012)

analysing interrelationships between subject and object, nature and society (Miettinen, 1999).

Activity Theory is a conceptual framework that originates from the former Soviet Union. The framework was developed by the Russian psychologists S.L. Rubinstein's, L.S. Vygotsky's and A.N. Leontiev who formulated an idea of human activity as the unit of analysis (c.f. Kaptelinin, et al., 1995; Sobkin & Leontiev, 1992). The theory has been employed throughout the world. For example, in Finland, it has been used for interpreting and explaining work within the field of health care (Engeström, 2000).

The Actor-Network Theory is an approach to social theory and research, originating from the field of science studies. It was pioneered by Michel Callon, Bruno Latour and John Law (Walsham, 1997; Murdoch, 1998). The theory is concerned with investigating social structures and technology as inseparable aspects, without promoting one over another. In the core of the approach is an actor-network, a concept used for depicting how collectives of humans and non-humans come and act together.

In the related empirical work performed after the MyWellbeing project during the currently (fall 2013) on-going Pumppu (Pump in English) project (cf. Lahtiranta & Koskinen, 2013), the ideas of Swedish philosopher Fredrick Svenaeus have gained foothold. In particular, his works on "homelike being-in-the world" (Svenaeus, 2001) used for describing being in "tune" with the surrounding world (Ahlzén, 2011) and therefore in a balance with oneself and everyday life, were included into the palette of examined theories. Particularly, in terms of self-care and motivation the ideas of Svenaeus provided a new insight into the development of the health and well-being services of the near future.

Out of these three influential theories, AT and particularly the works of Vygotsky on the concept of mediated activity (Vygotsky, 1978, p. 54) lead to a realization on the need and the potential of mediation in relation to health and well-being services that are becoming more and more electronic by nature.

On mediation and mediator

There is, and has been for a long time, a mismatch between health service providers and health service users. These groups have been "a world apart" since the formulation of patient-physician relationship that started between a priest and a supplicant in ancient Egypt sometime 4.000 BC. Reasons for this are numerous and multiform, varying from person to person and from time to time. These reasons can be born from power, money, authority, or simply from the fundamental fact that the involved parties do not always understand each other.

Throughout time this gap between the supply and the use, and others like it, have been crossed with the help of knowledgeable individuals proficient in the arts related to the domain in question (health care, banking, etc.). Common examples include, tax consultants, investment advisors, and in the field of health care, patient ombudsmen. These kinds of intermediaries are often related to a specific role, profession or organization, and they serve as examples of supply-side mediation. These intermediaries are often visible and formal, and particularly research on their relation to innovation process is abundant (cf. Howells, 2006, p. 721).

Another form of mediation occurs on the user-side. These kinds of intermediaries less-formal and invisible and they often work on practicalities, such as on the fixing or maintaining technology (ibid.). In literature, these kinds of user-side intermediaries are discussed in relation to technology adoption (“local experts”, Stewart, 2007), use of technology (“technology mediators”, Okamura et al., 1994) and technology customization (“tailors”, Trigg & Bødker, 1994). In the field of health care, the term case manager is often used to depict similar endeavors (Banks, 2004).

Positioning different forms of intermediaries between service supply and use is challenging. In a classification provided by Stewart & Hyysalo (2008, p. 302), content and scale define where the intermediary is positioned. In their analysis, Stewart & Hyysalo use a fourfold table of short-long and thing-fat dimensions to illustrate the nature of an intermediary. For example, an intermediary that links users and suppliers in the context of a specific service can be characterized as “long and thin”. Correspondingly, an intermediary that links a specific group of homogenous actors in a close proximity of a supply network can be characterized as “short and fat”.

The field of health care is complex one, comprising of different health care disciplines and specialties, such as oncology, obstetrics and anaesthesiology. In the field, intermediaries work primarily on the supply-side and their work is performed within the context of a specific role or a profession. It follows from this that the intermediaries are principally “short and thin” and they work within tight specialty boundaries (for example, when working as a member of a multi-professional care team). However, there are exceptions to this generalization, such as the role of a case manager which is supply-side oriented, but by nature “long and thin”. Depending on the setting, a case manager organizes services and treatment for the elderly patients before discharge and for a fixed period of time at people’s own homes (cf. Banks, 2004, p. 103-104).

One interesting form of an intermediary was a family doctor of old (approximately until 1970s in Finland). Unlike today, when family doctors are

specialist physicians who work in the context of a family (cf. WONCA, 2002, p. 10), family doctors of old were more akin to counsellors and trustees. Their work covered total health needs of an individual, or a group of individuals, from scientific to humanistic side of medicine (Wolfe et al., 1972). They provided care in more than one specialty fields of medicine and coordinated care with other health care personnel. Figuratively, Wolfe (ibid., p. 11) referred these kinds of service providers as “captains of a health team”. Providing that family doctors of old still operated within the premises of the wired world of today, they could be closest to a “long and fat” supply-side intermediary in the field of health care. Admittedly, this is an idealized interpretation on the role of a family doctor of old.

Intermediaries often offer their expertise in the form of bridging activities as “marriage brokers” using a characterization by Bessant & Rush (1995, p. 101) in their analysis on the intermediary roles of business consultants. These activities include selection of appropriate options, identification of needs, project management and managing external resources. Particularly in relation to the latter, activities described as gatekeeping and brokering by Howells (2006) enrich the original analysis by Bessant & Rush (1995). These activities include negotiation, deal making and finalizing the contract, fundamental aspects particularly in terms of managing external resources (Howells, 2006, p. 721).

Returning to the works of Stewart and Hyysalo (2008) and to the earlier works by Stewart (2000), a more generic classification to the roles and activities of intermediaries is provided using a three-tiered structure.

- Facilitating, providing opportunities to others, for example by educating;
- Configuring, technical and symbolic, such as in relation to use of technology;
- Brokering, representing appropriating individuals and institutions, negotiating on their behalf (for example, when brokering entry of new suppliers or sponsors to a project).

In the field of health care, the supply-side intermediaries principally fall (if not solely) to the last category. For example, using the classification above, the principal function of a case manager is often brokering; negotiating on behalf of the individual. In the user-side, different kinds of intermediaries emerge from the third sector. In the sector that comprises of non-profit and non-governmental organizations, intermediaries are often patient organizations. These organizations, such as the Finnish Heart Association, often provide services (such as education) that fall to the category of facilitation. These kinds of organizations are also commonly active in the field of regulation. However, in terms of configuring, it is difficult to pinpoint any (formal) actor that would act

in this role, especially in the user-side. Probably the closest match is a physiotherapist who acts close to the user-side and often with technological aids.

The health service provisioning of today, and the way different organizations are aligned, is a fertile ground for brokering intermediaries on different levels. The inherent fragmentation of the field in the form of different disciplines and specialties, and the technological challenges related to information exchange and integration, give rise to a need for supply-side brokering roles within and without organizations. For example, between the organizations of occupational health care and primary health care, intermediaries with different starting points and interests may operate on the same case, or on the same patient. This may call forth multi-mediation (Bødker & Andersen, 2005) where intermediaries operate in juxtaposition and they are organized in levels or are connected in chains.

Technologically, this kind of co-occurring brokering has been one of many stumbling rocks in the health care due to problems with interoperability standards, such as those of HL7 organization, that have not provided sufficiently stringent standards for information exchange (Benson, 2010, p. 76). Naturally, these technical shortcomings do not affect only the work of intermediaries. At the worst, the impact is widespread affecting negatively on co-operation on all levels, and therefore on the quality of care and even on patient safety. For example in Finland, the impact of low-quality health care information systems on patient safety has been widely discussed in the media since 2010 (cf. Turun Sanomat, 2010; Iltalehti, 2013).

In the light of on-going global trends of today, there is room for user-side intermediaries in the field of health care and well-being. The field is becoming more and more wired every day, and new technologies are introduced to beneficiaries. This gives room for intermediaries who can help the beneficiaries in configuring technology. The field is also more complex and multiform than ever before; and what can be traditionally regarded as health care is becoming intertwined with the field of well-being. This, again, gives room for intermediaries who can help in brokering and in facilitating. In this, elaborating user needs, and communicating them across different fields of business in a good rapport, is of the essence.

As the economic aspects of the health service provisioning are constantly underlined, a need for intermediaries has also risen on the business-side of health care and well-being. As the role of the patient is often more akin to that of a consumer, brokering and configuring functions can have an impact on the overall success of the business. For example, when the beneficiary is engaged in a requalification process (such as, in relation to acquiring physiotherapy services), and the attachment to the current service provider is questioned, the intermediary (e.g. a relative) can be in a position of power affecting the outcome

of the process. This implies that new health care and well-being markets need flexibility as described by Callon et al. (2002) and the role of the intermediary can play a key role in intensifying collaboration between supply and demand.

1.5 The Research Approach

With a focus on beneficiary-centric approach, the work in this dissertation can be characterized as exploratory and conceptual elaboration that based on literature review and is illustrated in empirical work (cf. chapter 1.6.). In contrast to a statistical study on a narrow research question, the work focuses on the emerging phenomena surrounding the health and well-being services of today and tomorrow. The research uses beneficiary as the “functioning specific” much in the same fashion as described by Robert Stake (2008) on his approach to case study methodology; the beneficiary is the locus and the principal agent in the health and well-being related activities. In this the influence of the theories forming the conceptual origins is particularly evident.

Primarily due to the exploratory nature of this dissertation that targets near future, the work does not follow stylistic patterns or taxonomy of a case study. It owes, however, much to the methodology. The demarcation and the focus of the work were done in the spirit of the methodology. The original scope on a user of health and well-being technologies was found to be too unbounded and nebulous and further measures of demarcation were taken. Firstly, the environment that draws boundaries for the target was set to user-side. Secondly, in order to highlight the nature of the practically-oriented conceptual work, the scope was set to near future; a timeline more fitting for discussion on ICT-artefacts that are not yet employed (or even available) in the set environment.

This choice of a discursive and even narrative approach was made in order to highlight the complexity of the target of the study and to highlight “softer” aspects of health and well-being (morality, quality of life, etc.). In this, the approach could be described as “Salutogenic” (Antonovsky, 1979). In it health and well-being are not perceived as an absence of illness, but as a constantly shifting scale between two ideals: absolute health and absolute illness. In relation to technology, this perspective gives room for thought when analysing its use in different situations of life: in perfect health, in the role of an intermediary and finally, in declining years. Due to its relative flexibility, the employed approach was also an ideal choice for research that was conducted in different projects, each with a slightly different viewpoint to the target. As a result, this dissertation is an assemblage of six chapters, extended from published articles, in which each chapter provides a unique insight into the chosen target.

In order to gain, what can be described as “emic” or “the insider” view to the development of technology in the field of health and well-being, the findings were enriched with insights (pp. 49; 85; 109-110; 128) originating from a decade of work by the author in an innovation intermediary organization operating in the field. Over the last years, this work in the organization was conducted under the National Centre of Expertise Programme under the Ministry of Employment and Economy of Finland. In the core of work were immersive research and development activities in which practical solutions were developed for the organizations. These include: development of telemedicine solutions for the diabetes nurses, and development of medication management solutions for the patients. However, it must be clarified that these insights are illustrative by nature; they are not by any standard scientific or formal (or documented as such). As a consequence, the amount of these personal observations that based on these intuitive insights, are kept to a minimum, and they are not used as scientific or formal evidence.

The published articles were extended and partially rewritten for two reasons. One, the field of health and well-being changes so rapidly that parts of the research had become obsolete. For example, the recent (publicly reported) advances in the field of military modernization contain elements that are of the relevance when ethical aspects of mediation are discussed. Two, mediation as a theme was not evident in the original articles; in some parts the theme was missing or the discussion was unfocused. In order to clarify the significance of this theme that runs through the dissertation, a degree of rework was required.

1.6 Structure and Background of the Thesis

This dissertation looks into the constantly changing field of ICT-mediated health care services. Through six chapters that extend the work done in scientifically reviewed and published articles, the dissertation highlights emerging aspects in the field and analyses their potential impact on the individual who is in the crux of the change. Due to the turbulent state of the field and global macro-level changes in the service provisioning (for example, due to ageing societies), it is difficult to see what the future of the health care and well-being services actually will be. In order to provide some insight on the potential future developments, the dissertation focuses on the probable immediate and short term developments in the field, while the analysis of the long term developments is mostly cursory by nature. The identified developments are investigated during the course of six chapters using the role of a mediator, i.e. an intermediary, as an overarching theme. The role of the mediator acts as a ‘lens’ through which a number of relevant changes are looked at, pinned down and addressed to a degree. Due to the complex and multiform nature of the field, and future orientation of the dissertation, the investigation is not intended as an all-inclusive one.

The first reworked article (chapter two) is related to the work performed in the InnoELLI Senior program in the 2006. During the period of 2006-2007 the program was carried out in seven Regional Councils of Southern Finland, South Finland Regional Alliance and it was part of Innovative Actions under the European Regional Fund (ERDF). The purpose of the program was to create integrated service models that would enable different organizations to adopt new working methods to the elderly care sector.

The chapter looks into the changing field of health care and well-being services as a whole, highlighting some of the primary challenges that the elderly users of ICT-mediated health care (and well-being) services typically encounter. The chapter introduces some of the basic characteristics of the mediator and opens up a discussion on the applicability of the mediator in resolving the identified challenges. The chapter ends with a summary of an outline to the remainder of the dissertation that will continue and expand upon the initiated discourse.

The third chapter is based on the work related to the preparation of 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 and well-being services, and conceptualize means for the beneficiary for coping with the electronic services that have become, and are becoming, more and more multifaceted over time. One of the focal points in the project was the role of the citizen (e.g. beneficiary) that was used as a cornerstone in the formulation of new service models that could be seen as more personal by nature when compared to the existing service models in the field. The chapter provides a non-exhaustive interpretation on the different roles an individual may have in relation to different health care (and well-being) services. In addition to the role of the citizen, the chapter includes those of the customer and the consumer.

The “traditional” role of the patient is touched upon as well, but on a lesser degree, due to abundant research on the role and its significance to the health care sector as a whole. The chapter also provides an interpretation on how health care services could be reformulated in order to better promote citizen-centricity and freedom of choice in relation to service provisioning. This reformulation is based on a three-stage service cycle consisting of articulation, declaration and execution phases that are further discussed in the chapter. The discourse on the role of the mediator is continued in the form of analysing the relationship between the base roles of the actual beneficiary (i.e. citizen, consumer and customer) and that of the mediator.

In the next chapter, the discussion moves towards ICT-artefacts. The chapter is based on the empirical work done in the MyWellbeing project that ended in 2010. The work that was done in the concept development research group

(figure 1.1.) by the author opens up the discussion on the state of the art in the field of Personal Health Information Management (PHIM). In the group, the role of the author was to look into the field (literature and market), and analyse what kind of functions an ideal PHIM solution could have. Even though the original article is reworked and extended, and the functions of the concept are examined in the light of the recent developments in the field, the literature review reflects primarily the situation in the field during the project. It follows from this that the original analysis, continued in this dissertation, are author's merit.

In the project, a concept for "The Coper", an aid for personal health information management was defined in a close collaboration with academic and industry partners (for a full list of partners, see Meristö et al., 2010), and the functions were tested externally in two use cases (figure 1.1.), the retired and the families (Kouri et al., 2010, p. 10-18). On the level of the project, the work was organized in four separate research groups (figure 1.1.), each having a different perspective (concept, technology, specific user group) to the challenges of PHIM. In addition to research groups, the project management worked as a separate entity.

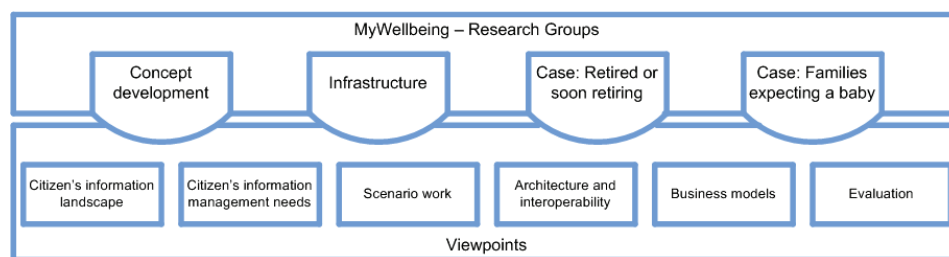


Figure 1.1. MyWellbeing project and the research groups.

This chapter reports the results of iterative process between concept development and evaluation on the level of the core functions, and the ideological reform (Citizen Pathways) on the level of the service provisioning. The purpose of the pathways that are defined in the chapter is to help individuals (incl. mediators) during their health related endeavours. In addition to the pathways the chapter reports a set of core functions that have not been reported earlier in relation to the project. In this, the chapter adds to the original findings of the concept development work group. After the original project, the work on citizen centric solutions has continued Pumpu (Pump in English) project that started in the turn of 2011-2012.

The fifth chapter continues the technology discussion, adding to the knowledge transfer theme of the previous chapter. The chapter discusses the role of different decision support systems in health care from the viewpoint of the actual

beneficiary, and describes some of the fundamental challenges related to computerization of best practices in the field. The chapter also highlights some of the changes these kinds of computerized solutions potentially have on the patient-physician relationship that is traditionally regarded as a paternalistic one. In terms of mediator, the chapter continues on the theme of trust and discusses the role of mediator in patient decision making.

Chapter six introduces extremely anthropomorphized, or human-like, health and well-being solutions that are rapidly emerging in the field, for example in the form of robotics that are used increasingly in the patient care. In terms of mediator, the chapter opens up a discussion on trust and technology literacy, issues that are of the essence in mediation, and in the use of health and well-being solutions in general.

The final reworked article (chapter seven) broadens the discussion to the field of military telemedicine. The chapter opens up with a short introduction to some of the well-known agreements of war and depicts how they are violated in spirit and in practice. The used examples reflect the time of the reported incidents; what kind of technology development was in the focus during that era and what kind of aspects emerged as a consequence. It follows from this that the examples are related to the use of drugs, chemical weapons and warfare agents. In the remainder of the chapter, the focus is shifted to technologies that are positioned similarly today, creating a connection between the past and the future. Using intentionally aggravating scenarios and real-world examples the chapter paints a stage, total institution, where self-determination of a person may be in a conflict with the assigned duties and authorities in charge. In order to create a sharp contrast between the real world and that of a total institution, the stage is set to the field of military. This black-and-white setting is used for depicting difficulties related to the role of the mediator in such clarity that its inapplicability to act as a universal solution to the emerging challenges in the field of ICT-mediated health and well-being cannot be disputed.

To summarize, the first two reworked articles illustrate on-going changes in the health service landscape and introduce the role of the mediator. The next two chapters that follow change the focus more towards technology in the form in information management and knowledge transfer, continuing the theme on the mediator. The remaining chapters delve into the specific technologies that create challenges - and opportunities - to mediation (figure 1.2). As a whole, the dissertation creates an outlook to the field of electronic health and well-being services that addresses different aspects (human, organization, social and technology) of the chosen research domain that is information systems.

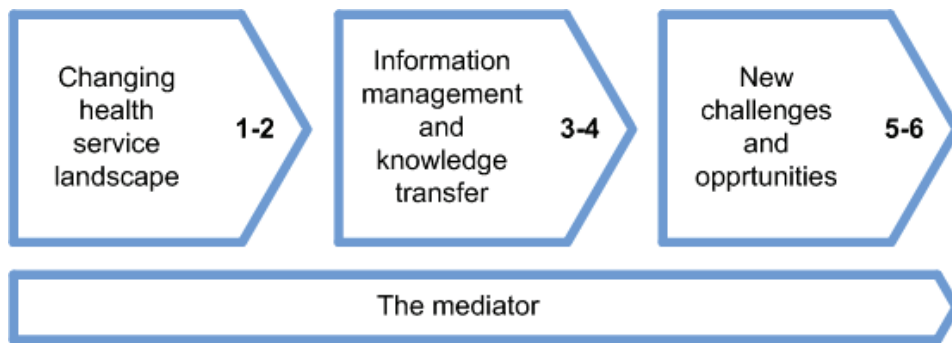


Figure 1.2. Reworked articles and themes of the dissertation.

The dissertation concludes in a summary about the use and functions of the mediator, describing some of the potential future avenues in implementing such a support mechanism to the changing field of ICT-mediated health care. The conclusions also describe some of the limitations of this dissertation, including remarks on methodology and content.

The following chapter is revised and extended from:

Lahtiranta, J. & Kimppa, K. (2006), “Elderly people and emerging threats of the Internet and new media”, in: Suomi, R., Cabral, R., Hampe, J.F., Heikkilä, A., Järveläinen, J. & Koskivaara, E. (Eds.) *Project E-Society: Building Bricks*, 6th IFIP International Conference on e-Commerce, e-Business, and e-Government, October 11-13, 2006. Turku, Finland. Springer, 2006. pp. 13-21.

2. Elderly People and Emerging Threats of the Internet and New Media

Use of the Internet and different new media (i.e. mobile devices, electronic games, blogs, podcasting, etc.) as a part of everyday activities has increased steadily over the past few years. As one indication of this continuous progress, the percentage of households with a broadband access has constantly increased in every country reported by the OECD between 2006 and 2010 (figure 2.1).

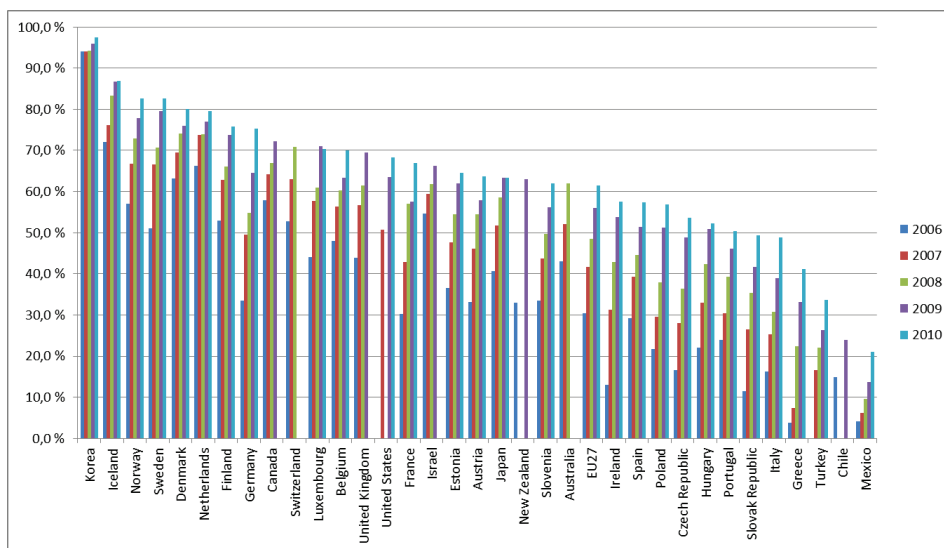


Figure 2.1. Households with broadband access, 2006-10, percentage of all households (OECD, 2011a).

In the latest estimates, wired broadband subscriptions in the OECD countries exceeded a milestone of 25 subscribers (25.6) per 100 inhabitants in 2011 while in 2009 the subscription rate was 23.1 (OECD, 2013). Another indicator on the increased use of the Internet is the percentage of individuals who have never used it. In the European Union, the percentage has steadily decreased and the current estimate is that only 18 % of the EU population has never used the Internet (European Union, 2012, p. 6). Altogether the percentage of Internet users in the region is close to the United States where 78 % of the whole population (ibid.) and 85 % of U.S. adults use it (Pew Internet, 2013).

Due to its worldwide popularity, the Internet can be regarded as one of the most important service channels in the digitalized world. What was first a technology

of the few, has now gained popularity amongst all population groups. As an alternative indicator of the popularity, the percentage of households with access to computer at home has increased steadily over the last years in the EU-27 countries. In 2010 the access rate was 74.4 % (OECD, 2011b).

Focusing on the elderly people who are at the moment a target of different initiatives and policies that promote the benefits of the Internet (cf. Silver Surfers' day in the UK), the usage is also on the increase. In the United States, as of April 2012 over half of the adults ages 65 and older are online (Zickuhr & Madden, 2012). However, amongst the elderly people of 76 years and more, use of the Internet drops of significantly and the Internet adoption amongst this group is only 34 % (ibid.).

In the European Union the numbers are similar. In 2011, the percentage of individuals who have never used the Internet is 65 % amongst 65-74 years of age, while between ages 55-64, the percentage was 42 % (European Union, 2012). In a different survey (European Commission, 2012) that focuses on the availability of Internet connection at home in the European Union the numbers are a bit different but in similar lines. According to the survey (ibid., p. 43) 59 % of the elderly between ages 55-64 and 38 % between ages 65-74 have Internet connection at home while only 17 % of the 75+ years of age have the connection (in the EU-27 countries).

Even though the Internet use has increased, it is still polarized when comparing different age cohorts with each other. Even though there are some indications that the elderly will close the gap with younger generations especially in health care (Lovett & Mackey, 2013, p. 94), it is still unclear what will happen in the future. Even though the future generations will be in general more competent and willing users of technology, a portion of population will probably not use computers or the Internet for reason or another (lack of skill or interest, etc.). Considering that in 2050 approximately 28.8 % of the population in Europe will be 65 years or older (Eurostat, 2011, p. 122), the number of technology "drop-outs" can be significant.

This potential outcome has an impact on wider issues besides the use of technology or electronic services. As the European Union is aiming for creating a digital single market for the whole of union in the near future, each "drop-out" means the loss of a potential consumer and revenue. This can have severe consequences as it is estimated that development of the digital market could result in 4 % increase in European Union's gross domestic product (European Policy Centre, 2014, p. 1).

Crime and abuse

Introduction of new technologies for the elderly has created new opportunities for crime and abuse. The elderly people of today who often have a better financial status than the previous generations have become an inviting target for crime and abuse, for example in the form of Internet fraud and online scam. While the very first crackers, hackers, phreakers, etc. attacked against the technology, focusing on the vulnerabilities of the operating systems, hardware and used applications. Now, regardless of the increased public awareness, the attacks have become more sophisticated by nature, focusing not only on the technology, but on the (elderly) user as well.

Integration of originally separate communication channels with each other and with new ones (i.e. digital convergence), and adoption of new communication methods such as social media, have created new opportunities for online crime and abuse. For example, Abraham & Chengalur-Smith (2010, pp. 187-188) report of sophisticated social engineering attacks, that are tailored against specific user groups. These include (ibid.) college students, corporate executives, sects, religious groups and residents of a specific country.

While the elderly cannot be regarded as the prime candidates for online fraud and abuse in general, there is some indication that the situation may change in the near future. One of the areas where elderly people are at particular risk of harms is online purchase of pharmaceuticals outside physician oversight (Lovett & Mackey, 2013). Unique dangers arise from their potentially dangerous sensitivities, such as polypharmacy or memory problems. Other identified risk areas include certain types of social engineering attacks, such as ones executed via voice messaging services (i.e. vishing attacks) (Ollmann, 2007, p.4). Ramzan and Wüest (2007, p. 2) also report on social engineering attacks where the elderly are regarded as a target population. Their investigations (ibid., p. 2) imply that phishing attacks executed in the banking sector focused on the elderly and students, population sectors that the authors regard as common fraud targets. In phishing, the attacker tries to “fraudulently acquire sensitive information from a victim by impersonating a trustworthy entity” (Jagatic, et al., 2007, p. 94). The attacker may be after personal or financial information, such as user identification details used in electronic banking.

Elderly people of tomorrow?

What has also changed, and is constantly changing, are the capabilities, approval and utilization of the Internet amongst the elderly people. The elderly people of today are in all likelihood quite different in their attitudes and technology adoption skills than those of tomorrow. What will change as well is the

technology; what can be considered as a cutting edge technology of today, will be obsolete tomorrow.

Even though the technology changes rapidly, the younger generation (i.e., the elderly people of tomorrow) is likely to become more used to the changes and sees them as a fundamental part of the technological advance. However, when these technological changes are combined with the changes in the surrounding world (such as, in the society and commerce, even in the legislation) unseen challenges that have an impact on the safety, integrity and self-determination of the elderly users of Internet and new media start to emerge. These challenges, such as “how to ensure that the individual receives the best available care via a digital media” might not be relevant today but if the electronic solutions become the prevalent means for providing health care services in the future, we might face the challenges much sooner than expected.

At a glance, these kinds of challenges that will present themselves over time are commonly linked to the services that are assistive or enabling by nature. In other words, they are implemented to support an individual in a specific endeavour, such as in using a specific service or in providing one. In this sense, the technology can be seen in a mediating role in relation to the provided service (hence the term ICT-mediated health care services instead of eHealth, telemedicine, or similar).

For example, if we look into the needs of an elderly person as described Ambient Assisted Living Joint Programme of the European Union (Gaßner & Conrad, 2010, p. 16), the areas into which assistive and enabling technologies are devised within the Joint Programme include:

- Health and wellness;
- Home care;
- Chores and supply with goods;
- Safety, security and privacy;
- Mobility;
- Information, learning and education;
- Social interaction;
- Hobbies;
- Working life.

Addressing these near future challenges today, when most of the electronic services still have a “traditional” or non-electronic counterpart, is of importance in order to ensure that the elderly people of tomorrow are able to cope in their everyday lives with the support of ICT and new service models.

2.1 Macro-Level Trends and Development of Electronic Services

At the moment, there are various different macro-level trends (economic and non-economic alike), which have an effect on the need and development of the different electronic services. The following trends, which affect the development of electronic health care services (eHealth), have been identified in the literature (cf. Haux et al., 2002; Saritas & Keenan, 2004):

- Demographic and societal change, ageing societies;
- Rising expectations and consumerism, from patients to consumers;
- Health informatics and telemedicine, changes in information access;
- New medical technologies, new treatments and new costs;
- The spiralling costs of health and social services, incl. ICT;
- Emergence of new service modes, empowered patients and families;
- Introduction of new financial models, increased private participation;
- Increased demand for therapeutic and diagnostic advice, incl. DSS.

More specifically in relation to the ageing societies and elderly people, van den Broek et al. (2010) have identified the following, socially polarized, mega-trends (p. 4):

- A growing number of elderly people living by themselves and in need of care, especially intensive care;
- A higher number of elderly people lacking basic financial and social resources that have difficulties in obtaining minimum health care services;
- A growing number of financially stable and wealthier elderly people with increased purchasing power (cf. above);
- Changing family relationships and living conditions, increased distances between family members;
- Ageing workforce and a need to keep elderly people active in the society and at work.

In addition to the ones listed above, the following trends and on-going changes should be taken into account in order to further broaden the discussion towards more generic electronic services, not just those belonging solely to the health care or social sector. The following list is not intended to be exhaustive; it merely complements the issues mentioned above with the ones that are current in today's public media and academic literature. These issues that depict the changing landscape of the electronic services (eServices) are not related solely to the elderly users of Internet and new media; they have a wider impact on the user base as a whole, irrespective of their age.

Changing users

- Changes in technology adoption skills, beliefs and attitudes. In general, people are more familiar with the different forms of ICT and they are more capable of adapting to the changes in it (on their terms). As an example of this on-going change, Brown (2008, p. 398) describes a concept of a “wired from birth generation” that comes to expect everything to be computerized. Similar characterizations have been presented by Prensky (2001) who uses the term “digital natives” to describe students who are “native speakers of the digital language of computers, video games and Internet” (p. 2);
- Preferring of electronic service models. Increasingly, different electronic service models are created, and preferred to a degree, by the customers and service providers. For example, the popularity of online banking has increased in the United States from 13 % in 1995 to 43 % in 2005 (Fox & Beier, 2006), and all the way to 51 % of adult population (Fox, 2013). In the European Union, the use of online banking is similarly high; one in two Internet users aged 55-74 used online services in 2012 for banking (Eurostat, 2012, p.5). However, the adoption rates vary greatly; from 4 % in Bulgaria to 82 % in Finland (Eurostat, 2013a).

Changing technology

- Maturity of the technology. The utilized information and communication technology is slowly maturing beyond unique and individual technology pilots. As a consequence, ICT has penetrated nearly into every profession in the OECD countries, ever-changing the way of working. For example, introduction of telecare in the delivery of mainstream health care services is constantly changing the way care providers are integrated into the everyday life of an (independently) aging individual (cf. Boulos et al, 2009; Palm, 2011; Scalvini et al., 2013);
- Maturing standards. The introduction of multiform ICT-artefacts into different lines of business has also created a pressing need for information exchange between the related parties. To address this need, different formal standards for information exchange have been defined (see e.g. ISO, ANSI, ASTM and IEC standards) and put into use with varying degrees of success, for example, via Integrating the Health Enterprise (IHE) coordination efforts. Despite of their harmonization efforts, one of the current problems in the field is the lack of semantic interoperability between the HL7 2.x and v3 messaging (cf. Oemig & Blobel, 2011) that impedes compatible data exchange.

Changing service landscape

- Increased global rivalry. Rivalry, not just in the private sector, but also between the private and the public sector is currently changing the nature of the (electronic) services industry. Markets that have been commonly closed or government-controlled (such as education, health care, social services, telecommunication, housing and transport) are currently opening for competition (cf. Price et al., 1999; Maarse, 2006; Battaglio & Legge, 2008). However, it is unclear whether this trend will continue and there is a possibility that some of the services that are indispensable to the society will remain under governmental regulation and control even in the future;
- Need for transparency and accountability. The change in the market conditions, such as regulation and supervision within and between economic regions (incl. market access) has created a need for transparent procurement models. In governmental procurement, these models are needed in minimizing inherent risks, such as inefficient use of governmental budget, discrimination and even corruption (Evenett & Hoekman, 2005, p. 178). Similar views on transparency and accountability were presented in the WHO Tallinn Charter (World Health Organization, 2008). In the Charter the member states in the European Region declared that they commit themselves, amongst others, in promoting solidarity, equity and participation through health policies;
- New mainstream behaviours. With ICT, power is shifting from corporations and brands to consumers, shaping the industry. The social media and new ways of consumer interaction can change the rules for conducting business overnight (Wolf Olins & Flamingo, 2013);
- Emerging health ecosystems. Traditionally fragmented health and well-being service provisioning is slowly transforming into what can be regarded as ecosystems (Hietala et al., 2009) where heterogeneous combinations of interest groups (companies, customers, etc.) are linked together with a common interest in mind. At the same time, technical infrastructures are maturing creating technological enablers for functional health and well-being ecosystems.

Considering the pace with which the electronic services are implemented and institutionalized today, covering nearly all parts of the everyday life, it is probable that in the near future some of the “traditional” or non-electronic service models will cease to exist. There is already evidence of this kind of development in the banking sector where online banking has become a preferred way of managing individual’s financial affairs, especially in most OECD-countries.

Also, new services that reach the customer regardless of time and place, and services that require constant updating of individual's technological know-how will become more abundant (for example, continuous online health monitoring and similar solutions described in Varshney, 2009, pp. 89-143). These changes in the service supply may cause unnecessary stress for the elderly people (regardless of their technological proves) as some of the service models they have grown accustomed to are no longer available thus striking a discord to the familiar routines and habits. This is a potential risk factor since changes in the routines and habits may even have influence on the well-being of the elderly (cf. Zisberg et al., 2010).

The transition from "traditional" or non-electronic service models to electronic ones may also have an impact on the quality assessment of the emerging models. In some cases, the original service models provide a point of comparison, or a baseline, for their electronic counterparts. However, some of the emerging models are completely new, or they combine different services in a novel fashion, and therefore a functional baseline does not necessarily exist.

2.2 Electronic Services and Elderly People

One of the simplest ways to categorize electronic services is to divide them into synchronous and asynchronous services on the basis their coupling in time. Typical synchronous services include a real-time communication between two or more participants. An example of such service is video conferencing, where participants communicate with each other using a real-time video and audio connection (figure 2.2).



Figure 2.2. An example of video conferencing (from News@Cisco press release January 28, 2009, http://newsroom.cisco.com/dlls/2009/prod_012809.html).

Video conferencing technology is widely used in the health care as well. Example services in this sector include telepsychiatry (cf. Neufeld et al., 2007; Shore, 2013) and remote consultation (cf. Handschu et al., 2008; Malandraki et al., 2013).

Asynchronous services, where data is transferred intermittently instead of a constant stream, are probably even more commonplace today than synchronous services. These kinds of services are used, for example, in banking and in electronic commerce where the user accesses different electronic services at irregular intervals via email, web browser, or similar application. In health care, similar examples can be found in the field of web based programs used for disease management (cf. Ralston et al., 2004; Timpka et al., 2008; Tang et al., 2013) and online Decision Support Systems (DSSs) for patients (cf. Symptomchecker³ by WebMD or Online Self Diagnosis⁴ by YourDiagnosis).

In the online Decision Support Systems such as the aforementioned ones, the users provide information about their current health condition in a progressive manner, gradually specifying their ailments according to the feedback from the system. For example, if the user has stated experiencing pain in the lower abdomen, the system could ask the user to specify the nature of the pain (such as sharp or throbbing pain) and the severity of it (e.g. mild, moderate or severe). As a conclusion, the user gains an analysis of the possible reasons behind their symptoms (such as appendicitis), how the condition is formally diagnosed and how it is commonly treated. As often stated in the service disclaimers, these kinds of solutions should not be used as a substitute for a professional medical advice, diagnosis or care; they are intended solely for informational purposes. In the following is an example from the Symptomchecker⁵ by WebMD:

“This tool does not provide medical advice. It is intended for informational purposes only. It is not a substitute for professional medical advice, diagnosis or treatment. Never ignore professional medical advice in seeking treatment because of something you have read on the WebMD Site. If you think you may have a medical emergency, immediately call your doctor or dial 911.”

Both of the service types, synchronous and asynchronous, contain inherent risks to the users. Not just to those with diminished capabilities, but to all users of the Internet and new media. Lieberman & Stashevsky (2002) examined perceived Internet risk components, such as supplying personal information and information reliability that can create barriers to the Internet use and the use of electronic commerce. The study was executed amongst 465 employed adults. On

³ <http://symptoms.webmd.com/> (accessed: 3.10.2011)

⁴ <http://yourdiagnosis.com/> (accessed: 3.10.2011)

⁵ <http://symptoms.webmd.com/> (accessed: 3.10.2011)

the basis of a literature review, the authors identified certain common demographic traits that are related to the risk components (figure 2.3).

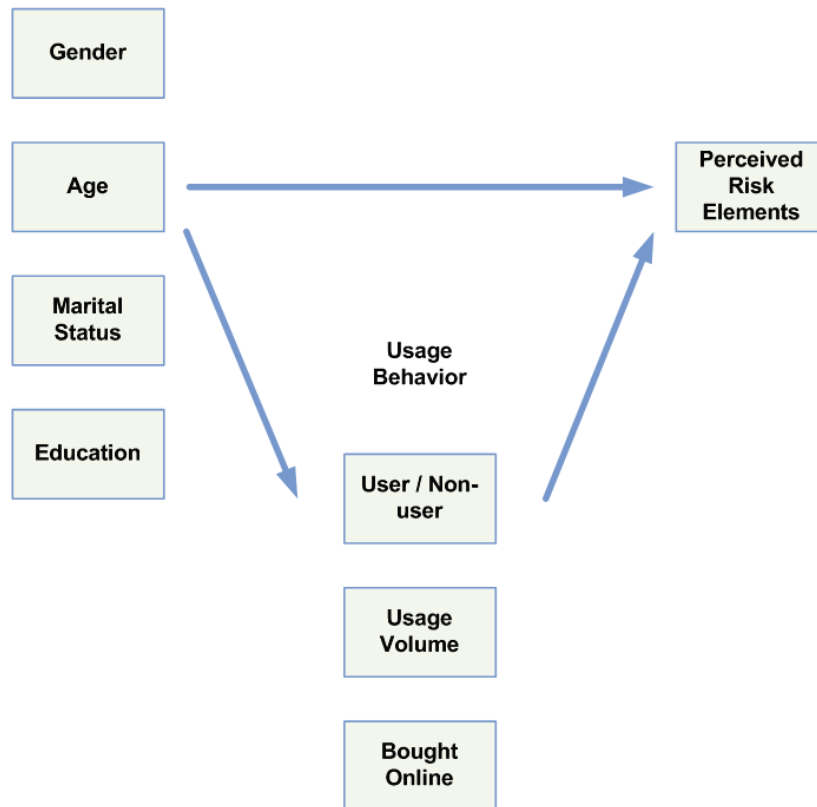


Figure 2.3. The factors affecting the Internet perceived risk components: demographic traits (Liebermann & Stashevsky, 2002, p. 293, figure 1).

The demographic traits and risk components identified by Lieberman & Stashevsky (2002) are generic by nature and focus on barriers related to the Internet use at that time. In a more recent study that focused on the elderly Internet use and markets in the EU-5 countries, a wider range of traits were examined. In addition to age, gender, education and usage volume additional factors were used in the Seniorwatch 2 study (2008). These factors included:

- Age bracket (for example, 50-59 years and over 80 years);
- Occupation and employment (such as, never worked);
- Education (upper secondary, lower secondary or less, etc.);
- Impairments (such as dexterity or vision problems);
- Long term conditions;

- Skills, Internet access and use;
- ICT related attitudes;
- Income and gender.

Focusing on the elderly people and emerging threats of the Internet and new media is challenging partly due to different viewpoints on what “elderly people” really stands for. Different definitions could be done, for example, on the basis of age (e.g. 60 years and older) or on the basis of individual’s current social standing (such as, whether the individual has retired from working life or not). An alternative definition, such as talking about individuals who have entered their “third age” is similarly ambiguous. According to authors such as Gilleard and Higgs (2002) the concept can be regarded as a class, cohort or even as a generation.

For the purposes of this chapter, the “elderly people” in a risk group are defined by using age and skill with ICT as the main factors. Selecting a narrower set of demographic traits used by Lieberman & Stashevsky (2002) and in the Seniorwatch 2 study (2008), the group can be characterized as follows:

- Age: 60 or more;
- Computer skills: low to medium;
- Internet access: Internet access at home;
- Usage volume: infrequent user of Internet and new media;
- Employment: retired or no longer in active working life;
- Impairments: capable of using ICT applications independently;
- ICT related attitudes: willing to use ICT;
- Bought online: rarely or never.

Of the chosen factors, one that probably needs some justification is the skill with ICT. Even though there are an increasing number of people retiring from working life who are skilled with ICT, it is estimated that the number of individuals who have never used the Internet will not dramatically drop in the near future. For example, in the European Union (EU-28), the change in the age groups of 55-64 and 65-74 was 3 percentage points between years 2011-2012 (Eurostat, 2013b). Since 2008, the drop has been approximately 3 percentage points per year amongst the 55-64 years old. At this rate in 2016 more than every fourth elderly person in that age group has never used the Internet.

If we look into the frequent (almost every day on average within the last 3 months) users of the Internet (Eurostat, 2013c) the change was 2 percentage points in the age group of 55-64 and 3 percentage points in the group of 65-74. In addition, it is plausible to assume that the elderly Internet users rarely gain up-to-date information on the use of the Internet and new media as they would in the active working life. Therefore, focus on elderly users aged 60 or more with

low to medium skills on ICT gives room for focusing on a demographic group that can be characterised as a high-risk in relation to the use of the Internet and new media.

The inherent risks related to the use of Internet and new media by elderly people is a somewhat less explored topic when compared to the general studies (such as, Chang et al., 2013) in the field. One possible reason for this could be that, in general, the use of Internet and new media by the elderly people has only recently started to increase (Seniorwatch 2, 2008; Jones & Fox, 2009), thus becoming an issue and stimulating the research in the field.

However, partially contradicting this argument, there is one field of ICT related to the elderly people that has gained a lot of interest from the marketers and from the academia; the field of assistive and supportive technologies. According to Florin Lupescu, previous director general of the European Commission Directorate General for Information Society and Media (DG INFSO, as of July 2012, DG Connect), European Union and Member States, and the private sector will invest 1 billion EUR in research and innovation for ageing well until 2013 (Broek et al., 2010, p. vii). These kinds of assistive technologies, such as intelligent medication reminders, will help the elderly individuals in coping with their everyday lives.

Technological literacy and the elderly

The general studies about the common risks and threats related to the use of Internet and new media often fail to take into account the physical, mental and cognitive declines commonly associated with the aging process. Furthermore, elderly people may have problems with the modern technology since they typically no longer acquire new skills through education or employment, and they have a high risk of being technologically illiterate; lacking the skill of technology literacy which has been identified as a key factor in formation of a knowledge-based society (Somerville et al., 2007, p. 9).

As defined by the International Technology Education Association (ITEA), technology (or technological) literacy is much more than knowledge about how to use technology (ITEA, 2006). The literacy is regarded more as a vision where the citizen has “a degree of knowledge about the nature, behaviour, power, and consequence of technology from a broad perspective” (ibid., p. 1). Stemming from this vision, the skill is defined as “the ability to use, manage, evaluate, and understand technology” (ibid., p. 4). All in all, mastering this skill does not only mean that the individuals are competent with different ICT-artefacts, they have also gained an insight into where and how the available information can be put into use most effectively.

Emerging electronic services and privacy

In addition to the physical, mental and cognitive declines that are always individual by nature, the changes in the surrounding society should be taken into consideration. Now, and even more in the future, the users encounter different ICT-artefacts in completely new situations (for example, when a “traditional” or non-electronic service model is replaced with an electronic one). Especially the elderly people can come to these situations unaware and unprepared. Different synchronous and asynchronous services will become even more multiform as different ubiquitous or ambient technologies are implemented. This development is of the essence due to its potential to enhance and lengthen the period of time during which the elderly people can stay living at home (or at some other preferred environment). Today different concepts, such as those envisioned by Continua Health Alliance⁶, are full of vivid examples of these kinds of supporting technologies.

In their web pages, the Continua Health Alliance consortium depict their connected health vision where different (intelligent) health and well-being applications communicate with each other, with the service providers and with other relevant parties (such as family members of the elderly) creating a comprehensive environment where the elderly can age independently in familiar surroundings.

All of the solutions envisioned by the Continua Health Alliance are not here quite yet. At the moment, the electronic services are based mostly on existing, non-electronic service models and preferences. For example, in the case of a virtual health care inspections the individuals often fill in similar, or even the same, forms electronically as they would done manually at the doctor’s appointment. Similar examples can be found from governmental electronic services where online tax filing is commonly implemented using similar forms as in the non-electronic tax services.

The solutions looming in the near future envisioned by the Continua Health Alliance, other consortiums, academia and industry at large are abundant and multiform. These include:

- Sensors at home, such as dawn/dusk lights, cooker controls, door alerts or smart carpets that detect motion or pressure (cf. Glaser et al., 2005; Scanail et al., 2006);
- Automated personal medication controllers, such as those developed in the ADICOL project (cf. Hovorka et al., 2004);

⁶ <http://www.continuaalliance.org/> (accessed: 9.10.2012)

- Point-of-care testing solutions, or home laboratories, such as the i-STAT® by Abbot Point of Care⁷;
- Sensors in clothing similar to the ones developed in the VTAMN project (Axisa et al., 2005, p. 332);
- Personal robotic assistants like the communication robot Wakamaru (Botsis, 2008, p. 335);
- Health monitors, such as SenseWear® Armband system⁸ or Vivago® Care products⁹;
- Robotic exoskeletons and orthotic devices (cf. Herr, 2009);
- Artificial beings, service and companion robots as those of the EURON Consortium (van den Broek et al., 2010, p. 84).

From the perspective of health care communication, these solutions may contain and convey information on all or some the following topics:

- Personal demographics (such as name, gender and address);
- Family background (genetics, hereditary or familial diseases, etc.);
- Common data (public information from Internet and social media);
- Customer relationship data (services, providers, reimbursement, etc.);
- Personal preferences and habits (information on hobbies and exercise routines);
- Financial data (information on credit cards, transactions, acquisitions, and so forth);
- Health status information (medications, vaccinations, prescriptions, diseases, disorders, etc.);
- Situational data (for example, measurements, current location, analyses, recommendations).

While most of this information can be regarded as sensitive, there are inherent risks related even into the use of common or public data especially when effectively analysed and enriched with information from alternative sources (for example, in the case of user profiling). In the following, these risks are analysed from the perspective of using electronic services (primarily health and well-being services) by the elderly people.

⁷ <http://www.abbottpointofcare.com/> (accessed: 3.10.2011)

⁸ <http://sensewear.bodymedia.com/> (accessed: 3.10.2011)

⁹ <http://www.istsec.fi/> (accessed: 3.10.2011)

2.3 Emerging Risks and Threats for the Elderly People

As the electronic health care and well-being services become more numerous and common, and as the individuals rely more and more on different ICT-artefacts in their care, they may become vulnerable in different ways. Information originating from different sources and parties related to the use of this information creates a mosaic-like structure where different threats start to emerge. These threats can be categorized using a two-fold structure: a) malicious targeted actions and b) unintended side effects.

Malicious targeted actions

Malicious targeted actions are intentional. When a person executes such an action, it is known that through the action, or omission, the results will have negative or even illegal consequences on the target (being that an individual, group of individuals, organization, ICT-artefact, etc.). The unintended side effects are more abstract by nature. While the intention behind an action, or a development path of some ICT-artefact is typically a benevolent one, the unforeseeable consequences of the act or development can have negative consequences.

In today's information society, one of the most common forms of malicious targeted action is phishing where the goal of the attacker is to acquire sensitive personal information, such as credit card details. In electronic health, the sensitive information acquired via phishing could contain information on one's health status, such as current medication and disorders; information which could be abused later on for example in the form of falsified or forged medical prescriptions or frivolous compensation applications. As elderly people often suffer different ailments, and they potentially have multiple health service providers, they are a rich source for different health related information. For this reason information that can be used for health insurance scams (such as for Medicare frauds in the U.S., see Kalb, 1999; Thorpe et al., 2012) can very well be the primary reason for phishing attacks against them in the future.

Online DSSs such as the Symptomchecker¹⁰ by WebMD, and social media platforms such as the PatientsLikeMe¹¹, are becoming more and more popular amongst the health information seeking Internet users. If used for dubious purposes, these kinds of solutions could be a valuable source of sensitive health information to be used in social engineering attacks and other forms of malicious

¹⁰ <http://symptoms.webmd.com/> (accessed: 3.10.2011)

¹¹ <http://www.patientslikeme.com> (accessed: 3.12.2012)

targeted actions (such as for illicit direct-to-consumer advertising via Facebook and Twitter, see Liang & Mackey, 2011, and for providing false testimonials via YouTube on a high-risk products such as Accutane, see Vance et al., 2009). The progressive function of these solutions could be also used for manipulating user actions and discreetly steering the individuals to false online pharmacies, for example, on the basis of intentionally false diagnosis (i.e. one's symptoms are a consequence from a specific ailment and remedying this ailment requires purchasing certain products from a given false online pharmacy). In theory, such DSSs could also be used for steering users to prescription-free sections in legitimate pharmacies in order to increase their revenue by "grey area" action (in other words, such as by providing fear invoking information via the systems).

It is difficult to intervene with these kinds of "grey area" actions where the line between the legal and illegal is too fine to be drawn. Companies operating in a shade; in a morally questionable fashion, utilizing loopholes in the legislation are hard to put out of business and once put out, they easily re-emerge under an alias or, in case of electronic services, another Internet service provider (such as one, operating in a different country). Sectors where "grey area" actions are notoriously abundant are health claims related to food and beauty. As a consequence, European Commission and standardizing agencies such as Food Standards Agency (FSA) in the United Kingdom have to constantly work on constraining the field (cf. European Parliament, 2010).

Playing with the fears of individual will borderline what is regarded in literature as scareware, where individuals are intimidated or scared to install malware applications on the basis of false virus alerts or similar (cf. Kirk, 2007). In the electronic health care setting, the scareware applications could rest upon individual's fears over one's health and well-being or, for example, that of one's relative.

Assuming that the online pharmacies will become one of the most prevalent forms of selling pharmaceuticals, information on individual's medication can open another possibility for malicious targeted actions. By affecting individual's purchasing habits for example by means of social engineering, it could be possible to manipulate the individual to use an online pharmacy where the products are different or of lower quality than those the individual typically uses.

Outside the scope of social engineering attacks (incl. phishing) possibilities for more direct malicious intended actions are severe. Already there are examples of so called ransomware where information on victim's computer is encrypted and the victims are extorted by demanding compensation for restoring the information (cf. Bridges, 2008). In electronic health care, the consequences of hijacking individual's (or one's elderly relatives) medical data, medication controller or other personal medical device could potentially result in a life-

threatening situation. This possibility almost became reality in the fall 2011 as a The Register reported that an insulin pump by Medtronic was “vulnerable to attacks that allow strangers to increase, decrease, or stop the flow of insulin being administered” (The Register, 2011).

These types of malicious targeted actions hinge on the kinds of technological options that will eventually come available, and on the kind of convergence between the new technologies. This limits how well we can pinpoint the threats beyond the foreseeable generic types of threats, associated with the likely classes of technology and the ways of handling data.

However, despite the difficulties in anticipating the kinds and foci of intentional attacks, identifying potential targets for malicious intended actions in the near future is relatively simpler than that of anticipating the unintended side effects of the technology development and deployment. The situation can be clarified acknowledging the fact that some of the emerging risks in this front are already present and there is a possibility that they will intensify in the near future unless corrective measures are taken. The rest then will require another type of anticipatory approach that is discussed later on.

Unintended side effect: digital orphans

Probably the most widely discussed problems in the field of electronic services presently are related to the digital divide (cf. Norris, 2001; Warschauer, 2003; Cruz-Jesus et al., 2012), especially the social implications surrounding this phenomenon, and to the lack of technological (incl. Internet) literacy (Spitzer et al., 1998; Eisenberg, 2008; Veerger et al., 2012). To partially address the challenges related to the lack of Internet literacy, the Council of Europe has published an online handbook for “parents, teachers and young people” (Hargrave et al., 2009).

From the perspective of the elderly people, one of the unintended side effects related to the institutionalization of electronic services is closely tied to the social implications of the digital divide. Emergence of the new electronic service models and displacing “traditional” or non-electronic service models with the new ones can cause, and has already caused, formation of a non-uniform social group described as the digital orphans.

Composition of this group is twofold. Firstly, it includes individuals who are not able to use the new services. There are possibly multiple reasons for this lacking; the individuals may not have sufficient technological literacy skills, they may suffer from mental or cognitive disorders commonly associated with aging, they might not trust the new service, or they are not able to assimilate what the terms of the new service (pricing, usage, extent, etc.) precisely mean to them.

Secondly, the group includes individuals who suffer the most from closing of the local point of service due to the new and preferred electronic service. For example, the continuous trend of closing local bank and postal offices in remote areas has raised the number of individuals who are no longer able to cope in their everyday lives in the way they are accustomed to. While this increases vulnerability to malicious targeted actions (see above), it also has other technology-related risks.

The concept of the digital orphans is rooted to the basic notion of orphanage, the condition of being 'desolate and without protectors', in a similar fashion as in the cases of orphan diseases, orphan drugs and orphan patients; concepts that have multiple concurrent, and often complementing, interpretations in the modern medical vocabulary.

In the case of orphan drugs, the European Union (2010) defines orphan drugs as "...medicinal products intended for the diagnosis, prevention or treatment of life-threatening or very serious diseases affecting less than five in 10.000 persons in the Community". This interpretation is probably the most widely employed in the medicine. However, when the concept is defined using a patient as the unit of analysis, different interpretations start to emerge.

Orphan drugs can also be seen as a reference to pharmaceuticals developed for the target populations who are too poor to afford them (cf. Griffin, 2002, p. 14). From the viewpoint of the patient, the concept can also be seen as a reference to uncommon or rare medicines applied when the recommended (i.e. evidence-based) medication is proven insufficient or even inapplicable.

The concept of orphan patients is commonly attributed towards patients who suffer from rare diseases (see orphan diseases), or whose rare and unusual problems remain outside the sphere of evidence-based medicine (cf. Shelley & Shelley, 2006, pp. xi-xii). In some cases the orphan patients are also described as patients who are "lost to the system", i.e. they are without assigned primary provider overseeing their care (cf. Sullivan, 2000).

Out of these three, the concept of orphan diseases is probably the most consistently defined. In general, the concept refers to a rare disease, such as one defined in the context of orphan drugs. However, there are other definitions for this concept as well. For example in the MedicineNet¹², which is an online, healthcare media publishing company owned by WebMD, the concept is defined as "a disease which has not been "adopted" by the pharmaceutical industry because it provides little financial incentive for the private sector to make and market new medications to treat or prevent it".

¹² <http://www.medicinenet.com/> (accessed: 4.10.2011)

With this definition, the concept opens up for another definition provided at the MedicineNet where the orphan diseases can be seen as ones ignored by the pharmaceutical industry because they are “far more prevalent in the developing countries than in the developed world”.

The concepts above are all related to inequalities amongst the individuals as well as to maximizing corporate revenue. Using these aspects as a starting point, the over-arching idea behind the concept of digital orphans starts to emerge; this non-uniform group consists of individuals who have, for one reason or another, drifted aside from the general tide of conducting their daily affairs electronically in a fashion dictated by the service providers who seek to conduct their business in the most economical way possible. They have become “rare” much in a similar fashion to orphan diseases or patients that suffer from an uncommon disease.

Even if the current trend continues, and it will be relatively easy to create affordable means for most of the population to protect themselves against social engineering and other forms of attack or digital fraud, there will always be a group of individuals who will remain outside the reach of the “safety nets” spun by the society and the service providers. For electronic services of the near future, these kinds of digital orphans are a challenge. There is a need to steer the patients to use new technologies and electronic services in their care and well-being in order to create more cost effective health care services. At the same time, there is a moral imperative to create egalitarian health care services that provides the same basic health care services to all, regardless of their economic or social status. For example, the WHO Tallinn Charter (World Health Organization, 2008, p. 3) promotes values of solidarity, equity and participation:

“Each country shall seek to contribute to social well-being and cohesiveness by ensuring that its health system distributes the burden of funding fairly according to people’s ability to pay, so that individuals and families do not become impoverished as a consequence of ill-health or use of health services...”

Unintended side effect: profiling

A more technology oriented unintended side effect emerges from customer profiling. While development of efficient customer profiles can be regarded as a key factor, for example, in the development of online recommendation systems (Park & Chang, 2009), there are inherent risks related to customer’s privacy, which have been already identified (cf. van Wel & Royakkers, 2004, pp. 132-133).

Especially in electronic health care services, advertising and profiling is a delicate matter. While the information is primarily used in providing better service for individuals, it gives rise to two questions in relation to the potential (re)use of the information: a) to what extent the profiling is used in direct-to-consumer (DTC) advertising, and b) how the information is used in customer selection and profiling.

In relation to DTC advertising, we are already seeing how information about demographic distribution of potential clientele is used in questionable manner. For example, as elderly people are often more prone to age-related illnesses, such as heart disease and cancer, emotional marketing pleas are used in online medical marketing (e.g. “be cancer concerned”) by dubious online marketplaces (Lovett & Mackey, 2013).

In electronic health and well-being services this kind of questionable advertising occurs especially in relation to pharmaceutical products and supplements. These kinds of products are promoted via channels where marketing cannot be effectively controlled by national agencies or by regulatory bodies, such as US Food and Drug Administration (FDA). Even outside the Internet, controlling DTC marketing can be a challenge. For example, in the United States where DTC advertising of prescription drugs is permitted, an average television viewer sees 16 hours of prescription drugs advertisements every year (Frosch et al., 2007, p. 6).

In the near future, a much more detailed real-time personalized advertising may be possible. For example, in the United States a patent application for a personalized marketing architecture which uses “real-time data and explicit customer input to augment marketing segmentation, analysis and video advertisement delivery” has been filed in 2005 (Looney et al., 2005). According to the patent application, the architecture monitors and identifies customer behaviour, preferences and intentions, and presents real-time video messages on the basis of the collected information (incl. location and movement of the customer, and time used proximate to a merchandising display). Considering what kind of features the next-generation consoles and media servers will have (namely the Xbox One), implementation of such solution may not be far in the horizon¹³.

On a more detailed level, according to the Claims 0097 and 0098 (ibid., p. 11), one embodiment of the patent can act as an online medicine cabinet, integrating biometric scanners and online services, providing the user suggestions for an appropriate medication. Early state experiments on personalized advertising in a

¹³ Side note: Microsoft applied patent for emotion-based advertising on December 2nd, 2010 (for details, refer to the U.K. patent application 20120143693).

digital television environment were introduced in the iMedia project where the first prototype was presented already in February 2001 (Bozios et al., 2001). Similarly to the patent application by Looney et al. (2005), the iMedia concept utilized consumer interaction with the television as a factor used in consumer profiling. These kinds of applications are of particular interest in relation to elderly people where the use of television is concentrated. In their homes, the television can be regarded as a dominant technology, and even as a companion (Östlund, 1995, pp. 251). In Östlund's research (ibid.) television and radio were the principal source of information for the elderly and they spent up to five hours per day watching television. How on-demand services, that are becoming more and more popular, will change this setting in the near future remains to be seen.

As a consequence of relatively unregulated and uncontrolled online marketing of pharmaceutical products and supplements, the authorities are forced to use their limited resources on public health warnings and announcements. For example, during the H1N1 pandemic of 2009 authorities such as Health Canada warned consumers about buying unauthorized products from the Internet (Health Canada, 2009). At the same time, security organizations such as the Sophos Inc. (Samosseiko, 2009) published analysis on what kind of business models are behind the multi-million dollar industry of false online pharmacies.

The Internet literate are commonly aware of the risks related to the use of online pharmacies. In particular illicit and unregulated pharmacies that are outside organizational or governmental control may pose a serious threat to the patient safety as the product that are sold may contain almost anything (dangerous chemicals, wrong pharmaceutical ingredients, see Lovett & Mackey, 2013, p. 96). The Internet literate are also aware of the fact that information on their electronic purchases and other activities are monitored, collected and even sold (Taylor, 2004, p. 632). However, the individuals who are less conscious about these matters, such as the elderly individuals who are struggling with the new and emerging technologies, are in jeopardy. If the dubious pharmacies target these individuals in their profiled direct-to-consumer marketing campaigns, their chances for succeeding are increased.

A large-scale success of the dubious pharmacies in this area would not only potentially harm the individuals, but it could also gnaw away the overall trust towards online pharmacies, thus dealing a harmful blow against the whole industry. Remedying this kind of damage and restoring the trust of the consumers might take a long time and it might not even succeed.

Particularly in relation to health and well-being information, profiling raises many questions. It is already a common practice to limit availability of some insurance products to people of certain age and state of health. The situation is even worse if genetic background and financial data is included in the

correlation. For example in Finland, we are already seeing how companies (e.g. S-ryhmä) specializing in daily consumer goods trade branch out to insurance and banking. In theory, with this kind of information the organizations can create a cross-section of the everyday lives of their customers. How this scenario changes the underlying business and how the legislation will eventually react remains to be seen. At least one potential outcome of this development is the increase in the number of digital orphans due to customer exclusion.

In another scenario, profiling in electronic health care and well-being services can lead into a situation where the excluded person is left adrift, without information on where the appropriate service provider can be found, and which parties are involved in the reimbursement of the provided service. We are already seeing this kind of unwanted development for example, in the health insurance policies where understanding what the policy covers in terms of coinsurance clauses, ancillary services, benefit packages, etc. might leave the insured “lost in the system” and literally running from one counter to another. In this kind of situation resources, especially those of an elderly person are easily drained and the person is left alone with one’s ailments. Especially the European countries have been criticized for this kind of lack of cohesion and coordination between sectors (Askim et al., 2010, p. 1451). One instrument that could address these kinds of coordination and integration problems is one-stop-shops. These organization models could act as a front for a complex organizational entity, or as an umbrella for several agencies (ibid.). In this, the one-stop-shop can be seen as representing a mediator in its role as a facilitator of services.

2.4 Recommendations

In electronic commerce, trust has been identified as one of the key factors for a successful adoption (cf. Pavlou, 2003, p. 70; Kim et al., 2008, p. 545; Sila, 2013, p. 205). In more general terms, trust can be considered as a prerequisite for all (electronic) services. There are various levels on which the trust can be built on. For example, one can trust the technology (i.e. encryption, digital signing, etc.), the service provider, the mediating agent, or the individual who has recommended the service.

Especially in the context of electronic health care and well-being services, the role of authorities and regulating agencies (such as the FDA) is a key element. From the perspective of the users, the service provider must assure that all social and technical aspects of the service can be trusted. In this context, the role (and trustworthiness) of the authorities and regulating agencies is of the essence; the challenges of trust the service providers are facing are very real ones for the users of electronic services in general, not just for the elderly or those suffering from cognitive impairments. All in all, the role of governments is essential

establishing the trust of health professionals and patients, and in creating a favourable climate for thriving eHealth markets (Friedman et al., 2009, p. 783).

Even though the discussion above has revolved primarily around the digital divide and possible exclusion from the electronic health care and well-being services, there are other (economic) factors that need attention. As the European Union is creating a digital single market, gaining the trust of the elderly people may have wide economic implications. Elderly people, especially those of tomorrow, are a viable market segment for consuming online entertainment, music download business, etc. It is estimated on the level of the objectives for the digital market that especially “the elderly, those with reduced mobility, those in rural areas, those with low purchasing power” (European Parliament, 2014) will benefit from it and “create a better place to meet the demographic challenges of today” (ibid.).

Considering the elderly people, the challenges they encounter in terms of using new and emerging technologies, and the mental or cognitive declines that possibly weigh them down, a new role comes forward. Today and tomorrow, it is quite probable that most of the elderly people in the countries where electronic services are a commonplace practice will at some point of life seek guidance of a mediator whom they trust in terms of using different electronic devices and services, and even in the affairs of the everyday life.

The mediator

The mediator can be a single individual trusted by the (elderly) person (such as one’s child), or the role can be context specific, changing in relation to the used service, time, meanings or values. For example, in the case of an unmarried or widowed elderly person who lives alone with a limited support from one’s family, the elderly person can have one mediator who is responsible of financial matters (incl. banking) and another who takes care of one’s health affairs. These trusted individuals create a support network for the elderly person that can be formal or informal by nature in similar fashion to the ones explored in Scott & Roberto (1985) and Carpentier et al. (2008).

In terms of electronic services and technological literacy, the need for a mediator, or a similar supporting individual by any other name, has been identified in the academic literature. For example, authors such as Bakardjieva (2005) refer to a computer literate friend or a relative with the term “warm expert” (p. 99). Other authors such as Stewart (2007) use a term “local expert” in reference to individuals who help laypeople in adopting new technologies (p. 511). The theme has been recently visited by Stewart and Hyysalo (2008) who explore the role of user-side intermediaries in the “development and appropriation of new technologies” (p. 295).

In reflection to the original views presented by Bakardjieva (2005), Stewart (2007), Okamura et al. (1994) and Trigg & Bødker (1994), the mediator discussed in this work should be considered in a similar manner as a user-side intermediary. The mediator acts as an active and immediate co-user of ICT and new media; as a recognized partner for a domain-specific technology user. In this, the mediator adds the activity of configuring, technical and symbolic co-use of technology to the field of health and well-being services. The mediator does not necessarily have a formal role in relation to the beneficiary or to the service provider (such as a case manager). One acts primarily as an auxiliary to the principal user lending a hand when ICT-artefacts or the electronic services seem alien or unfamiliar; or when one is unable to use them for some reason.

The role is ideally a “fat” one, using the classification provided by Stewart & Hyysalo (2008, p. 302), as the role links different electronic health and well-being services on the user-side. However, this interpretation has its limits; not all services in the domain have electronic counterparts, and if multiple mediators are appointed, it may be feasible to categorize their operation in order to support co-occurring mediation as described in Bødker & Andersen (2005). The limitation of the role to electronic services, and to the use of ICT-artefacts in the field of health and well-being has also impact on the reach of the role. If a mediated electronic service encapsulates most, or even all, providers and other relevant actors in the context of a specific ailment (such as diabetes), or in the context of a type of a service provider (such as municipal health care services), the role can be a long one as well. However, considering the current landscape, a “long” and “fat” mediator is an idealistic notion.

The concept of mediator also borrows from the principles of case management (also known as care management); a way of achieving an integrated and coordinated services. In case management, care is integrated on an individual level as a response to the assessed needs of the beneficiary. More formally, case management is defined as (Case Management Society of America, 2012):

“A collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services to meet an individual’s and family’s comprehensive health needs through communication and available resources to promote quality cost-effective outcomes.”

While there is some debate on the formal definition (Banks, 2004, p. 101) there is some consensus about the main components of case management. These are: a) client identification, b) assessment, c) care planning, d) implementation, e) monitoring, and f) evaluation (c.f. *ibid.*; Tahan, 2008; Rose, 2010). While the basic components are rather generic ones, the ideology of a collaborative process, coordinated by an external actor, brings the concept close to that of a

mediator. Even though there is some overlap, there are some fundamental differences as well; the case management is a more formal concept and linked to a profession or to a service provider. It is often described as a specific job or a task within an existing job role, or even as an organizational process (Challis, 1999, p. 72). A practical example of this is community matrons, experienced senior nurses who work closely with patients, providing and coordinating their care. These patients are often ones with a serious long term condition, or they suffer from a complex range of conditions (c.f. Brown, et al., 2008).

Even though the relationship between the mediator and the service provider is not necessarily a formal one, the relationship is potentially a valuable one in terms of formulation of a service or a product. Firstly, investigation into the role of the mediator, and its impact on the balance between the beneficiary and the service provider, may reveal new information on the formulation of digital orphans; what are the features of an ICT-artefact that require support from the mediator. In other words, what are the shortcomings of the artefact (for example, in terms of usability) that have an impact on the formulation of digital orphans?

Secondly, mediation can be an integral part of a business model, or it can form a business in itself. A “mediator service”, or extending services of home care to include functions of mediation, could be a welcome addition to the field. These kinds of services could also be seen as a differing factor for a flexible small and medium enterprise (SME) for its novelty. From the perspective of the service providers, functions that can be seen as ones falling to the category of mediation, are often neglected or performed in addition to normal home care chores by practical nurses or individuals of similar training. A quality counselling service that could address the personal and emotional problems in the way of using the ICT-mediated health and well-being services would not only bring new business opportunities to the field, but they could also be seen as ones contributing to lifelong learning after working life.

Thirdly, the role of a mediator is often overlooked. The electronic services are implemented from the perspective of the principal user, excluding the supporting one(s), emphasizing importance of the customer-centric experience. Taking the role of the mediator into account when designing electronic services that are used by the elderly people could be used to lessen the potential impact of the digital divide. In the light of discussed well-known demographic projections, giving attention to elderly people is imperative. There is no indication that the elderly of tomorrow need less health services than those of today. Without bridging the gap between the elderly people (in need of a mediator) and electronic services, the service providers face a very real risk of excluding a demographically significant group from the health service provisioning of near future.

Economically, the incentives for taking the mediator into account are also potentially appealing. In terms of possible economic savings, the two principal views to be addressed are a) self-managed care, and b) case management.

In the light of the current demographic development in the EU (Eurostat, 2013b), it can be estimated that in 2016 every fourth person between 55-64 years has never used the Internet. As such, they are also outside the immediate reach of electronic health care services (e.g. the services are not used at all, or they are mediated). If the use of the mediator can bring some of these digital orphans within the reach of the services, the savings can be similar as in the Expert Patients Programme (EPP) in the UK. The programme, that was piloted in 2001-2004 and mainstreamed in 2004-2007 yielded savings of £1.800 per patient yearly (Expert Patients Programme, 2013, p. 3). The savings came from self-management of health related affairs that resulted in fewer visits to their health service providers, and decreased medication costs (ibid.). In other recent sources, the potential savings of self-managed care are also emphasized. For example, it is estimated that health care costs can be 8-12 % higher amongst less active patients when compared to the more active and knowledgeable ones (Barlow-Oregon, 2013).

In terms of multiple comorbidities, mental and cognitive declines and general difficulties in accessing health care services via the health system, case management has been identified as one of the key elements in achieving economic savings. It is estimated that in the U.S., it is possible to save even 6.9 million USD per year amongst the top 5 % of patients with health complexity, or health issues that are complicated and interact (Kathol et al., 2011, p. 142). As it is estimated that in general 2 to 5 % of patients that have health complexity cost a third to a half of health costs (ibid.), potential savings of case management are considerable. If with the use of the mediator, case management practices could be adopted to other fields besides health care, and within the field to any case of multimorbidity, savings could be dramatic in the most reimbursement environments.

However, this is pure speculation as the costs of care vary from country to country, and the technological maturity of electronic health care services is similarly different. Even though economic aspects are outside the immediate scope of this dissertation, the opportunity for this discussion was worth taking in order to provide some insight into the potential savings.

Mediation and mechanisms of trust

Creating ICT-mediated health care services that take mediation into account is not simple. Considering that the mediator could be a layperson in terms of used technologies (and yet an expert in terms of provided services), the mediating

ICT solutions should not have such prerequisites in their use that require a through knowhow on the technical particulars. Domain-specific skills, such as practice of medicine or up-to-date knowledge on pharmaceuticals, are relevant and beneficial for a mediator. However, the only skills outside these kinds of domain-specific skills that can be seen truly as a prerequisite for mediation are a) people skills (ability to answer questions, give advice and to deal with emotionally charged situations, ability to act with discretion, etc.), b) communication and observation skills, c) understanding of medical jargon and concepts, and d) technological literacy. From this it follows that a level of competence in the use of ICT-artefacts should be present as well. Mediating services that employ ICT in their function is a challenge if the use of such technology is outside the mediator's comfort zone.

If we look into these skills more closely, we can make following observations. Firstly, the skills are fundamentally the same ones required from any health care worker in the field today (excluding the actual clinical skills that depend on the profession). In addition to communication and interpersonal skills, the health care professionals of today are required to have a degree of competence with technology that has become an essential part of most care professions of today in the OECD countries. Secondly, the skills can also be seen as enablers in terms of basic roles and activities of intermediaries (Stewart, 2000; Stewart & Hyysalo, 2008); facilitating and brokering are effectively linked to communication and interpersonal skills while configuring is also related to technological literacy (cf. chapter 1.4).

Even though a certain degree of trust is needed between the mediator and the beneficiary, there might be valid reasons for limiting mediator's access to certain information. However, making this division is not always clear-cut. For example, in the case of health care, limiting access only to a portion of information related to current medication (e.g. the mediator could see information on diuretic but not on antihypertensive drugs) is potentially dangerous. On the other hand, in terms of financial information, it is easier to fathom valid (and safer) reasons for limiting access to it. In order to support mediation, the ICT-mediated health care solutions should be able to encapsulate, and even hide, information that is not relevant in the context of the current transaction, employing the principle of "limitation of collection" as depicted in Fairweather & Rogerson, 2001 (p. 224). This kind of information encapsulation has been a commonplace practice in the context health care information systems for a long time where certain subsets of patient data can be regarded as a sensitive ones (cf. Denley & Smith, 1999 pp. 1329-1330).

Using ICT-mediated health care services in illustrating other examples of information encapsulation, access to the complete medical history of the beneficiary might not be important when the mediator uses an electronic service

for reporting weight, blood pressure or insulin levels of the elderly person to the General Practitioner (GP). However, certain particulars of the medical history that might not be available for the mediator are in all likelihood of the essence to the GP. While most of this pertinent information is available for the GP from health service provider's information systems, it is probable that in the future more and more health information originates from beneficiary (e.g. personal health monitors, sports computers, medication reminders, etc.) belonging thus to the beneficiary's personal health repository.

Division of information access to different actors can be challenging in today's fragmented health landscape. Considering that there might be multiple different health care providers and multiple different mediators related to beneficiary's health events, implementation of encapsulation methods should be carefully devised. In some cases the mediator can be seen as a gate keeper to the available information thus creating mediation fundamentally as a mechanism of trust from the perspective of the beneficiary (figure 2.4).

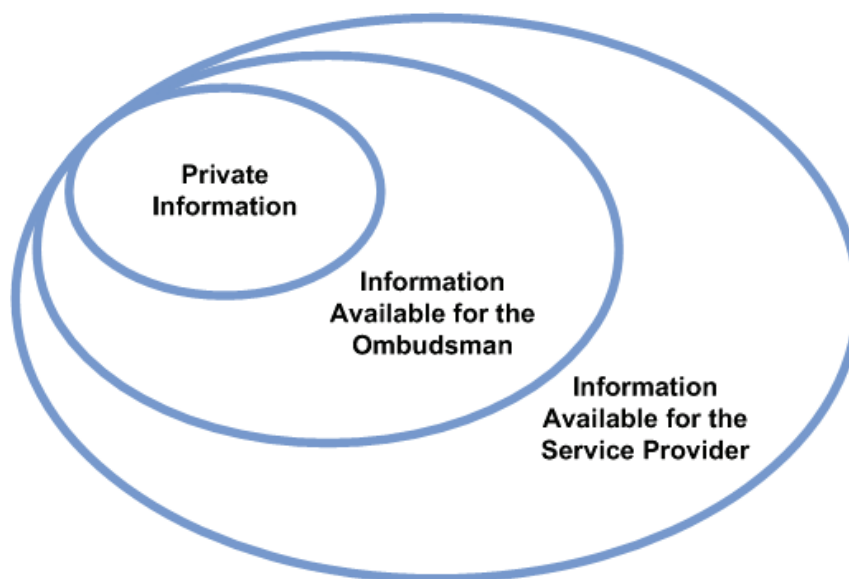


Figure 2.4. Layers of information available for different actors (illustration).

If the mediator acts as a gate keeper to the beneficiary's information, the transactions related to a particular health event occur only if the beneficiary considers the transaction trustworthy. Providing that the mediator's information and technological literacy skill are sufficient, this kind of arrangement and encapsulation of information can provide a partial cover for the elderly person

against some of the identified risks, such as in the case of deceptive or fraudulent DTC marketing.

The mediator has further significance in relation to the electronic services. In the services, such as in online tax filing, a special jargon is often used. The electronic services should provide sufficient tools for the mediator for translating the terms a) in a way understood by the elderly person, and b) in such a fashion, that the elderly person can understand the implications of using the service. However, implementation of these kinds of tools should not lead to services that are intentionally obscure and subject to mediator's interpretations alone. In this kind of situation, the balance between the beneficiary and the mediator could tilt dangerously in favour of the latter, placing the mediator on a pedestal instead of the beneficiary in terms of decision making.

In electronic health care services, these kinds of tools can make a difference when informed consent, not just "a name on a paper", of the individual is required. As characterized by Engelhardt (1996, p. 316), informed consent should be all about patient opportunity to be autonomous in their choice of medical treatment, it does not force them to be that. In this kind of situation of choosing, the role of the mediator can be seen as a one of promoting patient advocacy similarly when practices of good nursing are followed. In nursing, advocacy is a central element of nurse's efforts in safeguarding patient's interests. Advocacy involves nurses to ensure that the patients are aware of their rights and they have required information at their disposal for informed decision-making (Dykes et al., 2009, p. 70).

Retirement and alienation

Retirement can be regarded as a turning point in the lifelong learning; the individual no longer gains information (training, recommendations, experiences, etc.) on new technologies from work or colleagues. Lack of this kind of social network is a factor that has potentially negative impact on the information and technological literacy of the elderly person. As argued by Vandebosch et al. (2005, p. 956), it is possible that as the technology advances and new electronic services emerge, the elderly people may experience alienation. At the same time the authors (ibid., p. 296) see the adoption of the new technologies as a risk as well since it may lead to technology-dependency.

At the moment, the elderly people are amongst the population groups with the highest risk of digital exclusion (Cruz-Jesus et al., 2012, p. 279), placing them outside "information society" of today. Even though it is estimated that a division between the Internet and technological literate and non-literate will disappear as younger computer literate cohorts replace the older ones, there is

evidence that even amongst the young people, a group of individuals with low or none literacy skills exists (Broos & Roe, 2006, p. 307).

Alienation from technology can start already when the individual is still in the active working life. For example, lack of computer skills may result in earlier retirement in the case of well-educated male employees (Biagi, 2007, p. 20). In the case of low-educated men and women and in the case of selling, caring or teaching (women with high education) such results were not evident (*ibid.*, p. 20). One interpretation for these results could be that as the use of ICT has become a prerequisite in most high-education positions, individuals who lack the skill may not find sufficient conditions in terms of expected working conditions (incl. salary) that make postponing the retirement a preferable option.

In countering some of the negative effects originating from alienation or low technology adoption, the mediator is in a central position (providing that the relationship between the mediator and the elderly person is interactive and on equal footing). Ideally, in this kind of balanced relationship, the information and technologically literate mediator exhibits advocacy and takes the elderly person actively into account, supporting the person in the use of technology that is gradually becoming unfamiliar over time. To support these endeavours and to further support elderly person's autonomy over the technology, the familiarity aspect should be taken into account when new technologies and services are designed. For example, the research by Quadrello et al. (2005) suggested that in addition to ownership, familiarity could be another of the major factors affecting the use of technology in communication amongst the elderly people (p. 206).

Enhanced familiarity focuses on implementing new ICT-artefacts and services in the practical terms of the elderly people, using familiar constructs, mechanisms and communication models. In practice, this means that when new technology is developed, the traditions and existing service models that are familiar to the elderly people are taken into consideration and used as a point of reference. For example, in her research into electronic services intended for the elderly people, Männikkö-Barbutiu (2002, p. 634) concluded that the continuity and familiarity are important aspects for the elderly when they are approaching the new technology. With this kind of compatibility in mind it is, at least partially, possible to help the elderly users to maintain the acquired level of ability over the technology.

A need for this kind of familiarity came up in a networking session early in 2012. One particularly heated argument was provided by a specialist during a session that focused on analysing the current state of self-care portals for patients with a recurring, or long-term, ailment.

“It is obscene for [health] service providers to ask the patients, especially the elderly ones, to use these [self-care] portals. Each one of them varies from another. The portals provided by the public sector, such as the municipality, are fundamentally different from those provided by the private sector. Furthermore, if we talk about patients who are still in the working life, their occupational health service provider may still have a different portal. We just can’t expect patients to learn to use all of these systems, especially if their functions keep changing from one version to another.”

A problem with this kind of model is the potential burden of the existing, and potentially outdated, technology for example in terms of a service channel or a user interface. It might not be viable to mimic the operation of the legacy systems when more efficient and effective service models are available. Especially if the potential user group of the technology is a more generic one, covering different ages and population groups. However, a balance that does not make the new technology unusable by larger part of society must be achieved.

One perspective for maintaining enhanced familiarity is found in tailoring; a common function of personalizing ICT-artefacts to meet individual preferences (cf. Thirumalai & Sinha, 2010, p. 477). Already in 1994 Trigg and Bødger regarded tailoring as a function of adjusting software to the practices of the working place and in principle, their interpretation still has merit regardless of the recent technological advances, such as emergence of social media. Okamura et al. (1994) refer to the intervening actors performing the required adjusting as mediators. When new or updated services are implemented using existing media, e.g. new version of an online bank for the latest Internet browsers, functions that enable using services in similar fashion to the previous version could be used in maintaining familiarity.

Authors such as Gregor et al. (2002) also regard tailoring or as they define it “adapting to the changing needs of users as their abilities change” (ibid., p. 152) as a key aspect in designing user interfaces for the elderly people. In their work (ibid.) the authors introduce a paradigm called “Design for Dynamic Diversity” (D³) as design methodology that takes into account the changing needs and abilities of the elderly.

2.5 Conclusions

Even if the future generations will become more capable of adopting new technologies and service models, they too will get on in years. Regardless of the advances in the field of medicine and pharmacology, it is likely that the elderly people of the future will suffer from the same mental and cognitive declines associated with aging today. Like the young of today, the old of tomorrow will

be normal users in that sense that they will have their personal preferences (and they too will be reluctant to change).

To support the elderly of tomorrow in their health related activities that are becoming more and more computerized, and to take them into account as a viable market segment, new design approaches are needed. These approaches should take the mediator, lifelong learning and enhanced familiarity into consideration. If we are unable to put these approaches into use, we might not be able to lessen the financial and human burden that growing elderly population places on the society without cutting down the level of service for this group into which we all belong to at some point. In this, technology is not only an enabler for maintaining the accustomed level of service; it can also provide an opportunity for activating willing individuals to be more active in terms of their health and well-being, and that of their close ones. Some of these design principles were tested in the SeniorHaavi project within the InnoElli Senior program. In the project a new service portal¹⁴ that contained a counselling subsection for an individual who could work (to a degree) as a mediator for an elderly beneficiary.

In the following chapters the role of the mediator and its significance to the ICT-mediated health care are further investigated. In the following chapter, potential roles of the principal actor (i.e. beneficiary) are examined in the light of new and emerging electronic health care services. In the chapters following this examination, technological aspects of the mediation are highlighted. The final chapter draws a scenario that highlights some of the problems related to mediation and describes a situation in which mediation may even turn out to be a risk for the beneficiary.

¹⁴ <http://www.palvelupolku.fi/> (accessed: 19.9.2012)

The following chapter is revised and extended from:

Lahtiranta, J. (2008), “Emerging roles in eHealth”, in: Suomi, R. & Apiainen, S. (Eds.) *Promoting Health in Urban Living*, 2nd International Conference on Well-being in the Information Society, August 19-21, 2008. Turku, Finland. TUCS General Publication No. 49, pp. 141-152.

3. Emerging Roles In the ICT-mediated Health Care

Patient-physician relationship has been one of the focal points in the health care related ethics and philosophy research for at least a century, if not longer. Amongst others, Spanish medical historian Pedro Lain-Entralgo (1969, pp. 17-22) characterized the relationship between the patient and the physician as a form of *philia*, or friendship, already present in the works of Plato (Jowett, 1892). A bit earlier, Lain-Entralgo's contemporaries Szasz and Hollender (1956) looked into the formation of patient-physician relationship, defining three basic models for the relationship where the focus shifted between a patient and a physician: activity-passivity in which the physician has the initiative and the patient is unresponsive or inert, guidance-co-operation in which the physician tells the patient what to do and the patient complies, and mutual participation in which the physician and the patient are more akin to partners (Dixon, 1989, p. 10).

Later authors such as Childress and Siegler (1984) visited this popular theme and compared the role of a physician to those of a technician (p. 21) and parent (p. 18). Until 1980s inherently paternalistic views such as that of a parent (*ibid.*), where the physician assumes a dominant role, have been regarded as the "most prevalent approach to treatment decision making" (Charles et al., 1999, p. 652). Even though it is acknowledged that there is an on-going transition away from a paternalistic view (Swan, 2009, p. 513; Gafni & Charles, 2009), and other interpretations have emerged especially in relation to empowerment (*cf.* Aujoulat et al., 2007), the paternalistic view is still strongly present in the field.

As Kaba & Sooriakumaran (2007) describe in their analysis on the evaluation of the patient-physician relationship, the roles of the patient and physician have changed in the relationship ever since the priest-suppliant relationship of the ancient Egypt (figure 3.1). The political, economic and social distance between patient and physician has changed and new interpretations on the relationship have emerged. While not universally valid or applicable, these include equal partnership (*ibid.*, p. 64), and even a customer relationship, a relationship between a buyer and a provider, emphasizing patient's freedom of choice (*cf.* Tritter & McCallum, 2006).

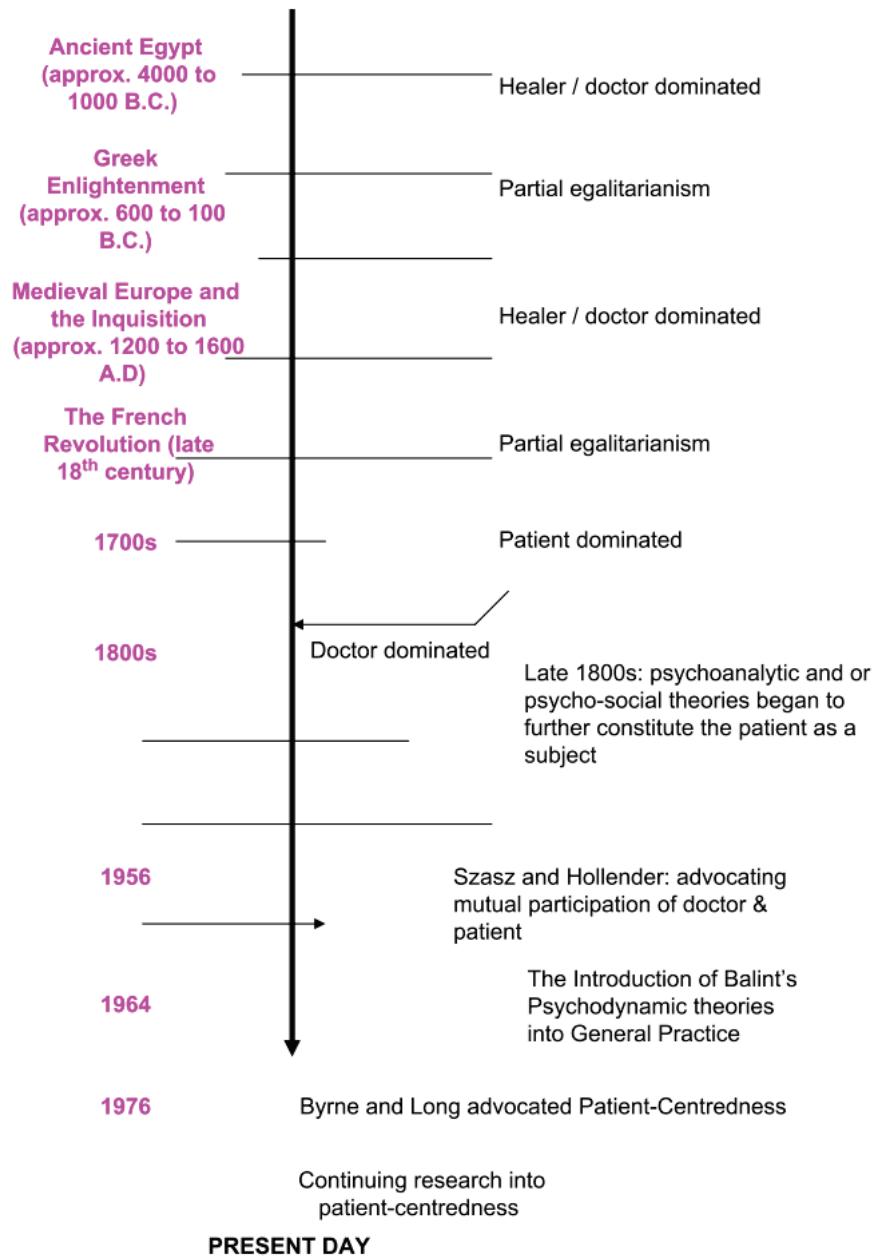


Figure 3.1. A time line indicating the evolution of patient-physician relationship (Kaba & Sooriakumaran, 2007, p. 64).

The recent changes in the patient-physician relationship are particularly visible if we look into the gradual disappearance of a traditional family doctor. Until the mid-turn of the 20th century, it was the practically wise family doctor who was responsible for organizing primary medical services of a particular social unit (i.e. family, line, or even a small village). As described in the “Family Doctor” by Wolfe et al. (1972), the work of this knowledgeable doctor used to cover total health needs of an individual, or group of individuals, from scientific to humanistic side of medicine (ibid., p. 10). In the Western World, the traditional family doctor was not just a physician, but also a counsellor and a family trustee on some issues that could not be solved by means of evidence-based medicine.

Varying from country to country, the situation changed around the 1970s. Domiciliary services provided by, often solitary, family doctors were for the most part replaced by general practitioner hospital units, or similar. In Finland, this change took form in a so-called population responsibility principle, which was piloted in 1985-1993 (Jäntti, 2008 p. 82). In the pilot, a named doctor and a nurse were appointed to an individual and in some cases, to one’s immediate family residing in a specific geographic region. However, this principle was not employed as a permanent nationwide practice. According to the Finnish Medical Association (2005), approximately 70 % of the population had an assigned doctor in 2005.

For various reasons, such as general advance in the field of medicine, availability of medical information, and demands of the overall health care industry, medicine as a discipline has been divided into specialties that are narrower than ever. In a medical profession, it is possible to specialize in fields such as cardiovascular surgery, clinical neurophysiology, and otolaryngology (just to name few). It is also possible to specialize in the field of family medicine (also known as, general medicine or general practice), a branch of practicing medicine which is by definition probably closest to the work of a traditional family doctor due to its general nature. For example, the World Organization of Family Doctors defines the specialty in the following manner (WONCA, 2002, p. 10):

“General practitioners/family doctors are specialist physicians trained in the principles of the discipline. They are personal doctors, primarily responsible for the provision of comprehensive and continuing care to every individual seeking medical care irrespective of age, sex and illness. They care for individuals in the context of their family, their community, and their culture, always respecting the autonomy of their patients. They recognise they will also have a professional responsibility to their community. In negotiating management plans with their patients they integrate physical, psychological, social, cultural and existential factors, utilising the knowledge and trust engendered by repeated contacts. General practitioners/family physicians exercise their professional role by

promoting health, preventing disease and providing cure, care, or palliation. This is done either directly or through the services of others according to their health needs and resources available within the community they serve, assisting patients where necessary in accessing these services. They must take the responsibility for developing and maintaining their skills, personal balance and values as a basis for effective and safe patient care.”

Increased specialization possibilities and other changes in the field created a situation in which the field of family medicine as a favourite choice of career amongst medical students lost some of its appeal. For example, in the year 2001, less than 28 % of the Canadian medical students selected family medicine as their first choice of career (Rosser, 2002, p. 1419). In the European Union the situation is similar as a whole the field has suffered from a “classic lack of popularity [...] among medical students and junior doctors” (Villanueva, 2009, p. 2). In Finland the trend was similar. In 1998 family medicine was the first choice of specialization for 24 % of the new doctors, in 2003 only 16 % were interested in the field (Heikkilä, 2007). However, the recent statistics indicate that the trend may be changing. For example, in Canada where the focus has been on the intake of family medicine training (Jaakkimainen et al., 2012), the recent surveys indicate that over third (36.3 %) of all new medical students selected family medicine as a preferred career choice (Lemire, 2013). Also in Portugal, the field has reported “unprecedented levels of popularity amongst trainees” (Villanueva, 2009, p. 1).

Traditional family doctors were in the trade for themselves and for the patient. They were also largely masters of their own individualistic behaviour and ethics. Nowadays, the doctor is a specialized entity and a part of a comprehensive health care provider organization. For its part, the increased specialization of medicine and medical practice has led to a fragmented pattern of care where patients are treated by various specialists in numerous different health care organizations and units. There is rarely a long-lasting friendship, or *philia*, between the patient and the physician since the one providing the care and overseeing the patient’s condition is often “the current doctor on call”.

However, it should be noted that even though the relationship between the patient and the physician has become, what can be characterized as, clinical by nature, the importance of “softer” aspects of care have not fundamentally diminished. For example Haynes et al. (2002, pp. 36-38) see patient values as a fundamental part of today’s evidence-based clinical decision making.

As an example of the fragmented nature of health care provisioning and increased specialization in the field, the figure 3.2 provides an example to the chain of service of a chronically ill elderly patient. The example is a cursory one, covering only a small portion of an overall chain of service which typically

covers a longer period of time and involves a more numerous group of different service providers (Lehto, 2000, p. 41).

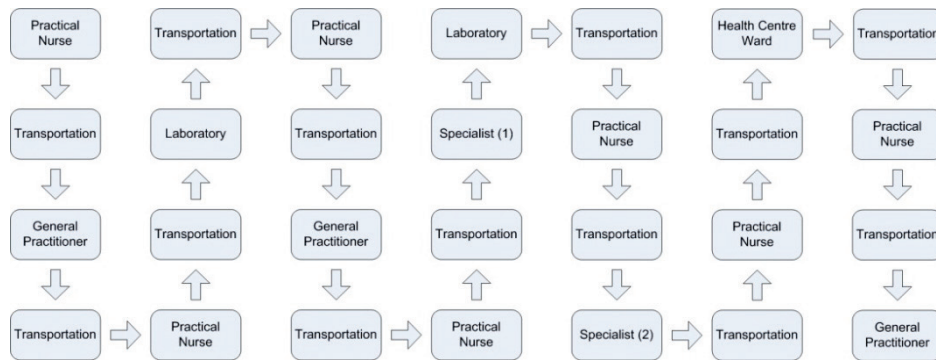


Figure 3.2. Example of a chain of service in the case of a chronically ill elderly patient (Lehto, 2000, p. 42, Finnish).

For its part, this fragmentation and specialization has led to adoption of different care pathways, best practices and other more detailed models. The purpose of these models is to help health care professionals in their work, to coordinate their efforts with other professionals, and to incorporate other guidelines, protocols, algorithms, etc. into everyday practice. While the rationale behind using these control mechanisms is, without doubt, a valid one in today's medical practice, they can also be regarded as tools of bureaucracy and control; a necessity that has risen from the current way of conducting medical practice. In terms of evidence-based clinical guidelines, they are internationally regarded as tools for implementing research evidence into practice, thus improving the quality of care (cf. Grol & Grimshaw, 2003; Becher & Chassin, 2001).

In this Age of Information, fragmentation of care providers has taken form, amongst others, in different services of ICT-mediated health care that have found their way into patient-physician relationship. Different online databases, Decision Support Systems (DSSs) and intelligent applications have provided means for the patient to challenge the traditional authority of the physician. The patient's perception of the situation might be such that the physician is not a true authority in the relationship but a service provider, and as such one can be confronted if the service does not meet patient's expectations. Partially, it follows from this, that the role of a patient is no longer a sufficient unit of analysis in the changing field of health care. Therefore, alternative interpretations should be brought up in order to understand the patient-physician relationship in the context of today's electronic health care services.

3.1 The Roles

Due to the on-going change in the field of health care, the role of a patient alone is no longer a sufficient unit of analysis when the nature of patient-physician relationship in the context of ICT-mediated health care services is examined. One problem with the role is that it inherently implies the existence of a physician and an active relationship between the two actors. Another problem is that the role does not sufficiently take account currently valid operations models in financing and organizing health care delivery.

In the recent times the scope of ICT-mediated health care services, and health care delivery as a whole, has expanded into adjacent spheres of operation, such as into fitness, complementary therapies, and even recreation. This expansion has brought new actors, such as nutrition and fitness specialists, family counsellors and life management “coaches”, into the health care markets. What can be perceived as a “traditional” patient-physician relationship does not necessarily exist between the actors.

Due to the on-going changes in the field and overall evolutionary trends in the society, such as steady growth of individualism, some authors such as Balint and Shelton (1996) even considered that the patient-physician relationship was in a crisis. Most of their arguments presented in the late 1990s, such as change of medicine from elitist context to a democratic one, are still valid today. For example, the health care reform initiative Patient Protection and Affordable Care Act under the president Obama’s administration in the United States (aka “ObamaCare”) highlighted some of the issues presented by the authors (ibid.). In particular, the discussed spending cuts to Medicare and other federal health programs (Smith, 2010) give a rise to questions surrounding the role and resources of the society in terms of health care delivery (Balint & Shelton, 1996, p. 888). Similarly, the discussed tax increases (Smith, 2010) can be seen as a shift in a scale between perceived elitism and democracy in the health care setting.

More and more of the services that can be regarded as ones traditionally belonging to the health and well-being sector are offered by the private sector, and to some extent, by the third sector (i.e. associations and societies) as well. As a practical example, some of the public health laboratory services are outsourced to the private sector in order to streamline the way public organizations do business (Avery, 2000). In Finland, it is estimated that for economic reasons, the use of alternative service providers is likely to increase in the near future (Laamanen et al., 2008, p. 296). One recent indicator of this development is the expenditure on outsourced services in the Finnish municipalities; in 1997 municipalities spent 471 M€ on outsourced services, in

2009 the expenditure was over 2 B€ resulting in average yearly growth of 13 % (The Ministry of Social Affairs and Health, 2012, p. 8).

Similarly, in Finland, it is also estimated that the cooperation between the public and the third sector will increase by the year 2017 (Laamanen et al., 2002, p. 65). This may very well happen since the role of the third sector has increased over the last years, partly due to the economic pressure to decrease public expenditure on health care and social services (Sillanpää & Lönnqvist, 2010). In 2010, there were already over 13.000 non-governmental organizations, employing more than 36.000 individuals in the field (ibid., p. 109). However, there has been some friction and according to Paasivaara and Suhonen (2005, p. 351) concrete co-operation between the sectors was rare in the early 2000, partly due to lack of incentives.

Other health care related services offered by the private and third sector, such as health coaching (cf. Palmer et al., 2003) are also increasingly proactive and typically require more self-initiative than the “conventional” health care services. The conventional services (effectively, ones belonging to the field of primary health care), which have always been in the core of health care service delivery, are traditionally offered by a health care professional, such as a general practitioner, to a patient. When it comes to health care in general, and more specifically to new and emerging electronic health care services, this view of health care service delivery will be valid in the future as well, if not necessarily the only one.

What has changed over the past years is that the health care consumerism has been on the rise and it will continue to do so – especially in the OECD countries. For example, in 2007 sales volume in German consumer health care markets were estimated to be 60 billion euro and during 1997-2007 the growth was 8-10 % p.a. (Grumbach & Mieth, 2008, p. 3). In practice, the increased health care consumerism indicates in all likelihood that a) health care is becoming more economics driven, and b) people are becoming more approving towards products and services that they consider as ones promoting to their overall well-being.

In other words, many groups of people are becoming, if not experts, at least commonly more aware and interested on their personal health and that of their family members; even co-producers of health as described by Teperi et al. (2009, p. 110). Due to these changes in the health care and in the individuals using the services, the relationship between the two primary actors cannot always be characterized as a patient-physician relationship but, for example, that of a customer connection.

With this on-going change in the relationship between the primary actors, the role of the individual receiving the health care service in question will expand,

amongst others, to those of consumer, customer and citizen (figure 3.3). These views are not new but they are different when compared to that of a patient. Each of these views has a unique perspective on the (electronic) health care services and products, and on the related information needs.

In the following investigation on the interrelated roles of the consumer and customer is brought into light in order to highlight issues such as freedom of choice and advertising. While in the colloquial language these roles often have a similar meaning, in the context of this chapter the roles differ from each other on a fundamental level; for example, a service provider does not have a (formal) relationship with a consumer whereas there is one with a customer.

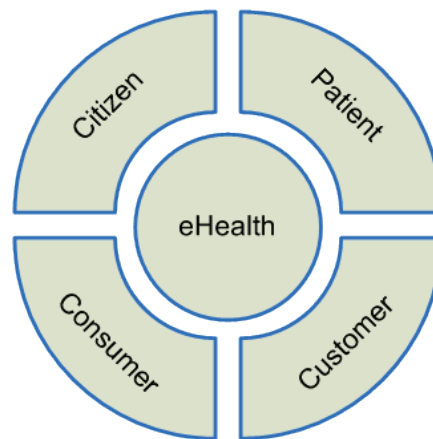


Figure 3.3. Different roles and ICT-mediated health care.

One of the key factors behind the change in the supply of health care services is the constant and increasing demand placed on them. For its part, this demand originates from an imminent and large-scale demographic change, and from related increase in demand for health and social services (e.g. supported living, home care, treatment-intensive care of aging-related illnesses, such as cancer, Alzheimer’s disease and diabetes, see Rechel et al., 2009). By the year 2025, the relative amount of elderly people (i.e. 65 years and more) in the world is projected to increase from the current 6 % to 15 % (Martin, 2000, p. 279). In order to cope with the societal impact of this demographic change, which will have a grave impact especially on the OECD countries due to the continuous rise in the old-age-dependency ratio (number of inactive elderly over 65 years to the total labour force), preventive measures should be taken. One measure that is discussed broadly especially in the European Union is increase of retirement age that could lessen the economic impact of retiring “baby boomers” (such as,

generation of people born during the post-World War II “baby boom”). This change the dependency ratio will have a gravest impact on Finland, Italy and Japan where the projected ratio is over 50 % by 2020. In other words, for every elderly inactive person there will be less than two people in the labour force (OECD. 2009, p. 18).

In addition to societal changes discussed more thoroughly in chapter 2, demographic changes in the population, are setting a stage for a health care paradigm shift where individuals are encouraged to take more responsibility for their own health, emphasizing preventive measures on population level, such as health education, and supporting individuals’ health endeavours by instructing them on the use of health information and health care services, that are becoming more and more electronic by nature. Amongst others, this tutoring aspect encompasses teaching technology literacy (from the perspective of health care, cf. Neter & Brainin, 2012); a skill which should be taken into the school curriculum already in the elementary school, for example in the form of technology awareness (Sharpe, 1996, p. 24).

Due to these societal and economic changes, it is probable, or even likely, that the ICT-mediated health care services will become a commonplace practice, preferred by the principal governmental and non-governmental health care funding organizations, such as insurance companies. It is also estimated that during the next decade, more ICT will be deployed in the health care in the health system than in its entire previous history (Coiera et al., 2012, p. 2). Regardless of these estimates, it is unlikely that these solutions will become sole means for conducting health care related affairs in the near future. Amongst others, the diversity in people’s ICT related skills and their attitudes towards technology will ensure that there will still be a need for conducting affairs in the “old way” (see discussion on digital orphans in the second chapter).

As the number of health care solutions that utilize ICT increases and becomes more commonplace, the diversity of people using them increases as well. For example, from the perspective of the patient, parties influencing individual’s health information management efforts may include acquaintances, colleagues, doctors, technicians, etc. (figure 3.4).

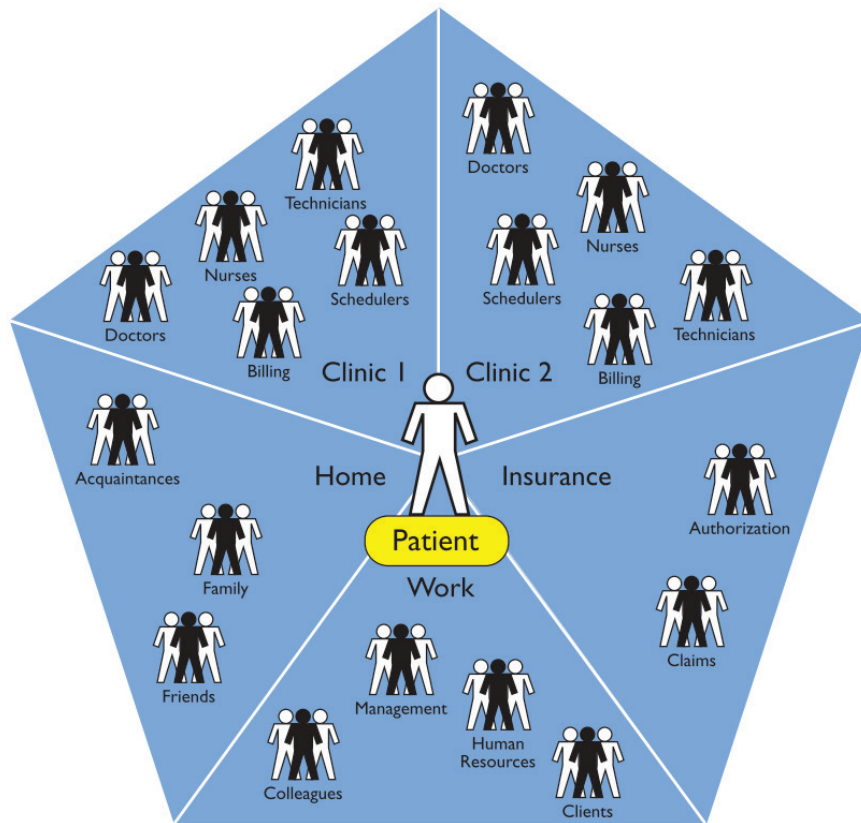


Figure 3.4. Spheres of influence (Pratt et al., 2006, p. 51).

In this Age of Information, increasing use of ICT in the field of health care will also have an impact on the issues related to information access and ownership. Especially in the context of Personal Health Information Management (PHIM) where the availability of different solutions of ICT is already abundant, special focus on security and privacy of the individual's health records should be paid. From this perspective, analysing individual's roles when they are managing (i.e. accessing, distributing, changing, etc.) their health related information could be a fruitful endeavour.

There has been relatively little research on the aspects of the "three C's", the Consumer, the Customer and the Citizen in the field of ICT-mediated health care. One of the notable researches in the field has been done around Sherry Arnstein's (1969) "Ladder of Citizen Participation" (figure 3.5); a model which

functionality was analysed by Tritter & McCallum (2006) in the field of health policy making.

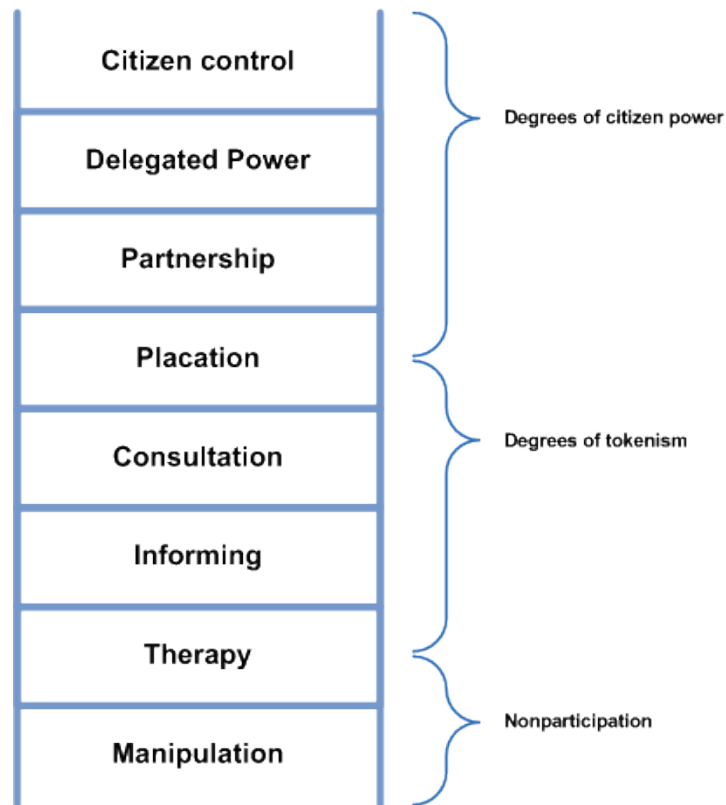


Figure 3.5. Eight rungs on a Ladder of Citizen Participation (Arnstein,1969, p. 217).

This simplified eight-step model depicts gradual increases in citizen influence. In the lowest rungs of the ladder are the illusory “nonparticipation models” where citizens do not possess any kind of influence and the primary objective of the decision-makers is to “educate” or even “cure” the citizens (ibid., p. 217). In the middle ladders the element of tokenism is dominant. Citizens are included in the decision making process, they are heard but not necessarily heeded. From this perspective, they are not included as truly equal stakeholders. In the highest rungs the element of citizen participation is strongest and the citizens possess some degree of actual power and influence.

In their analysis, Tritter & McCallum (2006) criticize Arnstein's model for its oversimplification, unidimensionality, and for its potential negative impact on the users and voluntary organizations due to misplaced delegation of power between different actors. However, if Arnstein's model is examined in the light of current discussion surrounding the patient empowerment, it has some merit. In particular, one question arises when the governmental strategies on electronic health care are considered; to what degree the strategies are put in place in order to "educate" and "cure" the citizens, and to what degree they aim for equal partnership and citizen control. The lines between obligation, involvement and empowerment can become easily blurred due to the acerbated rhetoric surrounding the discussion.

The significance and relationships of the roles is also examined in the context of social work. For example, McLaughlin (2009) investigated the interrelationships of different roles (client, patient, consumer, customer, service user and expert by experience) in order to clarify the relationship between those who commission or provide services and those who receive them. This kind of conceptualization is of the essence in the field of ICT-mediated health care in general, and particularly today, when new services and products are emerging in the field. In the following, the main emphasis is on the roles of consumer, customer and citizen in the context of ICT-mediated health care. The role of the patient is included as well, however the view on the role is a cursory one due to the abundant research on the role and on its relationship with the health care service providers. For example, already in 1951 Parsons investigated doctor-patient role and professionals' power over patients. After that, in 1962 DeLange investigated conceptions of the patient role in a state mental hospital. Since then, the role of the patient and its significance to the relationship with the health care professional has been recurring theme in the academic and professional literature.

In the following, the starting point is the role of the patient which is gradually expanded into those of the citizen, customer and consumer. The purpose of this expansion is to highlight differences of the emerging roles in contrast to the role of the patient, which in itself is in turmoil due to the changing landscape of the (ICT-mediated) health care delivery.

3.2 The Patient

Even though in ICT-mediated health care, products and services are often delivered in a different fashion when compared to majority of the other lines of industry, the role of the individual can be regarded as that of a consumer or a customer. Especially today these roles are highlighted contrasting the more traditional or paternalistic views to the service provisioning. However, these two

roles do not capture all the specific nuances commonly associated to field of health care.

The role of the patient is such that the individual, similarly to the role of the customer, has already acquired a specific product or a service, and a relationship between the individual and the service provider is already present in one form or another. In addition, the individual is also part of a process; in the case of a patient, a process of a health care provider organization (such as a hospital district or a health centre, etc.).

On a more personal level, the individual is most often a subject of some illness or ailment, or in a risk of becoming a subject of them. The individual may also have very specific health and well-being related goals, such as losing weight or lowering one's cholesterol levels. The role of a patient also requires that physician, or some other health care professional, a specific type of designated service provider is present in the delivery process. In the context of ICT-mediated health care, this does not automatically imply that the service provider is physically present in the situation but one's presence can be conveyed by an ICT-artefact.

Existence of this kind of designated service provider also brings forth one of the paternalistic legacies of the patient-physician relationship. The health delivery process is traditionally controlled by the service provider (i.e. physician, nurse, etc.) and the role of the patient is often that of a subordinate actor. The designated service provider controls the process in the favour of the patient according to the established conventions and best practices such as Current Care Guidelines (cf. Alanen et al., 2007, p. 233) exercising autonomous clinical judgment in the delivery.

Generally, formulation of a customer relationship is rather self-evident. When products or service are exchanged, related transactions are as required, and all relevant obligations are met, the relationship is practically in effect. In the case of ICT-mediated health care, the formulation can be more subtle. In "traditional" or face-to-face health care the patient-physician relationship is generally formed when the patient arrives to reception, is admitted to care, or receives some kind of medical advice. When the individual uses ICT-mediated health care services, such as message boards or different decision support systems, these kinds of notable transformations (i.e. admittance or arrival, etc.) do not necessarily occur.

The lack of notable transformations in product or service acquisition is not solely a matter of ICT-mediated health care services; they can be regarded as a characteristic feature of electronic services in general. In these kinds of services, the physical and social context, such as the store, trader and purchase, are replaced with objects and gestures of the virtual.

The changes in the environment where patient-physician relationships are formed gives rise to many questions on the matter of responsibility, such as when and with whom the relationship is actually formed. The Ethics Manual of the American College of Physicians (Snyder & Leffler, 2005, p. 562) states that “an individual patient-physician relationship is formed on the basis of mutual agreement. In the absence of a pre-existing relationship, the physician is not ethically obliged to provide care to an individual person unless no other physician is available. However, specifics on how the agreement is formed or how the relationship is initiated are not discussed in sufficient detail.

3.3 The Citizen

A citizen can be regarded as an individual who is a formal member of a state or some other political community. The citizen has certain rights and responsibilities that are legally established by one’s community. The citizen is an individual who has, what can be considered as a natural, allegiance to certain government. The citizen is entitled to government’s protection and to certain services. From this perspective, the role of the citizen can also be seen as an inhabitant of a municipality or similar administrative entity with a degree of self-government.

Similarly to the role of the patient, the role of the citizen, the concept of citizenship and the relationship between the state and the citizen have been under scrutiny for ages. The earliest works related to the concepts include the Code of Hammurabi, written approximately in 1727 B.C.E. and the Medina Charter written around 622 C.E. Other works of importance, include the “Second Treatise on Government” (Locke, 1960) and the “Leviathan” by Thomas Hobbes (1651).

Focusing on the health care services provided for the citizen, the perspective incorporates an egalitarian notion of equal health access, meaning that all citizens should be entitled to the basic health care services on even terms. Effectively, this kind of universal health care requires, at least partial funding from public sources (i.e. from tax revenue) and on average OECD countries spend 6 % of their GDP on health services (Adema & Ladaique, 2009, p. 26).

While the actual organization and public-private mix of funding of universal health care varies from country to country there are at least four (idealized) basic models for health care delivery (Tuohy et al., 2004, p. 360-361):

1. Parallel systems (parallel public and private systems for given range of services);

2. Group-based (only certain population groups are eligible for a public coverage);
3. Co-payment (financing is partially subsidized through taxation for a wide range of services);
4. Sectoral (only certain health care sectors are publicly financed while others rely on private finance).

Each nation incorporates characteristics from these models, applying them differently to specific sectors. As a result, the actual implementation of health care system is in practice a hybrid of these models (cf. *ibid.*, p. 368). In Finland, there is currently an on-going discussion on what kind of model should be applied to the field in the future. For example, Aronkytö et al. (2010) propose in their report a centralized model where citizens have more leverage in selection of their service provider. If the citizens are not content with the offered services, they may change the service provider free of charge once per year. In terms of funding, the model is based on a co-payment model (public funding, such as state subsidy for municipalities, and a deductible), and a “free” competition amongst service providers (within the set quality criterion).

The degree of which right for the universal health care is ensured by the law varies from country to country as well. For example, the Finnish Constitutional Law dictates in its section 19 that the public authorities must guarantee (not produce) “adequate social, health and medical services and promote health of the population” (Ministry of Justice, Finland, 2007). Similar examples can be found globally. For example in Peru a law on health insurance was set on 9th of April, 2009. In the core of the law is a notion which states that quality health services should be available to all Peruvians (Agencia peruana de noticias, 2009). In Israel, a law setting the stage for universal health care was set in 1995 stating that health care organizations may not bar applicants on any grounds, such as age or state of health (Israel Ministry of Foreign Affairs, 1995).

The role of the citizen has other implications as well, such as those leading to solidarity and transparency in service provisioning. Solidarity as a concept of social ethics implies a union of interests, or even kinship, amongst members of a society. In the context of ICT-mediated health care services, this kind of social cohesion can be seen as a function of empowerment; whilst the society provides or guarantees universal health care to its member, the individuals themselves are responsible for contributing to their health care through a “preventive lifestyle or, whenever required, through active participation to their medical treatment” (Weide, 2005, p. 1147).

Transparency in relation to service provisioning is related to egalitarian health care signifying that rationale behind access to the provided health care services (for example, in the case of group-based delivery model) should be transparent

and open to public criticism. The citizens should be able to articulate their needs and contribute to the service provisioning through means of citizen participation (e.g. elections, changing their consumption practices, etc.). Following the ideas presented by Gaventa (2004, p. 25), the citizens should be encouraged to seek new ways of building active relationships with different institutions in order to lessen the gap between them. With a more immediate and unreserved connections to the public bodies, the citizens should have a better chance of having their voice heard.

3.4 The Customer

The roles of a customer (i.e. client, buyer, purchaser or patron) and a consumer are similar in ways. The similarity extends to other languages as well and their translations can be even seen as synonyms of each other. In Merriam-Webster Dictionary®¹⁵ the terms have following definitions.

Consumer:

1. One that consumes: as
 - a. One that utilizes economic goods
 - b. An organism requiring complex organic compounds for food [...]

Customer:

1. One that purchases a commodity or a service
2. An individual usually having some specified distinctive trait.

From the perspective of these definitions and the use of terms in colloquial language and academic literature, the following characterizations can be made using a purchase as a primary act signifying transformation from one role to another. The transformation from a consumer to the customer can also be seen as a transformation from an archetypal representative of a collective to an individual; an act that consequently personifies the acquisition of goods or services. In other words, the existence of a customer automatically implies to the existence of a customer connection, a relationship between the service provider, or commissioner, and the one who is in receipt of it. The role of a consumer may exist without this kind of active relationship and personification.

¹⁵ <http://www.merriam-webster.com/> (accessed: 9.10.2012)

Formally, existence of a customer also implies the existence of specific needs and expectations, even problems that can be solved with a product or a service. In a business dictionary¹⁶, the following definitions are provided for the concepts.

Customer needs:

Problems that customers intend to solve with the purchase of a good or service.

Customer expectations:

Perceived-value customers seek from the purchase of a good or service.

In the academic literature, probably the most ground-breaking insights into the customer needs were presented by Theodore Levitt who investigated the concept in his article “Marketing Myopia” (1960). The article challenged the concentration of the post-war companies on production, emphasizing the importance of customer satisfaction: “The organization must learn to think of itself not as producing goods or services but as buying customers, as doing the things that will make people want to do business with it.” (ibid.).

Considering the intertwined natures of the customer and the product (or a service), the existence of a customer can be seen as a primary requirement for a product or a service, and therefore for a provider or a commissioner as well. Without a customer, there is no need for them to exist. Customer, which can be seen as a more instantaneous role than that of a consumer, is also the one who primarily benefits from the existence of a product or a service, a beneficiary.

As per definition above, the customer is an entity (“one”) who has taken part in a process (i.e. purchase process). Excluding the exogenous factors and behavioural aspects having an effect to the purchase decision (cf. Nicosia, 1966; Engel et al., 1968), the simplified form of the process involves transaction of certain products or services and a compensation for them. Customarily, there are also certain responsibilities, or even obligations, between the entities. For example, some (if not necessarily all) rights related to the acquisition are typically transferred to the customer. Other examples on responsibilities and obligations include product warranty and filling of a compensation form at one’s insurance office.

In ICT-mediated health care, the role of a customer overlaps with that of a patient, and the latter can be regarded as an extension, or a special form, of the former. However, especially in the case of public health care services of today,

¹⁶ <http://www.businessdictionary.com/> (accessed: 9.10.2012)

the service provider is typically a general practitioner, a nurse, or some health care professional, and the reason for acquiring the product or service is typically more cogent than just use or enjoyment. Furthermore, acquiring products and services of ICT-mediated health care typically involve heavy and many-sided responsibilities from involved entities. For example, De Vries (1980, p. 96) approaches the dilemma of health care responsibilities stating that regardless of the angles (medicine, sociology, psychology, economy or law) used for characterizing the nature of the responsibilities in the field, one rapidly becomes entangled with the philosophical aspects of the medicine.

In countries, such as in Finland, where “free” (funded primarily by tax revenue) health care is effectively considered as a basic right for a citizen, emergence of private health care customer markets has shifted the service landscape from universal (in practice, a hybrid of co-payment and sectoral funding) to parallel (Tuohy et al., 2004, p. 360-361) and a phenomenon that can be called as a “double payment” has emerged. In a society with universal health care, the well-to-do portion of the community pays two times for their services; for the first time in the form of taxation, and for the second time by buying the (same) services from the private sector. From the perspective of customer needs, the overlap and rapprochement of the roles of the patient and the customer is rather evident.

3.5 The Consumer

Following the widely employed definitions in the Merriam-Webster Dictionary®¹⁷ and in the WordNet® Lexical database¹⁸, consumer is an individual to whom services are offered; a buyer. This definition already differentiates the concept from that of a customer on a level of principle. Whereas consumer is an individual, customer can be seen as an organizational entity as well. The consumer acquires services or products within the economy of one’s personal consumption, use or enjoyment. The consumer is an (nondescript) actor, one that browses through supplies of different providers, or commissioners, and picks the one that is most to one’s liking according to personal preferences and priorities.

Partially, as a consequence of this freedom of choice, the consumer is protected by different conventions of trade of which some are obligatory and stated in the law. For example, in the United Kingdom, an Act of Parliament known as “Unfair Contract Terms Act 1977” (Parliament of the United Kingdom, 1977) was set in order to protect the consumer by restricting the operation and legality

¹⁷ <http://www.merriam-webster.com/> (accessed: 9.10.2012)

¹⁸ <http://wordnet.princeton.edu/> (accessed: 9.10.2012)

of certain terms. Since its publication, this Act has been revised multiple times, for example in 1991, 1995 and in 2003 (ibid.).

Another example on consumer protection laws can be found in the United States legislation where the consumers are protected against billing errors, such as inaccurate and unfair credit billing and credit card practices (Federal Trade Commission, 1986). In addition to different laws, the consumer is often protected by other conventions and practices that do not base on legislation. These include different quality standards (such as the ones of ISO 9000 family) and agreements covering the used method of payment (credit cards, checks, etc.).

It goes without saying that most of these laws, conventions and practices apply to the role of the customer as well. However, as they are put in place without a specific individual or a unique transaction in mind, they set the stage for a transformation from the role of the consumer to that of a customer, using purchase as a primary act from the perspective of the change.

In today's world, there is a relationship between a consumer and advertising. This relationship is not explicit or absolute. Firstly, there is advertising without consumers, for example in relation to political and ideological advertising. Secondly, there is (and has always been) consumption without advertising. For one's part, the relationship between consumer and advertising bases on consumerism, an ideology that feeds on consumer greed and encourages purchasing goods in increasing amounts. In this, advertising and more fundamentally contemporary media culture are essential in building brands and creating consumer loyalty; key factors influencing individual's purchase behaviour. In the context of health care products and services, marketing is a delicate matter. For example, the actual or principal payer might not be the consumer, and the consumer is not necessarily in the position of power in terms of selecting the service provider. In addition, as established in the second chapter (section 2.3), some of the challenges arise from the lack of control in the direct-to-consumer (DTC) marketing, others from the nature of the trade.

When providing health care products and services, or those belonging to the adjoined spheres of operation, they must be actively promoted, advertised and packaged in an enticing fashion; something that the current health care services rarely are. The image of a hospitalized patient, even a recuperating one, is hard to overcome. This challenge of creating alluring health care services is in the core of medical tourism (Connell. 2006); a new and emerging field where patients' expected value does not just include a successful operation or increased health, but a positive overall travel experience as well (relaxation, exercise, visits to spas and local attractions, etc.). One of the regions profiled as a region

for medical tourism is Tamilnadu¹⁹ in India. The marketing strategy of the region emphasizes its state-of-the art hospitals as well as the local ambience (see figure 3.6. for a practical example). In align with these kinds of services are so-called “concierge services” where primary care is often offered with a 24/7 access and the care is complemented with “a spectrum of ancillary services”, such as medical spa (Accenture, 2012, p. 2).

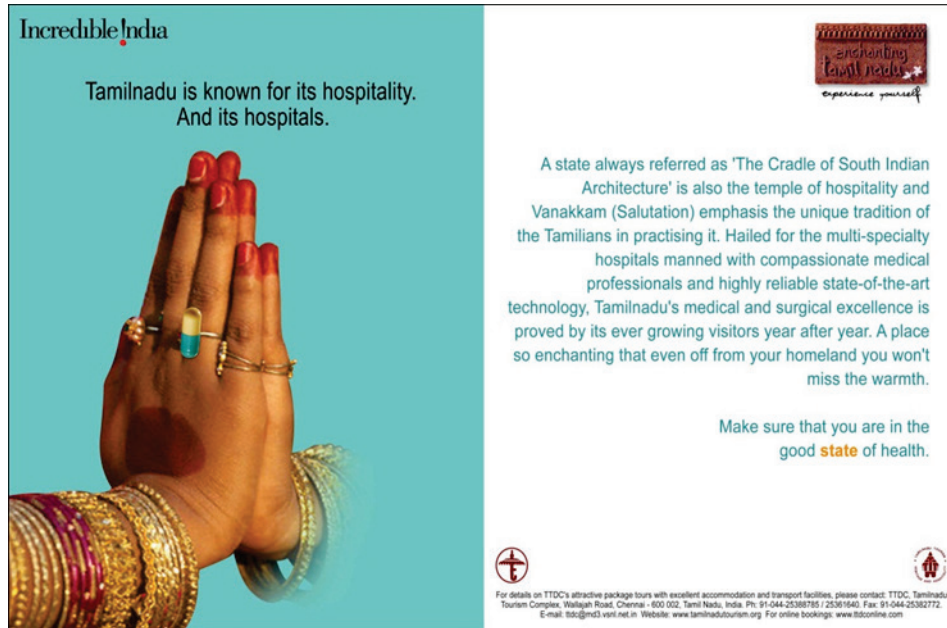


Figure 3.6. Tamilnadu advertisement (from: <http://adsoftheworld.com/>).

Even though consumption of material goods can be regarded as a global phenomenon, or at least a prevalent one in the OECD countries, consumer itself is a culture dependent term that has changed over time. Depending on the context, this singular term can refer to a population group, or even a stereotype. Use of the term can vary due to the background values, experiences, etc. of the individual using it. The relationship between the individuals and material goods they consume has been a focal point of research in the field of consumer culture (cf. Slater, 1997), a field born from a wide range of disciplines, including communication, culture studies, sociology, marketing and philosophy.

As an example of challenges related to the characterization of a consumer in the field of ICT-mediated health care, the definition of “ageing eHealth consumer” can have quite different interpretations in different parts of the world (such as, in

¹⁹ <http://www.tamilnadutourism.org/> (accessed: 27.1.2012)

the Republic of China and the United States where the fields of medicine have been regarded as traditionally different from each other). Only with demographic profiling, which has matured and evolved rapidly primarily due to developments in ICT, it has been possible to open this aggregated term and understand better what it means in the context of the specific market area and commercial society of the region. As a practical example of this, the living arrangements and housing of the elderly vary from country to country, and they are quite responsive to social insurance benefits (Engelhardt & Greenhalgh-Stanley, 2010, p. 229). This factor alone has an effect on the potential health care markets in the area.

On the other hand, with the advance of ICT, the consumer has become, if not more empowered than before, then at least one with more options. As services go online and the physical location of the service provider becomes more or less irrelevant, the consumer has often more choices at his or her disposal. In addition, one has often more information available, for example in the form of online reviews or support from one's peer group in social media, that can be used in making 'buy' or 'no buy' decisions.

For example, in the United States, 72 % of the Internet users²⁰ searched online for health information within the past year (Fox & Duggan, 2013). In Europe, the amount of individuals using the Internet for health information changes from country to country. On average 38 % of all individuals in EU-28 searched online for health information in 2011, ranging from 23 % in Poland to 58 % in Finland (Eurostat, 2013d).

3.6 Interrelationships of the Roles in the ICT-Mediated Health Care

The roles of the patient, citizen, customer and consumer are not distinct from each other and the classification here is not intended as enumerative. The roles may overlap with each other and with the ones that are not discussed here (such as, peer or participant). In the case of ICT-mediated health care, particularly roles of the customer and the patient are difficult to analyze as separate instances (cf. Deber et al., 2005, p. 346). Similarly, role of the citizen is hard to disconnect from any other; the role is, in practice, always present in a form of different rules, regulations and legislation that are in effect in the said relationship.

²⁰ May 2013 survey by Pew Internet indicates that 85 % of U.S. adults use internet <http://www.pewinternet.org/Commentary/2011/November/Pew-Internet-Health.aspx> (accessed: 6.9.2013).

The mediator and overlapping roles

Whilst dealing with these roles is difficult on their own right, their interrelationships become underscored when the individual is acting on behalf of another, as a mediator (see chapter 2). One interpretation is that in this kind of situation, the role of the mediator is extended from that of the actual beneficiary or principal user. However, in the context of health care services this kind of interpretation can be problematic due to a potential conflict of roles.

In the other lines of industry acquiring products and services on behalf of another individual is typically a straightforward matter (for example, in the case of perishables). In health care, the assigning control over one's role to a mediator, for example in a form of a proxy, is typically regulated by different laws and practices and the assignment contains more obligations (cf. Annas, 1991). In this kind of situation, the laws and regulations set to protect the actual beneficiary in a role of the citizen may prevent the mediator from effectively acting in the extended role of a patient or a customer. These kinds of conflicts between roles may occur especially if the mediator does not hold a position of a legitimate representative of the beneficiary (for example, when the mediator is a friend or an employee, not a close relative or a parent).

Examination of the role of the patient points out another example of an overlap. When one uses home care services (electronic or not) that are acquired out of one's free will without any initial counsel from a health care professional, and out of one's own funds, it is effectively impossible to draw the line between roles of the patient and the consumer. Certainly one's role is that of the customer and when a patient-physician relationship is formed, one's role will become that of the patient as well. This simplified example draws more strength if an issue of compensation is examined. Even though one has acquired the service in the first place out of one's own funds, it is possible that one is entitled to compensations later on. If these compensations are provided by the state or municipality, for example, due to mechanisms embedded into universal health care provisioning in the society, role of the citizen emerges as well. This scenario may become reality in the near future as cross-border care is enabled between the member states in the European Union (directive 2011/24/EU) and some of the related costs are compensated afterwards to the patient. When the directive comes into force the citizens of the member states are, in principle, free to obtain care from any member state. At this point it is still unclear what are the public finance implications and how national health policies are coordinated on the level of practice.

Influence and freedom of choice

It is easy to picture other examples where the roles can be considered as overlapping and inseparable from each other. Another way to look into interrelationships of the roles is to examine them in terms constitutive effect and influence (see figure 3.7 below).

Role	Constitutive effect	Influence
Patient	Health care services, products and overall system	From limited to consumer markets (universal vs. non-universal health care)
Citizen	The state	Citizen participation (e.g. elections)
Customer	Product or service	Freedom of choice; termination customer relationship, use/no use
Consumer	Advertising and media	Freedom of choice; (re)acquisition

Figure 3.7. Roles, influence and constitutive effect (illustration).

Simplifying, the role of the patient can be seen as constitutive to health care products and services, and even to the overall health care system. Without the patient, the one “consuming” (e.g. in the need of) health care products and services, there is no need for organized health care delivery either. Beyond this simplification, the term “consumer” does not portray nuances present in the relationship between the health service provider and the patient. In other areas of business the relationship between consumer and consumption is more symmetrical and active; the consumer has power, authority and influence to make consumption related decisions, in health care this freedom of choice might not be similarly in effect. For example, authors such as Coulter & Jenkinson (2005, p. 355) report different degrees of freedom in selection of primary care doctor within the Europe. For example, in Switzerland people can go straight to a specialist doctor if they wish to, while in the United Kingdom long waits and limited choice of location are “the norm” (ibid.). This degree of freedom, or lack of it, is present in the nuances of the service provisioning. It is a common notion that the patient “receives” care instead of “acquires” or “consumes” it. In this the term “patient” has a connotation of passivity.

For example, in the universal health care the service provider could be assigned to the patient on the basis of one's residential area. In this kind of service provisioning, which is known as the Local Population Responsibility (LPR) in Finland (cf. Mäkelä et al., 1998), the patient's freedom of choice can be limited to the assigned service providers on call. However, in the case of universal health care where the services are funded by tax revenue, the individual gains additional methods for influencing the service provisioning from the role of the citizen. In this role, the active and willing individuals have means to address the society at large by employing the means of citizen participation such as, voting and participation in different citizen forums (cf. Farrell, 2000, p. 32).

In the case of the consumer and customer, the means for influencing service and product supply are more direct (i.e. buy or no buy decisions and general consumer habits), the underlying revenue model is clearer, and the constitutive effect of these roles is straightforward as well. Effectively, these roles give justification to the overall markets, and to the overall mechanisms that are in place to affect the consumer habits (such as, advertising and media). These two roles are separated from each other by their interrelated constitutive effect; the role of the consumer can be regarded as having a constitutive effect on the role of the customer.

The service cycle: articulation, declaration and execution

Consumer health care markets have created new opportunities for the consumer and customer roles to emerge. If we look at the patient-physician relationship from the perspective of interaction, it is basically formulated of three consequent stages: a) observation, b) diagnosis and c) therapy that, when combined, create the so-called diagnosis-therapeutic cycle (van Bemmelen, 1997). If we consider observation and diagnosis as inseparable acts (e.g. one can't make a proper diagnosis without observation), we can depict the cycle as one consisting two consequent stages: articulation and execution that typically repeat in an iterative manner during a (patient) trajectory; sequences of encounters an individual have with the service providers (cf. Bigelow, et al., 2005). In the articulation state, the current health status and the need of the patient are investigated (i.e. observation). In the case of an on-going care, impact of the treatment that has been put into effect can be assessed as well.

In the articulation state, the individual is primarily in the role of the patient. However, should one decide to opt for a second opinion, or change from a public service provider to a private, the roles of the consumer and the customer emerge. Naturally, the role of the citizen is present as well, for example in the form of legislation that has been put into place in order to protect the individual regardless of one's current role as a consumer, customer or patient.

Customarily, the articulation state ends in a declaration (i.e. diagnosis) where individual's treatment plan is devised. While real-world examples of declaration are often more intricate, outright examples of declaration could be: "overweight" or "diabetic", conditions that require care and attention to be implemented in the execution phase. Naturally, this phase can, and often does, lead to a new articulation-execution cycle via care assessment (figure 3.8). This kind of iterative view to health care processes has a close kinship to well-known process models such as Walter Shewhart's PDCA cycle (cf. Best & Neuhauser, 2006, p. 142) and the basic model of human activities as described in van Bommel (1997, p. 4).

In principle, the PDCA cycle is a model for continuous quality improvement that has four stages. Plan: identifying what can be improved and what change is needed, do: implement the plan and collect data, check: study the results, and act: perform corrective measures if the results are not what they were hoped for (Best & Neuhauser, 2006, p. 143). The basic model for human activities is even a more straightforward model as it consists of three basic activities: observation, reasoning and action (Bommel, 1997, p. 4) and as such, it can be applied universally (sports, research, warfare, etc.).

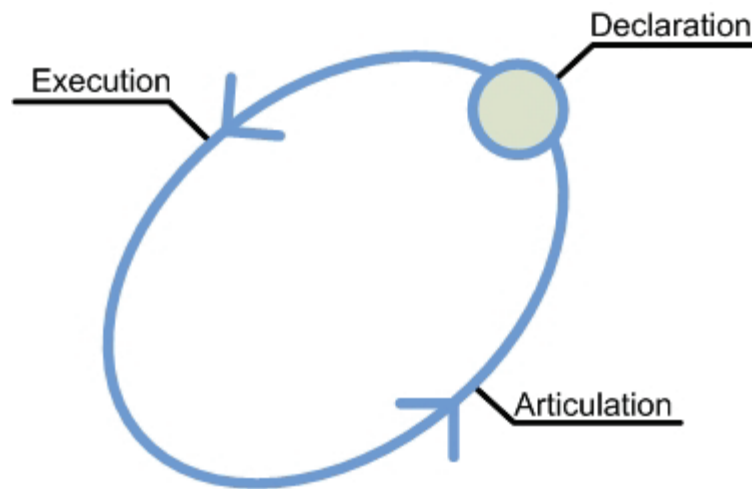


Figure 3.8. Cyclic nature of articulation, declaration and execution.

In the execution phase, actual care and corrective measures to individual's health status are implemented (i.e. therapy). In the case of universal health care provisioning where purchase and provider of the health care services are often part of the same entity (such as, a municipality), the party responsible of

execution state is often set by the party responsible of the articulation and declaration, or at least there are conditions in place that limit the selection.

Similarly to Mexico, Portugal and Spain, these conditions have been very strict in Finland (Joumard et al., 2010, p. 32). However, for example in Finland, there are on-going initiatives that increase individual's choice over where and by whom they will be treated (Teperi et al., 2009, p. 77). One of the proposed changes is that the individuals should be able to choose which health centre to use within a special responsibility area (ERVA in Finnish), which is specific catchment areas for the provision of specialized level medical care. Each catchment area includes a hospital district in which there is a university providing training for physicians (Finnish Government, 2013).

On an operative level, functionality of these kinds of initiatives is supported by the use of ICT. In Finland, an online service known as a "Service Scale" (Palveluvaaka²¹ in Finnish) has been implemented in order to support the individuals in their selection of the most appropriate service provider. With the service, the individuals are able to compare service quality (waiting times, cost-effectiveness, etc.) between different service providers. At the end of year 2012, the service contained information on hospitals, services for elderly people and health centres. However, the coverage was not extensive at the time, and the service did not include information, for example, on day care.

Similarly, different cash-for-care programs where individuals are offered cash payments or different vouchers by the state or the municipality are a prime example of increased freedom of choice amongst individuals. In these programs, (often elderly) individuals who are in need of care can use allocated funds or vouchers for selecting the most appropriate service provider, with a varying degree of freedom. Amongst others, these kinds of programs are in effect in Ireland (Home-Care Grants), United Kingdom (Direct Payments), Finland (Service Vouchers) and the Netherlands (Personal Budgets) where they have changed health care service provisioning with varying degrees (Timonen et al., 2006). One of the most interesting near future developments in the field of health care provisioning is the patient mobility (e.g. cross-border care) policy in the European Union. The policy facilitates movement of patients and professionals across the EU. According to the policy, the patients have a right to seek high quality care and reimbursed treatment from another country within the EU. The member states had until the end of 2013 to adjust their legislation to meet the challenges arising from the policy.

Because of initiatives such as the aforementioned, and due to opening health care consumer markets, the roles of the consumer and customer are becoming

²¹ <http://www.palveluvaaka.fi> (accessed: 20.10.2011)

more evident in the societies where universal health care provisioning is prevalent method of health care delivery. “Mandated” with the declaration of the health care professional, the individuals may, at least in theory, browse through different public and private service providers, and choose the one that meets one’s preferences. The new and emerging ICT-artefacts have also created new means for self-declaration. Whereas individuals previously used different medical advice books in their stocktaking, new solutions such as online Patient Decision Support Systems (PDSSs) have made their endeavours less burdensome (cf. chapter 6; Frosch et al., 2008).

Interrelationships of the roles are also evident when long term relationships are examined. For example, during a care pathway or similar framework that defines an outline for the anticipated care over a period of time, the individual may go through different roles in a cyclic manner. Assuming that the designated health care professional has a general view to the overall situation during the care pathway, the individual returns to the role of the patient during each articulation phase (such as, during each scheduled patient visit).

During the execution phase, individual’s roles may change to that of a consumer or a customer depending on the relationship with the service provider of that time. Choosing a small portion of the identified parties (Eloniemi-Sulkava, 2009, p. 36), the potential service providers in the case of the elderly people include the following ones (figure 3.9) where the roles of the individual may change from one to another.

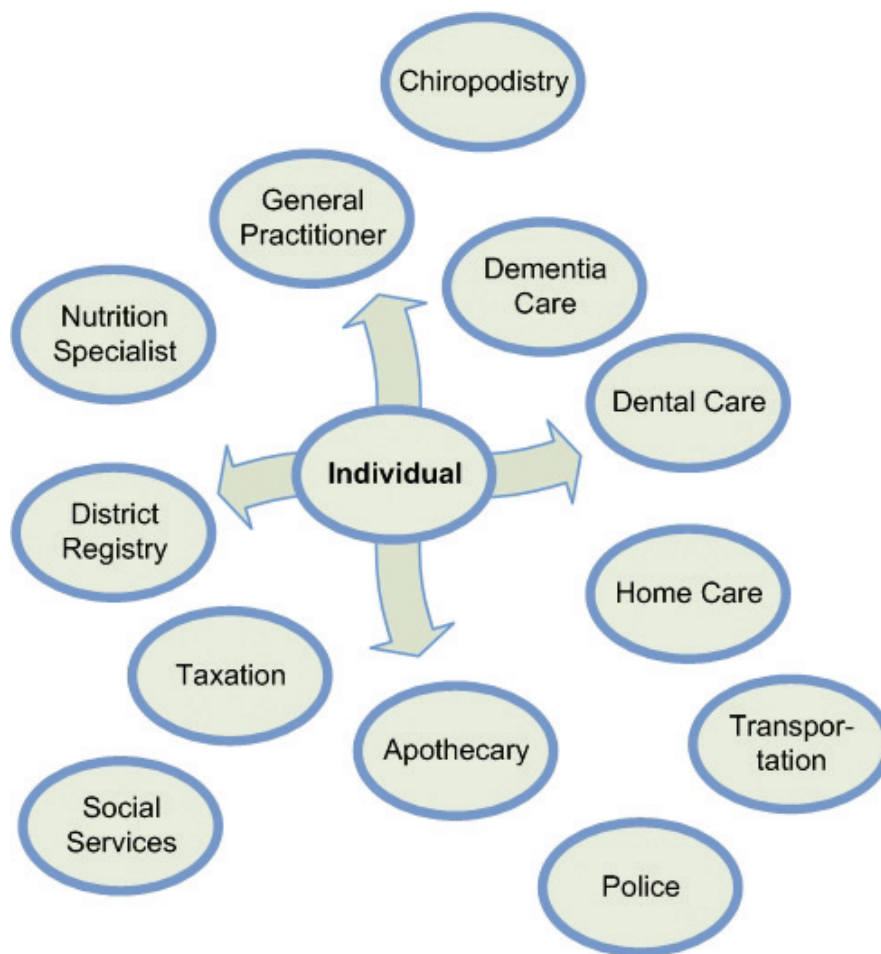


Figure 3.9. Some of the potential service providers in the case of the elderly people (example).

Considering the sample of service providers listed above (figure 3.9), it is easy to picture technological challenges that are related to management of multiple different service relationships. While the communications standards such as those defined by the HL7 organization²² can support integration of different health care information systems to a degree, it is practically unfeasible to create a universal information exchange standard that takes all service relationships (and individual's roles in them) into account. For example, if an elderly person renews one's driving license, the overall process typically requires information

²² For a comprehensive list of HL7 standards, see HL7 Standards - Master Grid available at: www.hl7.org/implement/standards/product_matrix.cfm (accessed: 6.11.2013)

exchange with numerous different service providers, potentially covering all of the discussed roles (e.g. patient, citizen, customer and consumer).

3.7 Recommendations

It is probable that different ICT-mediated services will become a commonplace practice in the field of health care. In some areas, for example in the case of laboratory examinations (for example, in Nordic countries), it already has. Similarly, it can be argued that at some point of time in the near future, ICT-mediated health care services will become a preferred method for providing health care services by the principal governmental and non-governmental health care providers and commissioners.

This expansion from, what can be regarded as, “traditional” service models to those supported by new technologies will give room for different health care service models in which the private and the third sector (i.e. associations and societies) can be an integral element. This on-going transition from physical to virtual draws some of its strength from on-going demographic change related to ageing societies, from the need for lowering health care expenditure, and from the changing users themselves (see chapter 2), and it will face at least two probable challenges.

Firstly, electronic service models applied to the health care from other lines of electronic service industry should be reviewed before they are applied to the field. In addition to the competitive environment, which is typically dominated by the organizations of the public sector, elements such as value proposition, revenue model and marketing strategy should be carefully evaluated prior to introducing new services to the field. For example, in the countries where the health care services typically belong to the basic services provided by the society, creating a functional revenue model may prove to be a challenge. Practical examples of this are the subscription-based health care services that are a commonplace practice in many countries, such as in the United States. Introducing this kind of a service model to a country with pay-per-visit compensation model, could lead to a situation where the offered services are not eligible for any kind of compensation from the public funds.

Creating these kinds of refined and adapted service models can be a complicated matter also due to the underlying philosophy and core values of the health care sector. It is in the very nature of the sector to “improve the health status of a particular individual, to cure disease, to ameliorate disfunction” (Kaveny, 1999, p. 212). What should be kept in mind is that operating from the premises of the “individual good” (i.e. good for the patient) is not necessarily the most valid foundation for a profitable business activity. Therein lays the allure of creating

business artificially or with false pretences, such as in the case of referrals where the patient is sent to an entity to which the referring physician has a financial relationship (cf. Kalb, 1999; Krause, 2013).

Secondly, the functionality of the current health care provisioning should be re-evaluated on the terms of a) emerging roles (especially, those of the consumer and the customer), b) new technologies and service channels, and c) electronic service models. In Finland, this work has already begun and the emerging role of the customer in relation to health care services has been taken under scrutiny by the Finnish Funding Agency for Technology and Innovation (Virtanen et al., 2011). A comprehensive look into the roles and the related changes in the service ecosystem gives rise to extremely current questions, such as:

- How to support meaningful transitions from one role to another;
- To what degree (if any) personal health information can be used as a commodity (cf. individual's social networks and social media);
- How to take concurrent roles into account in the services;
 - How to ensure that rights of the citizen are ensured regardless of the type of the service provider (public, private or third sector);
- What mechanisms can be put in place in order to take individual's personal preferences into account in the public health services;
 - How to promote individuals as active actors in relation to their own health;
 - To what degree it is possible to ensure freedom of choice especially in the case of the public health care services;
- How to guarantee the quality of health care when using services in different roles;
- Where responsibilities lie in the case of multi-actor service provisioning models that combine providers (and ICT-artefacts) from different sectors.

It is clear that an answer to these questions does not lie in technology but deeper in the core of health care. Factors such as legislation, ethics, applied best practices and individuals' attitudes are the relevant ones when the scene for the ICT-mediated health care services of the near future is set. Meanwhile, enabling the role of the mediator (and mediation in general) can prove to be a partial solution especially in protecting the rights, privileges and privacy of the individuals who are less literate in terms of new and emerging technologies.

Information management, care pathways and the mediator

As information on individual's health and well-being is needed outside the sphere of public health care delivery, the individual's demands for information ownership and access change. In practice, this means that a) individuals,

especially those who actively promote their health and well-being, need access to their health information stored in the service providers' health archives and b) Personal Health Information Management (PHIM) solutions in one form or another will become a more commonplace practice (see chapter 4). In Finland, the access to the national health archives for the citizens was implemented as part of KanTa services²³ where citizens have a possibility to view part of their official health documents, such as prescriptions (eViewing).

In addition to information access, the emerging roles also have an impact on the formulation of the overall care pathways. Breaking individual health events into separate articulation and execution trajectories, using declaration as a logical stopping point, will give patients more leverage in terms of selecting their service provider. Considering how the patient mobility act will potentially change the health service provisioning in the European Union, this mechanism should be integrated to actual care pathways and guidelines before the window for complying with the Directive 2011/24/EU closes.

Implementing this kind of mechanism that has an impact on some of the fundamental aspects of the service provisioning is a challenge. Firstly, control mechanisms for costs are needed. Freedom to choose a service provider for the execution phase should not be absolute or it may have a dire impact on national health expenditure. Secondly, the service providers should respect the two-tiered structure of articulation and execution and openly support acquisition of care according to the patient's preferences regardless of the nationality or type (public, private or third sector) of the potential provider. Thirdly, the changing roles of the beneficiary should be acknowledged in order to open more the health sector markets, and to make good use of the private and the third sector as a (partial) solution to the chronic lack of resources in the public sector.

Technologically, this kind of individual-centric integration needs functions that support integration on three levels: a) data (integration, information exchange), b) service (making of aggregates of different articulations and executions), and c) information (making meaningful assemblages of information for different users in different roles, such as the mediator). One possible, principally technical, solution for this is the Coper, a personal health information management solution described in the section 4.4.

Changes to the existing care pathways and similar control structures should not be implemented just for ideal reasons, or to highlight roles of the individuals in the changing service landscape. It goes without saying that these changes also need justification from the perspective of funding and reimbursement. Without support from municipalities, insurance companies, and other organizations that

²³ <http://www.kanta.fi/en/> (accessed 9.10.2013)

can be seen as potential financiers, it is probable that the changes will not be taken into wider use. Naturally, these changes also need support of those performing the actual work, and of those receiving the related services.

The service landscape that is changing from physical to virtual has room for support mechanisms such as mediating. Especially in the case of technologically illiterate elderly people, and those with lowered mental or cognitive capabilities, the need for a mediator is practically self-evident. For example, in the case of revised care pathways where individuals have a possibility to change from one role to another, and from one service provider to another, mediation can provide means for “breaking through” the health care provider’s professional jargon and bureaucracy potentially associated with the service provisioning. When successfully carried through, the co-operation of the actual beneficiary and the mediator may advance beneficiary’s understanding on one’s overall health status and significance of the provided care from the viewpoint of one’s personal endeavours.

There have been mediators by other names in customer service work, and even in health care. Examples of this include personal banking advisors who deliver financial products and provide referrals in a close interaction with the customer, and patient ombudsmen who give advice in relation to patient injuries and compensation. These mediators are a profession in itself and even they are co-operative by nature, they differ from the role of the mediator pursued here. In the fragmented health and well-being sector of today, the role of the mediator is beyond co-operative; it is integrative. It follows from this that the role is not limited to any single service provider, and it is inherently multi-professional. In order to support the beneficiary, the mediator is often required to operate with different service providers, even with different sectors of industry (such as, insurance companies), in order to cover what can be regarded as relevant to the beneficiary’s health related endeavours. This kind of role requires a wide perspective to the field, and electronic tools that can be trusted.

Taking account the work done in the field of shared decision making and trust, the coding systems and screening tools such as those of the Health On the Net Foundation (HON)²⁴ and Discern²⁵ should be taken into wider use and their applicability should be evaluated in terms of mediation and emerging roles. For example, while the Discern and the HON focus primarily on quality of online (written) health information, they contribute very little on terms of the provided service. In addition, the coverage of the services is rather limited. For example, at the moment the HONcode, a certification provided by the HON organization covers only approximately 5000 web pages from 72 countries. Considering the

²⁴ <http://www.healthonnet.org> (accessed: 27.10.2011)

²⁵ <http://www.discern.org.uk/> (accessed: 27.10.2011)

number of health related web sites (including the relevant social networking sites used, for example following friend's personal health experiences), the coverage is noticeably lacking. While it is practically impossible to give accurate information on the number of health related web sites, one indicator of their popularity is their use; as described in the section 3.5 above, 72 % of the Internet users in the U.S. searched online for health information within the past year, and one in three American adults have gone online to figure out medical condition (Fox & Duggan, 2013). In a recent survey conducted by Bupa in 12 countries (Australia, Brazil, China, France, Germany, India, Italy, Mexico, Russia, Spain, United Kingdoms and United States), the numbers are a bit lower. However, in all countries at least six in ten of the responders were making some use of the Internet to search for advice on health (McDaid & Park, 2011, p. 3). According to the same survey (ibid.) nearly half of the individuals who used the Internet to find health information, did it for self-diagnosis purposes.

A need for this kind of function of trust was brought up in a panel where a group of domain specialists discussed on the functionality of the upcoming Taltioni²⁶ service. Taltioni as a consumer-centric health record service will act as a marketplace for a wide range of health and well-being solutions. At that time, it was estimated that the service will be released early 2013 and it will complement the development of (governmental) electronic health record (EHR) solutions in Finland (KanTa).

In terms of ethical clearance of solutions provided in Taltioni, the panel members who worked in the public sector argued that all solutions should go through a transparent clearance process. The panel members who worked closely with the Taltioni service agreed, but they highlighted a need for a process that would not impede the product development process, for example, by delaying the process for weeks at the time. As a conclusion of the discussion, it can be stated that the need for an ethical clearance mechanism is evident, but the mechanism should be developed with the realities of the business in mind.

This contradiction portrays a general dilemma in the field of software development, highlighted by the intricacies of the application domain (i.e. health and well-being). Following ethical standard and guidelines such as those of the ACM/IEEE-CS (2013) is not always easy in today's competitive software markets. It follows from this that a software developer may be forced to face the difficult question of "which master to bow before"; the client (or the employer), or the actual end-user. There is no simple answer to this question, and the situation is rarely so black-and-white that interests of different actors are polar opposites of each other.

²⁶ The service was released according to the estimate, see <http://www.taltioni.fi/> (accessed:6.9.2013)

One potential answer emerges from the Connecting for Health Common Framework by the Markle Foundation (2013), which proposes a set of practices for “appropriate handling of personal health information”, taking the Personal Health Records and similar applications into account (ibid.). Amongst others, the principles discuss the appropriate level of openness in terms of the collected information and use, and the level of control consumers should have over their personal information. Effectively, the framework provides a hands-on approach in a form of policies and technology papers to most of the ethical dilemmas discussed in Fairweather & Rogerson (2001, pp. 224-225). If widely recognized and applied on the level of marketplaces (such as Taltioni), the framework could work as a mechanism of trust that create healthy new business in a field that has been traditionally regarded as a difficult one.

3.8 Conclusions

The face of health care is changing fast. In addition to the “traditional” role of the patient, changes in the health service landscape have given room for additional roles, or interpretations on one’s position in the market, to rise. The emerging roles include those of the consumer, customer and citizen, of which the last has always been present in the background, for example in the form of different rights, privileges and laws put in place in order to protect the individual.

The changing service landscape needs adapting. The emerging roles and changes in the values and attitudes of the individuals acquiring the services need addressing. These changes potentially have a profound impact on the formulation of care pathways and similar structures that define trajectories (e.g. sequences of encounters) an individual have with the service providers. These structures should be re-evaluated from the viewpoints of the roles, their interrelationships, and mediation. Similarly, transitions from one role to another, especially within a context of a trajectory, need attention.

This calls for work on support mechanisms that may also exist outside a profession and a service provider. Profession-centric support mechanisms that operate on the premise that health services are offered by a singular entity, such as municipality, are outlived and they no longer align with the reality. What the field of health and well-being of today needs is a beneficiary-centric support role, a mediator, where the service provider has means and a mandate to operate within limits set by the beneficiary’s capacity to cope with the health related issues.

As the role of the mediator may be linked with a formal one, such as that of a practical nurse, or with an informal one, such as that of a relative or a friend, it may also exist as a business on its own as discussed previously (section 2.4). Regardless of the way the role put into practice, careful analysis on the actual costs and potential reimbursements is needed. In this, balancing the costs against anticipated savings (section 2.4) is of the essence. Without a positive outcome, it is difficult to see that the role will be realized in the form of publicly funded or subsidized health services. Especially in the economic setting of today, it is difficult to justify any increases to health budgets or taxation.

Evaluation of health care service provisioning from the perspective of emerging roles and mediation may also help in understanding how the individuals today perceive the clinical processes in terms of their personal preferences and (health) goals. As a conclusion, it can be argued that without taking the emerging roles and the changing nature of the actual beneficiary into account, we face very real risks of stagnation and even regression; the overall health care sector and the individuals themselves will not be able to reap the benefits of the on-going paradigm shift that is empowerment through technology bringing opportunities for new business models in its wake.

The following chapter is revised and extended from:

Lahtiranta, J. (2008), “Current Challenges of Personal Health Information Management”, *Journal of Systems and Information Technology*, pp. 230-243.

4. Current Challenges of Personal Health Information Management

The field of health care is changing rapidly. Partly due to exigencies of (public) health care services and partly due to vociferous demands of the empowered individuals the responsibilities related to one's personal health care are shifting from health care professionals to individuals themselves. In order to make savings in the (public) health care sector, and in order to streamline the overall health care business, individuals are to take more control over their own health and in some cases over the health of their relatives. At the same time individuals have become more knowledgeable about their personal health and health care in general, and they yearn to know more.

What individuals perceive as health care has changed as well. Nowadays health care is considered more than just a visit to a doctor, and health is more than absence of disease. Different well-being and even fitness services have broadened the scope of health care and brought different service providers into the field. Amongst others, physiotherapists, nutrition specialists and personal health trainers have found their way to into the everyday life of an individual who wants to stay fit and in good health. Health care is not just about health anymore (if it ever was); it has become more of an issue of a comprehensive well-being covering mental, physical and social dimensions. In this the change is almost salutogenic; from reasons of disease (pathogenesis) the focus has moved to causes of health (Antonovsky, 1979). Some individuals have even gone so far in their quest for the perfect health and well-being that the term "health optimization" can be used to depict their efforts and tendencies that borderline the extreme.

These changes have increased demands put on individual's health information management. Storing information on paper and binders is no longer a sufficient measure. In a similar fashion to other online services on the Internet, personal health information and different health care and well-being services must be immediately available on individual's terms. The sources of related information have become multiform as well, increasing the amount of information to be stored and accessed. For example, already in 2008 Kaelber et al. (p. 729) argued that 70 million people in the U.S. alone have access to some form of a personal health record. In a more recent national survey (2010) that focused on actual use instead of access, the estimate was more moderate. On average, 7 % of the surveyed had used a PHR, doubling the proportion from earlier surveys (California Health Care Foundation, 2010). Another indication on this increase is the amount of medical images that are estimated to occupy even 30 % of world storage capacities (Müller et al., 2012, p. 516).

In addition to new services providers, the individuals themselves have acquired different health devices such as sports computers²⁷ and other devices that monitor and gather data about their current health and well-being status. The availability and increased use of these kinds of monitoring devices has given room to a behaviour accurately described as quantified self-tracking where individuals regularly collect measured biological, physical, behavioural or environmental information about themselves (Swan, 2009, p. 508). Other examples of personal health devices include a PDA-based ECG beat detector for home cardiac care (Goh et al., 2005) blood pressure and glucose monitors, and personal medication reminders²⁸. As these solutions are gaining a foothold amongst the greater audience, the most recent advances in the field introduce wearable sensors used for continuous vital signs collection (González-Valenzuela et al., 2011), implantable biomedical devices, such as pacemakers and defibrillators (Yang et al., 2012), and ingestible capsules used for non-invasive drug delivery (Chen et al., 2011).

The rapid increase in information produced has had twofold consequences. Firstly, management of acquired health information has become increasingly difficult. Individuals struggle with the vast amounts of information that originates from numerous different sources (cf. Boardman & Sasse, 2004; D'Mello & Rozenblit, 2007). The available information contains inaccuracies and contradictions, and the amount of historical and out of date health information has started to accumulate. Secondly, the health care professionals are starting to have problems in coping with the information originating from the individuals. Unfortunately, the health care industry that has been slow to change has been caught unaware in front of this new and valuable information source. Empowered individuals who come to the appointment well-resourced with information about different aspects of their personal health and well-being are easily overlooked. The risk for this kind of behaviour is particularly high if the patient-physician relationship is formulated on paternalistic premises, potentially creating a conflict between authority of the physician and sovereignty of the patient employing a different metaphor to the relationship (cf. Beisecker & Beisecker, 1993).

From this viewpoint, the challenges of Personal Health Information Management (PHIM) do not apply solely to the individuals themselves, but they have profound impacts on health care as a whole. In order to make the health care industry ready for the empowered consumers, and in order to make better use of individual's electronic health information, new information management practices should be devised and disseminated.

²⁷ cf. <http://www.traxmeet.fi/>; <http://www.polar.fi/> (accessed: 22.3.2012)

²⁸ cf. <http://www.microsoft.com/en-us/healthvault/default.aspx> (accessed: 3.1.2012)

This chapter identifies some of the current challenges in the field of Personal Health Information Management and provides an outline for overcoming them. Proposed guidelines include a concept of Citizen Pathways (CPs) that can be used for complementing the current available solutions from a citizen-centric perspective.

4.1 Research Method

In order to create an overview on the PHIM research, a bibliographical review was conducted in 2008. The review was conducted in three stages of elimination using 5 major online databases (IEEE Xplore, Elsevier ScienceDirect, ACM Portal, Wiley InterScience and Emerald Journals). The review focused on articles a) emphasizing the personal nature of the health information management, and b) describing current challenges in the field of PHIM.

The purpose of this inclusion criteria was to point out articles that approach the emerging phenomenon from the perspective of the health care service user, the beneficiary, not that of the provider (i.e., health care professionals). The review was also extended to some of the literature cited in the discovered articles.

In 2008, the challenges of the bibliographical review were lack of qualitative, wide-ranging, literature that would provide a multidisciplinary approach to the phenomenon, balancing the view on the information and communication technology with other disciplines, such as psychology or nursing science. Another challenge was diversity of metaphors used in describing the role of the individual using the (electronic) health care services. Amongst others, the used metaphors included those of the patient, customer, consumer and citizen (for practical examples, see Adams & de Bont, 2007; Krohn, 2007 and Lahtiranta, 2008).

The first stage of the bibliographical review yielded over 80 articles of which close to 40 were chosen for the second stage. Out of these, 27 were chosen for in depth analysis in the final stage on the basis of their contribution to the subject. To support findings from academia with those of business, the findings from the analysis were compared against the analysis on the PHR solutions (Tuomainen et al., 2010; Lahtiranta & Nurminen, 2010) from the national MyWellbeing project that ended in 2010. Goal of this project was to define means and practices for managing individual health and well-being services, and related information. In the core of this project was the conceptualization of the next generation PHIM solution called the Coper; an aid that would help individuals to cope with their everyday lives and, in particular, to help in managing their health related efforts. In 2012, the results from the previous work were compared

against the Personal Health Record Functional Model (PHR-S FM) of the Health Level 7 organization that summarizes the common characteristics for a PHR today.

4.2 Personal Health Information Management Today

Personal Information Management (PIM) as a practice and a field of study refers to activities we as individuals perform “to order our daily lives through the acquisition, organization, maintenance, retrieval, and sharing of information” (Teevan et al., 2006, p. 40). The idea behind the concept is that the individuals should have the right information at their disposal at the right time. The concept in itself includes the notion of quality; the information at hand should be complete (e.g. comprehensive in terms of judgement and decision making), usable and in a right format. As a derived concept, PHIM defines an application area in which the general PIM practices are carried out (i.e. in health care and well-being).

In today’s health information management the central concept is Electronic Personal Health Record (ePHR), or more commonly, Personal Health Record (PHR), which can be regarded as a longitudinal record into which personal health information is stored. This concept heavily overlaps with the concepts like Electronic Medical Record, EMR (cf. Coiera, 2003, pp. 111-123) and Computerized Patient Record, CPR (cf. van Ginneken, 2002) which emphasize the role of public health care bodies, such as regional health authorities, as the primary source of individual’s health information.

Stand-alone PHRs

Considering technical aspects and maturity of the implemented solutions, authors such as Crawford (2006), Tang et al. (2006) and Krohn (2007) have identified different forms of PHRs. Their work covers a wide range of different solutions, starting from the manual and spreadsheet based ones, continuing to online solutions and finally interoperable “health banks” that aggregate data from different service providers. These most mature and technically advanced solutions are approaching the model for consumer health informatics described by Lewis et al. (2005, p. 5) where the informed health care consumer is brought to foreground, instead of the patient. In other references, these kinds of future-oriented solutions are referred as Personal Health Space; a paradigm that includes future developments of health care provisioning from the citizen-centric perspective (Sanromá & Adserá, 2010).

Focusing on the information management aspect, ignoring the traditional pen and paper solutions and focusing on ICT-artefacts, it is possible (amongst others) to divide artefacts related to PHIM into two main categories: stand-alone and networked PHIM solutions. The stand-alone solutions are implemented using ICT-artefacts like Personal Computers (PCs), portable data repositories (such as USB Flash Memory Drives²⁹ and devices similar to the ones described in Bardram, 2004) and online data storage services that are intended (primarily) for individual's personal use. In practice, the stand-alone solutions are similar to paper and binders with their benefits and challenges (see below).

While the individuals can categorize the information in any way they choose to, or are capable of, the information management can be considered laborious. Primarily, all information must be stored by individuals themselves in electronic format. This means that information received on paper or as printed-out images (such as X-ray or Computer Tomography) must be digitized and stored in the chosen ICT-artefact(s). The individuals themselves also act as guardians of the information; they ultimately define quality and security of the information, what information will be stored, from what source and how current the stored health information will be.

Another challenge with the stand-alone solutions is access to the information. While the networked models are typically implemented in such a fashion that a wider audience can have access to the information, access to the standalone solutions can be limited. For example, if the information is categorized using one's own preferences, using solely colloquial language, searching for relevant information can be challenging. Furthermore, the access to the standalone systems can be problematic due to the technical properties and requirements of the used ICT-artefact (e.g., due to the user interface and connectivity issues). Connecting an artefact to another, installing required software and drivers for example at the General Practitioner's office does not necessarily yield intended results.

Networked PHRs

Continuing with the theme of PHIM, the networked solutions can be divided into three categories: a) extended EHR solutions, b) solutions of the non-health care industry and c) sponsored systems (figure 4.1). The first category, extended EHR solutions, can be regarded as more traditional EHR systems and data repositories that contain patient's medical information (laboratory test results, allergies, medications, etc.) as well as their personal information (occupation, number of people in their household, etc.). By using these systems, the individuals gain limited access to the EHR and are able to view what most of

²⁹ cf. <http://www.911medicalid.com/products.php> (accessed: 3.1.2012)

their “official” health records contain. One of such systems known as eViewing³⁰ (eKatselu) is currently developed in Finland as a part of the national KanTa services. In this form, the dimensions of managing information are limited. The available PHIM practices are similar to the electronic banking; individuals can access and manage information related to them solely on the provider’s terms (incl. available tools and media). The fundamental problem with these kinds of solutions is that PHIM and personal health information access cannot be regarded as equivalent terms.

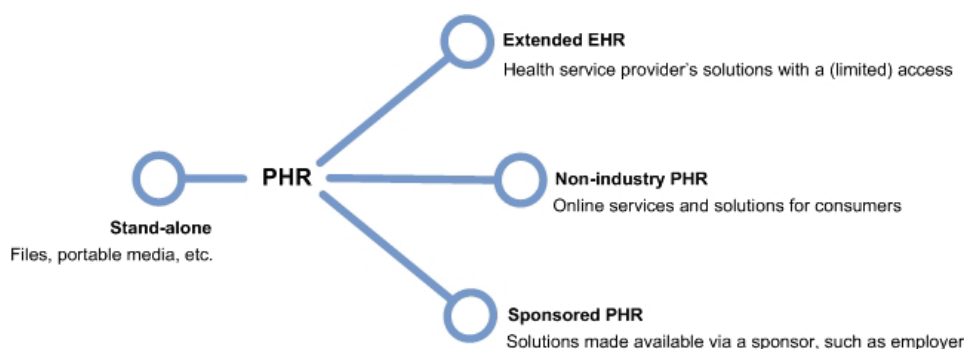


Figure 4.1. Stand-alone and networked PHR solutions.

In the middle ground between the stand-alone and extended EHR solutions are the ones of the non-health care industry. Service providers in this field have approached the dilemma of PHIM from another perspective placing the individual, not the health care service provider, primarily in control of the information. Amongst others, Wang et al. (2004) have presented this kind of web-based PHR concept in theory and similar ones have been realized as actual services like the Microsoft HealthVault, the (now discontinued) Google Health and the Finnish Taltioni.fi portal³¹ which was released in early 2013. In these kinds of solutions, individuals themselves (in principle) decide what kind of personal health information they want to store and who has access to the information. Unlike with the extended EHR solutions, individuals can modify the stored information and enrich it, for example by adding their own interpretations or information from their repertoire of instruments (sports computers, health devices, etc.) into the service provider’s systems. Naturally, the individuals may also degrade quality of the information (intentionally or accidentally) when removing, commenting or altering it.

³⁰ <http://www.kanta.fi/en/omien-tietojen-katselu> (accessed: 9.10.2013)

³¹ <http://www.taltioni.fi/> (accessed: 3.1.2012)

However, regardless of the relative autonomy and control over the information, similarly to the extended EHR solutions, the service provider has significant control over the stored information, including format, classification, and so on. In some cases, the service provider even claims, at least partial, ownership over the stored information, and is able to sell it, use it for profiling and advertising, etc. (see section 2.3) unless prohibited by the law. For example, in the case of Finnish PHR portal terveyskeskus.fi, the service provider(s) claim (in September 27th, 2008) “immaterial rights to the service contents and related information” (translation from Finnish).

Particularly in terms of free-to-use personal health record systems and related services, it is understandable that the service providers need a working revenue model in order to continue business. However, claiming ownership over health information that is highly personal by nature, and potentially preventing its use in the near future, is not only morally dubious. It may also have a negative impact on individual’s aspirations to become an active subject and a principal actor in terms of their health and well-being, and that of their close ones.

If the information is held under lock and key inside service providers’ information systems, the beneficiaries are at risk of losing perspective. Without access to health information, it is impossible to build continuums and assemblages on it that could help the beneficiaries to understand where they stand in terms of their health. This, in turn, could help the beneficiaries to live out their health related aspirations as events and their outcomes are made visible. If applied throughout the health care system, beneficiary controlled health information could also enrich the system, for example in terms of analysing care outcomes and recruiting candidates to clinical trials.

One interesting form of networked PHIM solutions is the sponsored systems, such as the one provided by the Verizon Communications. In this case, a non-health care PHR solution is provided by the employer to the employees. The solution provided by Verizon Communications is integrated with the services provided by WebMD, a service provider that enables the employees to store their personal health information on an online data repository. Even though in this case the partnership between the employer and the service provider is formed with a non-public health care provider, it is probable that in the near future similar allegiances can be seen between the employees and public bodies as well.

4.3 Current Challenges in PHIM

Using a scenario built on health information management needs of a cancer patient called “Irene” Pratt et al. (2006) list three central challenges in the field of PHIM that touch upon some of the fundamental problems in the intersection of health, well-being and technology. Summarizing, the described challenges are:

- Integrating personal, professional and health related information;
- Using integrated information to make health related decisions;
- Sharing information with individuals from social, professional and health care networks while maintaining personal privacy.

The first challenge effectively depicts the fragmented nature of the health information (and as a consequence, state of the health and well-being services). Information is commonly scattered on multiple devices and it is stored in various different formats (cf. Kim et al., 2009). Integrating information from different sources and using it on a daily basis (for purposes such as time management, scheduling for treatments and appointments, etc.) is problematic and suffers from non-trivial technical and policy problems (cf. Brennan et al., 2010, p. S5).

Similarly to the first challenge, the second challenge, using integrated information, arises from the current challenges of the health care industry as a whole. Due to problems with the exchange of information that is constantly on the rise, for example in the different EHR solutions, an overall view to one’s current health status cannot be effectively maintained and the available information is not usable for decision making purposes (Halevy, 2011, p. 3). It is difficult to understand the relevance and implications of the information in the context of one’s personal health status, even more so if the view on health record substantially varies from role to role, from patient to physician (cf. Liu & Hayes, 2010).

The final challenge described by Pratt et al. (2006) focuses on the information sharing. Providing information in a controlled manner, to chosen networks (such as friends, mediators, relatives or co-workers) needs implementation of new tools and practices, such as the Connecting for Health Common Framework by the Markle Foundation (2013), which proposes a set of practices for handling personal health information. In addition to controlling distribution of the information, the final challenge focuses heavily on personal privacy, emphasizing an individual’s need to define what information is shared (e.g. not just the medium) and how it is used as discussed in Fairweather & Rogerson (2001, pp. 224-225) in relation to the use of patient information in electronic patient records.

While all of the challenges described are valid in the field of today's PHIM and health care sector as a whole, they are somewhat lacking in perspective and focus. The principal actor in the scenario is a patient, who already is a part of a health care process. To complete this view, other perspectives, such as that of a citizen (or similar neutral term that does not indicate involvement in a service or a process) in the context of well-being should be introduced. With this broadened perspective, it is possible to add the following challenges to the previously presented ones.

- Supporting service integration;
- Enabling mediation;
- Supporting knowledge transformations.

Supporting service integration

The field of health care and well-being services is in constant turmoil. What individuals perceive as health care is changing and expanding. Similarly, the relationship between the patient and physician has changed as well. What can be interpreted as a paternalistic relationship (Childress & Siegler, 1984) is slowly changing into an equal partnership, and even into an individual-driven consumer connection (Emanuel & Emanuel, 1992; Cohen et al., 2010). This on-going systemic reform has brought new service models and providers into the field and as a consequence the service palette has become difficult to maintain. What the health care as a whole now needs is service integration; not just technological or standards-level integration between ICT-artefacts but service level integration as well.

The service integration can occur on many levels. It can occur within single organizations providing different services, between separate organizations (actors, agencies, etc.) providing multiple services or it can occur as a combination of the two. From the perspective of PHIM, service integration requires focusing on the primary actor, the beneficiary, and creating tools and techniques for managing service trajectories from one provider to another, and from single event to another within the context of a specific condition, ailment or even chain of service. Benefits from this kind of scheme do not fall solely to the individuals themselves, but also to the service providers in the form of synergies between different services that often results in health improvement of the beneficiary (Hietala et al., 2009, p. 50).

Service integration also challenges the scope of current PHIM practices. It is possible to get a comprehensive view on beneficiary's state only by integrating actors and activities outside the scope of, what can be regarded as, "traditional" health care services. In order to acquire such a view, health information

management should expand into life information management, containing information on one's lifestyle and daily living (incl. hobbies, projects of personal nature, and so forth), and their relationship to the appropriate social context (family, friends, relatives, and so on). However, it must be acknowledged that with such expansion, the complexity and the amount of information increases (exponentially), intensifying the identified challenges related to the information management. This again calls upon even more effective solutions and practices for information management.

Enabling mediation

Mediation, for example in the role of a mediator, an advocate of sorts (cf. Lahtiranta, 2008) should be supported in order to lessen the impacts of the digital divide, to enable caring for close relatives, and to improve communication and information exchange between different actors participating in individual's care. Supporting this function does not automatically mean the creation of new ICT-artefacts but first and foremost creation of new service models that are effectively established as a common practice. In addition of having support of the wider audience, including health care professionals, these models must conform to the current legislation, best practices in health care and they must be economically feasible; a challenge which is not always easy to overcome or demonstrate. For example, if the role of the mediator is implemented as a "job within a job", the costs and the benefits of the function are hard to balance. For example, if the time allocated for mediation is taken from other tasks, such as direct care, the overall effect of mediation may be even negative from the perspective of the beneficiary.

From a technological perspective, effective mediation has a certain connection to the findings of Pratt et al. (2006) in terms of sharing information with individuals from different networks. In practical terms, mediation could be supported with different software semi-automatons and agents, which could incorporate anthropomorphic aspects in their design. For example, if online pharmacies reach such a status that they become part of everyday practice, agent technology could be used to find a pharmacy that meets the individual's personal criteria in terms of price, quality, trust or accepted compensation models, and so forth. The risks related to the use of these kinds of artefacts, such as the ambivalence of the interaction between "man and machine", and effects of illusion of life and intelligence, are discussed in the sections 2.3 and in 6.2, and in Lahtiranta and Kimppa (2008).

Supporting knowledge transformations

Another widely explored issue in today's health care is health literacy. Particularly the use of health care documentation (narratives, recommendations, etc.) that is created by one health care professional to be used by another using appropriate medical jargon can be a challenge for a layperson. Considering that the beneficiary is considered more and more as a legitimate source of health related information, the challenges related to the use of language are becoming transitive by nature; the health care professionals need to understand the information that originates from the beneficiary and is stored according to the preferences of the beneficiary (for example, in terms of categorization, ranking or labelling).

While health care professionals are today the primary source for health care documentation (including most of the written patient instructions), the situation is changing rapidly. The nature of emerging health and well-being services may fundamentally differ from those of today. For example, different synchronous and asynchronous services, such as online consultation and decision support services, are rapidly put in use and they are slowly regarded as de jure service models, especially as a part of different (sponsored) PHIM solutions (cf. the previous example about Verizon Communications). For these reasons, and in order to narrow the "competence gap" as a source of miscommunication between health care professional and a patient (Waitzkin, 1985, p. 82; Santana et al., 2011, p. 2), and to support the work of a mediator, knowledge transformation should be supported as a PHIM core function.

Alavi and Leidner (2005, p. 171) characterize different forms of knowledge by using taxonomies (figure 4.2). As in the context of knowledge management in general, identifying and integrating different types of knowledge into existing and emerging PHIM practices is essential.

Knowledge Types	Definitions	Examples
Tacit	Knowledge is rooted in actions, experience, and involvement of specific context	Best means of dealing with specific customer
Cognitive Tacit	Mental Models	Individual's belief on cause-effect relationships
Technical Tacit	Know-how applicable to specific work	Surgery skills
Explicit	Articulated, generalized knowledge	Knowledge of major customers in a region
Individual	Created by and inherent in the individual	Insights gained from completed project
Social	Created by and inherent in collective actions of a group	Norms for inter-group communication
Declarative	Know-about	What drug is appropriate for an illness
Procedural	Know-how	How to administer a particular drug
Causal	Know-why	Understanding why the drug works
Conditional	Know-when	Understanding when to prescribe the drug
Relational	Know-with	Understanding how the drug interacts with other drugs
Pragmatic	Useful knowledge for an organization	Best practices, business frameworks, project experiences, engineering drawings, market reports

Figure 4.2. Knowledge taxonomies and examples (Alavi & Leidner, 2005, p. 171).

Considering the nature of health care and well-being, transforming information from one form to another, storing it as information, and enriching it is ideally an iterative process that involves all related parties. For example, integrating a health care professional's causal knowledge into individual's knowledge pool on the individual's terms, and enriching it over time with the individual's personal insight, or tacit knowledge, is a process that already occurs in face-to-face patient/physician appointments with a familiar doctor, but less so in electronic asynchronous services. Similarly, generalizing or creating explicit knowledge about health care professionals' declarative and relational knowledge and

disseminating it as information for a wider audience, can be regarded as one of the key factors in health education.

For example, in wound care, taxonomical translations could be of essence. Currently, the home care instructions answer to the questions “how” and “when”, providing information on how the wound is treated at home and when the stitches are to be removed³². With taxonomical translations, answering to the question “why” the patient could be more aware of the reasons why the wound should not be unnecessarily touched and what are the consequences of inadequate wound treatment. With this kind of information at their disposal, the patients could be encouraged to take more responsibilities over their care and that of their close ones.

Technologically, knowledge transformations require changes in document management and distribution principles. From a health care or well-being service provider’s perspective, information from the individuals should be integrated, when appropriate, into information systems, such as EHRs in order to provide comprehensive audit trail of care decisions. Similarly, individuals ought to acquire their copies of the “official” health care documents according to the PHIM practices. This kind of two-way information exchange requires tools for taxonomical translations (incl. colloquial language and jargon translations), for example in the form of data mining and Natural Language Processing (cf. the Louhi project³³).

Use of appropriate language requires further consideration. Not just from the perspective of the individual, but also from the perspective of the service provider. Building tools for two-way taxonomical translations and enabling the use of the stored information potentially from generation to generation should be considered. Even though the used language in the stored information may be comprehensive today, the situation may change as the next generations start using the information. Language, particularly colloquial language, changes over time and inaccuracies start to emerge and (perceived) quality of the information may decrease.

In certain EHR solutions there are already tools that take care of taxonomical translations of the used classification into a format understood by laypersons. However, there is no categorization or classification standard that can be used by individuals as a part of their personal information management. If such colloquial, or common, classification (like, “sports injury, knee” or similar) will be implemented, or if each individual chooses to use a personalized one, the rationale and principles behind the categorization should be made known to the

³² For a practical example, see <http://ohjepankki.vsshp.fi/en/3936/10284/> (accessed 17.10.2013)

³³ <http://www.med.utu.fi/hoitotiede/tutkimus/tutkimusprojektit/louhi/> (accessed: 4.1.2012)

professionals. On the level of individual documents, such as an epicrisis or a referral, that originate from the service provider, the original coding and classification should be maintained in order to maintain their validity and integrity. If this cannot be implemented, inconsistent information management principles and incomplete information can gnaw away the trust the stored information; the classification can even be seen as a hindrance in terms of using the information in clinical decision making.

4.4 PHIM of Tomorrow?

What the field of PHIM is currently lacking is a truly personal aid for health care and well-being information management; a solution that would combine best properties of the present PHIM solutions. The three basic technology requirements for such solution are: modularity, mobility and adaptability. In the context of PHIM, this implies that the solution is platform independent; the individuals should be able to use it to some degree, for example, on a mobile phone, locally on a personal computer, or via Internet as an online service.

Truly personal PHIM solution should ideally also adapt to individual's personal health management practices, and it should seamlessly support service integration and mediation. Such a solution could be potentially utilized outside the sphere of health care and well-being; even in the management of individual's everyday activities. Creating this kind of solution does not mean that the existing solutions, extended EHR solutions in particular, become obsolete or that their use should be avoided.

To connect information systems of health and well-being, and Enterprise Systems (ESs) outside their sphere, integration on the level of the proposed PHIM solution is needed. The integration should be done bi-directionally in a controlled and regulated fashion. This implies that a) information originating outside the PHIM solution should be integrated to the solution in such a way that it can be used in other systems, and b) information originating from the beneficiaries themselves should be brought to the ESs in a reusable format (when applicable). One consequence of this kind of bi-directional integration is that as the overall data flow increases, so do the potential privacy and security risks.

While some of these risks are technological by nature, as are their solutions, there are other more complex challenges that need addressing. In the wired world of today, one of the fundamental challenges is related to the secondary use of information outside the primary or intended use, such as health care delivery. Naturally, secondary use of health information can be used for legitimate purposes, such as for expanding knowledge on diseases and their treatments.

However, there is another side the use of health information; use for strictly commercial purposes, for example, under a vague pretence of enhancing “health care experience”. These kinds of challenges cannot be necessarily fully addressed with technological needs, but technology can provide a partial solution to them as discussed later on in relation to the principal functions of the proposed solution.

On the level of integration, one view to devising a solution that combines different spheres of operation, originates from Web 2.0 mashups. In these kinds of solutions different services and data sources are integrated as hybrids that bring more value to the users than the original ones (cf. Laudon and Traver, 2009, p. 3-2). As an example, in the health care and well-being domain, a mashup could be a combination of separate solutions that track a) individual’s medical history, b) drug usage and c) proposes the most affordable (and reliable) source for acquiring new medicine when the currently used ones are about to run out. In theory, a combination of these solutions could be implemented as a mashup that combines individual solutions and Public Sector Information (PSI) into a singular and coherent application, which could be run on different technological platforms therefore augmenting to the existing devices of the individuals.

In a technological sense, PHIM solutions have become more mature over the last few years. Advance from ad hoc pen and paper solutions into networked ICT solutions of today has been rapid and will continue to be so in the near future. Similarly, health care practices have evolved and the individual is rightfully becoming the key actor in all health care and well-being practices. However, as Toiviainen (2007) describes, there is still a long way to all-out consumerism in the sector.

Considering what kind of discussion revolves around different aspects of (health) information ownership (cf. Brown and Adams, 2007, p. 56 and Leino-Kilpi, 2004, p. 346), it is also clear that principles for ownership must be defined prior to implementing PHIM solutions of the future. The central principle behind these solutions should be that individuals themselves own and control (to a reasonable degree) their health and well-being information and the information is not used without their explicit and informed consent. The terms of use should be applicable on a global scale and it is of utmost importance that the terms are clear and precise, not a collection of terms written in abstract or juridical form.

Admittedly, this idealized notion is far from current state of affairs. Health related information is often locked inside service providers’ systems and the individuals have little or no control over it. A blatant example of this the recent dispute between the Milwaukee Health Services and Business Computer Applications. Due to a disagreement over an EHR contract between the parties,

the technology provider stated that it will not allow the physicians to view any patient data stored in their information system (Bresnick, 2013). The European Union tries to prevent similar problems in relation to sensitive personal data by employing a directive that aims to guarantee that every EU citizen has a right to the protection of personal data. This is a welcome reform of the EU's 1995 data protection rules that have been employed in varying degrees throughout the region.

The Coper – a partial solution?

One interpretation of what kind of functions a truly personal aid for PHIM could incorporate emerged during the national MyWellbeing project. In the project means and practices for managing individual's health and well-being services, and related information were defined. In the core of the project was the concept for a next generation PHIM called the Coper that encompasses functions used for integrating a) information from different sources in the terms of the beneficiary, and b) different services around a trajectory of a specific ailment or concern (such as, a high blood pressure or knee arthroplasty). The starting point for this outlook on integration was that all health related activities (principally) share the same subject, the beneficiary, who should be regarded as the principal actor in the activities.

The envisioned functions of the concept pictured the artefact as a health navigator; a solution that could help the beneficiary to manage different transactions as coherent trajectories of health related events. These trajectories would be formed from the starting points of the beneficiary, not that of a service provider. A trajectory, such as "my life with diabetes", would be supported with different functions of the artefact and the artefact be seen as an ICT-based mediator in itself, or at least a tool that could support it. With the latter interpretation, mediation can be seen as a particular case of tool-mediated activity as described in the activity theory, and transformations within a specific trajectory as results of interaction with the artefact (Kaptelinin, 1996).

The principal functions of the Coper are related to: a) information, b) services, c) devices and d) transactions (figure 4.3).

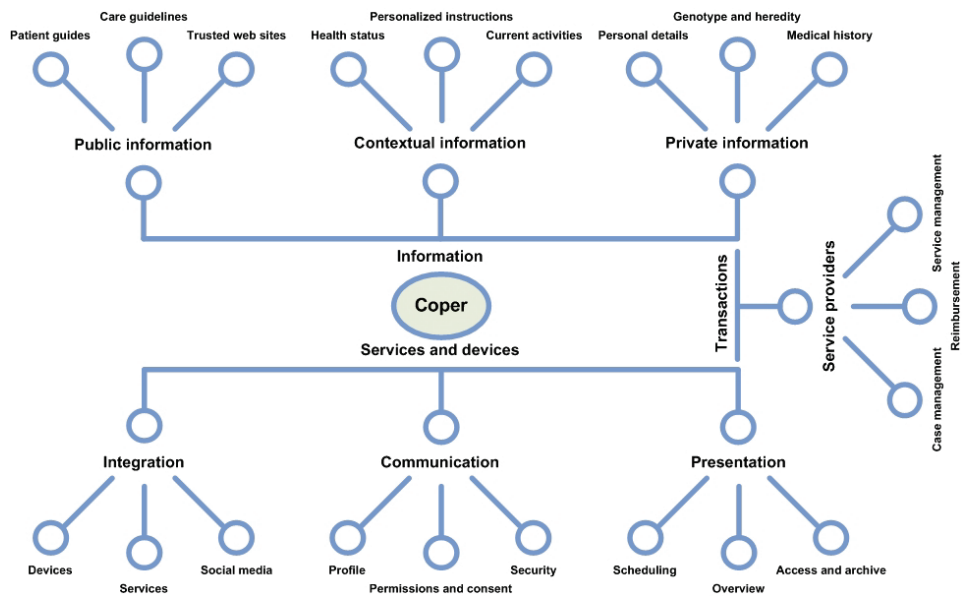


Figure 4.3. The functionalities of the Coper (author).

The nature of public information can be regarded as intuitively explicit. It contains generic and open information, such as patient guides, common dietary instructions and tutorials on how to live a healthier life. In this sense, the information could be linked to public health information programs, outreach and training. The opposite, private information is similarly explicit. It contains personal particulars (for example, name and next of kin), family traits and genetic information. Of the three information types, the contextual information is the most complex construct and needs more clarification.

The contextual information can be described as something that is relevant to the current health status of the beneficiary. In its simplest form, this kind of information could be tailored physiotherapy instructions or vaccinations that are valid for an upcoming travel. In a more complex form, the information could be a care recommendation that is based on the information originating from a) health care professionals, b) personal health devices and applications and c) decision support aids; solutions that are designed primarily for the patients to help them to make decisions about their treatments, medical tests and maintaining status quo (c.f. O'Connor et al., 2009). The contextual information also incorporates the notion of knowledge transformations. Information and its use are seen as inseparable from this viewpoint. Without context, information is

more akin to structural data. Only the process of contextualization makes it meaningful, valuable, useful and relevant.

Like public and private information management functions, the integration, communication and presentation functions contain features that are intuitively explicit and common to other PHIM solutions. For example, the security function of the concept is principally technological. It enables management of passwords, security certificates and trusted service providers; functions that are integral even to the commonly used smart phones of today. Outside technological features, there are numerous security (and privacy) challenges that cannot be solved with technical means. One of the fundamental challenges stems from the relative novelty of citizen-centric approach to health and well-being services.

In the professional setting, protecting patient-related information has a long history starting from the Hippocratic Oath. Even though there is no legal obligation to for medical practitioners or students to swear on the oath, it creates an ethical backbone for their service commitment. In modern times, legislation, directives and whole juridical frameworks have been put into place in order to protect the clinical and sensitive data, and the patient. For example, in the recent news NHS has been legally barred from selling patient data for commercial use (The Telegraph, 2014). In terms of citizen-centric services, and especially those belonging to the field of well-being, protective juridical frameworks are largely missing. As a consequence, it is practically impossible to supervise how one's health and well-being related information, shared by the beneficiaries themselves, are used outside the professional setting (such as, in social media, cf. Williams, 2010).

In order to address these kinds of challenges that are primarily related to the secondary use of health information, data stewardship mechanisms such as the information encapsulation discussed in the chapter 2 (figure 2.4) could be of the essence. In addition to the security, there are other functions that need further discussion and investigation in order to gain a clearer picture on the nature of the concept of the Coper.

One of the design principles behind the concept was that the beneficiary acts as an integration point, not the backend systems, such as a Hospital Information System (HIS). The reason for this principle, and to a degree the *raison d'être* for the whole concept, is that health information by its nature is deeply personal and sensitive. As such, its confidentiality should be protected in such a fashion that individuals are not afraid to search health information online or to use electronic health services. In addition to rigorous technological security, the use of personal health information should be controlled (to a reasonable degree) by the beneficiary, or by the mediator when a need for one has arisen.

It follows from this that the integration of health information systems can be complemented with an individual level integration and if the systems level integration fails, access to personal health information is guaranteed by the concept. As such, this insight into security, confidentiality and use of personal health information also addresses one of the commonly acknowledged challenges associated with the health and well-being industry as a whole; the (technical) integration standards, such as those of HL7 organization, have “failed to provide sufficiently stringent standard specification to enable plug and play” and lack of interoperability “is one of the limiting factors in the market growth for health information systems” (Benson, 2010, p. 76).

As a related matter, an interesting national initiative has been put into motion in Finland by the Ministry of Finance (February 7, 2013). The initiative called The National Service Bus employs principles already tested in Estonia (X-Road) where different services are integrated to single service architecture (Ministry of Finance, 2013, p. 18). When implemented, the architecture should enable a secure data exchange between public (such as the vehicle register) and private sector (such as banks and energy companies), and it will provide individuals access to data stored in the services of the public sector. In theory, similar service architecture could be implemented on the level of the European Union, enabling cross-border and cross-sectorial electronic services. In this, the co-operation between Finland and Estonia may act as a trendsetter for the rest of the member states.

The individual level integration envisioned in the concept also supports the use of information originating from personal health devices and applications in the clinical decision making. As the integration point is the individual, not a backend system, it is possible to distribute the information originating from such solutions to the health service providers, and if necessary, even to one’s peer groups in social media. At this point, it must to be acknowledged that sharing information in the social media needs caution as it has become increasingly difficult to maintain any reasonable control over the shared information. For example, personal sensitive information and information about one’s friends and associates is systematically collected by different service providers, such as payday lenders Wonga and Kreditech, and used as a source for detailed analysis on one’s economic standing (Deville, 2013).

As a beneficiary-centric concept, the Coper has characteristics depicted by one domain specialist during a steering group meeting in the fall 2012 as a “Chinese PHR”:

“Few years ago, I was in China. I noticed that in some areas, local doctors run their practice at stalls or small booths that were situated next to crowded

pedestrian walkways. This made me curious so I decided to observe what really happens at them. I chose a booth that was conveniently located and started to follow the day-to-day routines as discreetly as possible. One thing in particular caught my attention; when a patient arrived to the practice, the patient handed over a small notebook to the doctor. Before a brief examination and consultation, the doctor more often than not flicked through the notebook. Afterwards, the doctor usually wrote something to the notebook and handed it back to the patient. I consulted a local associate of mine on the matter of the notebook, and I was told that it contained the patient instructions and prescriptions. Considering the problems we have with our health care provisioning, this down-to-earth approach to the patient information management was an encouragement. Henceforth, I have referred this notebook as a Chinese PHR.”

The concept of mediation is also present in the individual functions of the Coper. The function of permissions and consent is not just a technological means for restricting access to the beneficiary’s personal health information; it is also a way to delegate responsibilities between different actors and roles, such as mediators and case managers. In principle, the function enables encapsulation of information in a way that different actors have a better understanding of their duties and expectations, and they have access to all relevant information. One example of this kind of encapsulation could be a practical nurse that is responsible of the beneficiary’s medication. With the permissions and consent function, the nurse on duty could have up-to-date access to a) relevant parts of beneficiary’s medical history, b) current prescriptions, c) medical inventory, d) electronic medicine reminders, and if needed e) health service provider’s backend systems into which the parts of the beneficiary’s health information is stored (for example, due to reimbursement arrangements).

A similar mechanism that addresses issues of trust is the profile function. With the function the beneficiary (or the mediator) can use different ICT-artefacts with different, often predefined, information sets and security settings. In addition, the function also enables use of artefacts anonymously; in a user mode which is often overlooked in the context of PHIM solutions. One reason for the common lack of this function is probably related to re-identifying. When the beneficiary decides to disclose personal health information, it can be potentially used for re-identifying the beneficiary, or other individuals (c.f. Chaytor et al., 2006, p. 29). In other words, implementing this function in a real-world PHIM solution is challenging, at the least. The profile function can be seen as complementing the permissions and consent function. It provides means for creating a digital representation of the beneficiary identity for a specific purpose. Especially the built-in function of anonymity can be of importance when one is addressing delicate health issues, which could include matters of reproductive health or sexual behaviour. A need for this kind of anonymity is also particularly

evident when one wishes to use social media for discussing health issues. In this kind of media, limiting exposure of one's personal information can be a viable option (c.f. Boyd, 2008; Deville, 2013).

The presentation function of the concept is effectively the most defining function in terms of user experience. It provides means for searching and sorting health related information, and for making meaningful aggregates of it. On a practical level this means that the available health information does not have to be accessed or archived on the basis of information provided by the health service provider (name of the attending physician, LOINC of the clinical observation, etc.). With the function the beneficiary or the mediator may create personalized assemblages of information according to one's personal preferences. A practical example of this could be a hobby: an assemblage could contain information on health related events (injuries, operations, physiotherapy) that originate from playing football in the high school varsity team, and are also ones affecting to the hobby today. This possibility of creating personalized assemblages was probably the most welcomed idea by the members in the focus groups who assessed the functions of the Coper. The possibility was compared to the current information management principles in the following matter (example from the MyWellbeing project):

“It would be nice to know which piece of paper is related to what. Today, all the papers are in the drawers; the left drawer is for my husband and the right one is for me. The oldest and the least frequently used papers are in the bottom while the newest ones are on the top. Except for the x-ray images, they are on the top of the cupboard because they are so big and cumbersome.”

It was also envisioned that the concept should support the beneficiary in achieving, what can be referred as, “the big picture”. With the overview function it is possible to visualize how different health related events are aligned to each other and to one's personal health aspirations. Practical examples of this could be related to the beneficiary's cholesterol: how the physical activity correlates to the weight and to the cholesterol levels, or to discomfort: how the heart bypass operation aligns to the experienced pain in the chest and left arm during a specific workout at the gym. This kind of functionality may also have a positive impact on prevention and motivation. With the overview function, the beneficiary should be able to perceive the health benefits (or drawbacks) of their hobbies and lifestyle on a grander scale, potentially supporting a long term shift towards healthier life.

The functions of time are also amongst the most common functions to existing PHIM solutions. In the concept of the Coper, these functions are characterized as scheduling. The scheduling function includes notifications (time from last laboratory test, available medicines, etc.), reminders (medication, upcoming

appointments, etc.) and opening hours of the service providers. In addition, the scheduling function covers the everyday activities, such as sports and hobbies, integrating them into the health information. Naturally, the scheduling function complements the overview function. Without the scheduling function, alignment of the health related events would be less informative. Scheduling also complements other functions adding value to their use. For example, with the integration function it is possible to address issues related to patient adherence, assisting different actors in managing beneficiary's compliance with medications. With the integration function it is also possible to link the Coper to other scheduling systems decreasing a need to run parallel systems.

Transactions management was regarded as the most novel idea by the domain specialists in the Finnish health care setting. Even though the original project has ended, it still represents a set of functions that are still missing as a whole from most of today's PHIM solutions. The importance of transactions management is also identified on the global scale and the Health Level 7 organization has included most of the functions into the Personal Health Record Functional Model (PHR-S FM), which is currently a draft reference (Draft Standard for Trial Use, DSTU) and not an implementable specification. Unlike the original version of the Coper concept, the redefined set of functions emphasizes the significance of case management, or a way of organizing care on the level of the beneficiary (Banks, 2004, p. 101). With the case management function a health care professional assigned to the role of a case manager (or mediator) can use the concept in defining the required services and level of care. Alternatively, the beneficiary may arrange the functions with the service management function. With the function, it is also possible to renew prescriptions and to manage agreements with the service providers.

Agreements are also integral part of reimbursement function. The function enables transactions management with individual service providers, and management of related reimbursements (for example, with insurance companies and national health insurance organizations, such as Kela in Finland). With the function, it is also possible to follow up correspondence with the providers and, when applicable, integrate received counselling into the information function of the concept (as public, private or contextual information).

Even though the functions of the concept, even in their redefined state, are not all-inclusive and could be defined on a more detailed level, they still add to the existing standards such as the Personal Health Record Functional Model (PHR-S FM) and to the PHIM solutions currently on the market. In particular, the functions of presentation and transactions contain novel ideas that await actual implementation.

4.5 Recommendations

The field of PHIM is growing fast. New solutions and even completely new insights into the management of personal health information are emerging. Some of these are incorporated into the information management practices of the computer-literate individuals in this information age. However, the real challenges related to the widespread adoption of the different PHIM solutions lie often much deeper than in the technological properties of the used ICT-artefacts and information systems.

The current paradigm shift, that is rapidly placing responsibility over one's own health and that of their relatives (such as elderly parents) on the shoulders of the individuals themselves (and their mediators), needs process-level integration of citizen-centric practices and supporting ICT. In order to enable this level of integration, Citizen Pathways (CPs) should be devised.

Citizen Pathways

Formally, Citizen Pathways can be defined as “a group of voluntary policies, standards and protocols that lead or direct a course of action of an individual to a desired outcome in everyday life in conjunction of a clinical encounter”. Purpose of the pathways is to complement different guidelines of the clinical domain from the citizen's perspective (see illustration in figure 4.4).

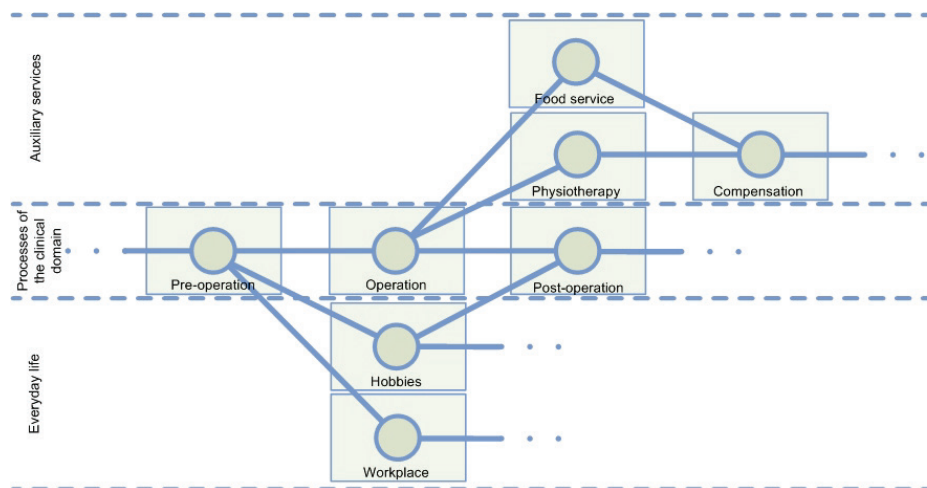


Figure 4.4. Citizen Pathways, illustration (author)

In the figure 4.4, the lines describe service trajectories where CPs could be potentially defined. Service trajectories are aggregates of services, triggered by a

clinical encounter, if not necessarily provided by a health care organization. For example, CPs defined for the clinical domain would help the citizen in relation to the operation itself (e.g. how to prepare for the operation at home) while CPs defined for the auxiliary services would help the citizen in acquiring physiotherapy services and taking care of the processes related to the compensations (e.g. insurance). In everyday life CPs could help citizens in taking care of the processes related to one's work (e.g. filling in the documentation in relation to a sick leave).

From the perspective of PHIM, in the core of the CPs are instructions, models and in some cases stepwise scripts that help individuals and their mediators in managing events, distribution of documentation, scheduling, and so forth, in relation to the treatment or care within national setting (e.g. within the current legislation and practices). For example, in the case of a kneecap surgery, the CPs could cover instructions related to referrals and (if appropriate), insurance and deductions. As an ICT-artefact, such as the Coper, the solution could also provide means for contacting other parties affected by the consequences of the operation (i.e. one's workplace or hobbies such as one's football club).

A central aspect in the CPs is the degree of freedom. In the spirit of guidelines of the evidence-based medicine that are defined with the notion of clinical freedom in mind, CPs are to be defined in a such fashion that the individuals are able to use their own judgment and common sense when employing them into their situation within the framework of their role as a citizen. From this perspective, voluntary and adaptable practices could also serve individuals when they are having a discourse with their mediators on how they want their health related affairs to be conducted.

On a larger scheme of things, voluntariness is also a central aspect when countering arguments of digital divide. Mandatory practices and involuntary use of ICT could potentially lead to increase of digital orphans as discussed in the chapter 2.

Why Citizen Pathways?

In addition to the paradigm shift of the health care, the motivation for defining CPs is related to overcoming current challenges of PHIM. In particular, overcoming the challenges of a) integrating personal, professional and health related information and b) enabling service level integration, would benefit from definition of practices such as CPs, and implementation of PHIM solutions that support such practices.

Citizen Pathways also play a central role in overcoming the challenge of using integrated information in making health related decisions. By supporting the use

of these practices, the individuals potentially have information from multiple sources to support their decision making. If the PHIM solutions support mediation and the role of the mediator, the individuals have information available to make justified decisions that have an impact on the whole social unit (e.g. family, elderly relatives, relatives with mental or cognitive declines). In theory, the pathways can be also seen as supporting multi-mediation (Bødker & Andersen, 2005), delegating tasks between different mediators when there are more than one present in the situation.

Supporting CPs that integrate multiple information sources and service providers further emphasizes the need for solving the challenge of knowledge transformations. Without sufficient support for the transformations, the individuals may have information at their disposal, but lack the means for effectively utilizing it. For example, combining health information with formal or legislative language often used in insurance agreements can be a daunting task even for the most highly educated computer-literate young.

The Citizen Pathways do not only benefit the individual, by helping them in their health endeavours, but can also have a positive impact on the overall health care system. If the CPs and the supporting PHIM solutions can be successfully used as tools of empowerment it is possible that the individuals will become active experts in their own health as described in Falk-Rafael (2001) and therefore a valuable information source in all health related events. This kind of evolution from passive health care recipient to active individuals en masse who are willing to take more effective measures for their health goals could potentially result in improved health outcome in terms of increased self-care, therefore potentially reducing costs of the health care delivery.

In terms of empowerment a central aspect in Citizen Pathways is the building of links between different health related events. Creating these kinds of pathways that would link different events into each other and into other sectors of life would not only help individuals in managing the related information and related processes. More importantly, CPs would also enhance the individuals' awareness of their current health status by providing means for a) understanding interrelationships between events that are directly and indirectly related to the clinical encounter, b) creating aggregates of individual events, or chains of events, and c) helping individuals to piece together a horizon of future events.

How to enable Citizen Pathways?

It is in supporting individual-centric issues such as Citizen Pathways where the new and emerging PHIM solutions really draw their strength. Creation of independent and isolated solutions solely on the terms of the service providers only degrades the situation. As the information sources are becoming more

multiform than ever, continuing on this path makes personal information management and information exchange between different solutions even more challenging than it already is.

Unless the situation is rectified (partly, through following open standards for the storage and access of the health information), the individuals face again the current challenges of the prevailing electronic services where the transactions are executed on the service provider's or device manufacturer's terms, using solely the means dictated. Only now the situation has been intensified by the severity of the contained health and well-being information. To use the currently available solutions in the field of PHIM means upholding "status quo"; nothing has been learned. The individuals have silently forfeited their opportunity for empowerment and handed over their health and well-being information to be used by the public and private industries as they see fit.

Enabling Citizen Pathways requires what can be characterized as a small-scale service revolution. Existing care pathways should be re-evaluated from the citizen's perspective taking one's everyday life into account. Effectively, this means that the pathways are opened to all relevant service providers, including the third sector, in order to enable service integration and information exchange within service trajectories. To make concrete developments, different actors, especially those in the third sector, need support as it is unlikely that their resources are sufficient to carry through a change of this magnitude. This change also needs a different mind-set and the health care and well-being service providers of the future should leverage principles of openness, standards and transparency in their operation as discussed in Olla & Tan (2009, 52). Hopefully, a momentum for this change emerges from the patients themselves and influences those in charge.

Technologically, enabling Citizen Pathways requires a definition and dissemination of interoperability standards, robust security models, and trustworthy solutions that combine best properties of the discussed PHIM solutions. The new PHIM solutions should adapt to the health information management needs of the individuals (and their mediators), not the other way around. This implies that technological key characteristics of the new solutions are modularity, mobility and adaptability. The new solutions must be platform independent; the individuals should be able to use them independently to some degree, for example, on a mobile phone, locally on a personal computer, or via Internet as an online service.

4.6 Conclusions

The forthcoming changes in the provision of health care delivery where responsibility over one's health is placed on the shoulders of the individuals themselves, and the increased awareness of the individuals about their current health status, have created a developing market for different ICT solutions in the field of health care and well-being. New solutions, and new ways of operating in a sector that has been regarded as a traditional one, have brought up new challenges to the field of PHIM. Solving these challenges would benefit from re-evaluation of existing health care and well-being practices, and defining new ones, from the perspective of the individual.

The crux of the matter are the Citizen Pathways that help individuals and their mediators in the everyday health information management efforts, and support from the surrounding society in carrying through this fundamental change in the health care landscape. In today's information society pen and paper are not sufficient tools. Effective management and distribution of information, and integrating it to decision making on an individual level, requires efficient ICT solutions. In the field of PHIM, such solutions are not readily available and next generation solutions that utilize Citizen Pathways should be devised.

General principles of Citizen Pathways are currently (2012) tested in a national level project called "Pumppu" ("Pump") following the original MyWellbeing project. Goal of this project is to define means and practices for managing individual's health and well-being status after a cardiac episode with a solution that is based on the notion of the original Coper.

In personal information management better information tools and practices mean that the individuals are able to better use their increasingly precious time. Hopefully, with the next generation PHIM solutions, the individuals will be able to have a comprehensive view to their current health status, they are more able (and willing) to control their health and well-being related activities, and they have more time to take care of themselves and those they care about. New solutions also mean new opportunities for business and a way forward for a domain that faces an opportunity unlike anything seen in the past; a patient that cares.

The following chapter is revised and extended from:

Lahtiranta, J. (2011), “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.

5. Changing Nature of Best Practices in eHealth

Use of generally-accepted methods, processes and techniques (i.e. best practices) in order to increase operational effectiveness has become a preferred way of conducting business in the industry. Particularly, in manufacturing and supply chain management, the idea of doing things “better than before” by adopting operations models from other organizations, and even from other lines of industry, has gained a strong foothold. The idea is not novel in the field of health care where best practices have been used in patient care for decades in the form of algorithms, guidelines, protocols, etc. that commonly base on the evidence-based medicine (cf. Rosenberg & Donald, 1995, p. 1122). The term “evidence-based medicine” refers to the use of best available information that has been systemically reviewed in the clinical decision making. While the term has been coined in 1980s (ibid.), authors such as Sackett et al. (1996) track philosophical origins of evidence-based medicine all the way back to “mid-19th century Paris and earlier” (ibid., p. 71).

What has changed over time in the health care sector is that best practices have become more multiform, originating from other sources besides reviews of evidence-based medicine, and they are applied throughout the sector, from physical activity of elderly people to disease prevention (cf. Cameron et al., 2001; Cress et al., 2006). These practices are today so diverse that companies such as Pharmexx Nordic have created a service called Nurse Adviser³⁴, where the use of different practices is tutored to health care professionals. Different best practices have also found their way to homes of the patients, for example, in the context of diabetes self-management (cf. Mensing et al., 2002).

In similar fashion to other lines of industry, best practices in health care have found a new form in Information and Communication Technology (ICT). Different practices are computerized and embedded into different information systems. These systems are used by health care professionals in their daily work and by patients in their own care, and that of their close ones (e.g., children or elderly parents). From the perspective of the health care professionals, commonly used systems in this context are different intelligent systems, such as Clinical Decision Support Systems (CDSSs) and Diagnosis Decision Support Systems (DDSSs). Example solutions include: POEMS, a postoperative care decision support system and SETH, a clinical toxicology advisor (Coiera, 2003).

³⁴ <http://www.pharmexx.se/en/Nurse-Advisers/> (accessed: 25.3.2011)

From the patient's perspective, the computerized practices are customarily embedded into different Personal Health Record systems (PHRs), Patient Decision Support Systems (PDSSs) and Internet sites that are used to support patients in their health endeavours (cf. O'Connor et al., 2007). These kinds of solutions are used, amongst others, in interactive patient guidance, such as in prostate cancer screening (cf. Frosch et al., 2008).

Intelligent systems, in particular knowledge-driven DSSs that facilitate adherence to best practices in their operation (cf. Coiera, 2003, p. 32) have so far been primarily used by health care professionals. However, there are some examples that such systems are gaining foothold amongst consumers as well. For example, service providers like WebMD³⁵ have created a PDSS called "Symptom Checker" that supports patient's decision making when faced with different treatment options. In addition, WebMD offers different interactive tools, such as one for analysing whether one's lifestyle adheres to the principles of diabetes control. As an example of a different PDSS, Segal & Shahar (2008) present a web-based solution called the PANDEX. The system, which applies Bayesian probabilistic model in the decision support rationales, is used in the domain of prenatal testing. The system is intended for the health care professionals as well as for the patients in the spirit of shared decision making.

It appears that these kinds of consumer-centric intelligent systems that base on varying degrees to best practices are becoming more and more widely used in the field of eHealth. These kinds of systems create acute challenges to the traditional patient-physician relationship, placing patients (with their mediators) more in charge of their health outcomes. In the following, the significance of computerized practices is investigated primarily from the perspective of the patient; what kind of impact these practices potentially have on a) the individual's decision making and b) the relationship with the health care professional. Looking into these questions now is of the essence in order to understand how to help the patients of the near future to make better health related decisions with the aid of intelligent systems.

The findings in this chapter base on a 2-year national level project called MyWellbeing where an artefact called The Coper was conceptualized. Aim of the project was to look into the changing service landscape of the ICT-mediated health care services and conceptualize means for a citizen for coping with the electronic services that have become, and are becoming, more and more multifaceted over time. In the field of electronic health care services, one of the identified mechanisms was supporting individual's autonomy with the use of DSSs and automated scripts. The primary means used in the concept

³⁵ <http://www.webmd.com/> (accessed: 25.3.2011)

development were use scenarios, prototypes and focus groups in which feedback on the use of the prototypes was collected directly from the citizens.

5.1 Best Practices in Health Care

Enrico Coiera 2003, pp. 401) defines a (clinical) guideline as “an agreed set of steps to be taken in the management of a clinical condition”. These kinds of established guidelines are used particularly in routine clinical practice, for example, when a particular set of findings is investigated in a patient, or when a certain disease, or some other (commonly occurring) ailment is encountered. Clinical guidelines, such as Current Care Guidelines (CCGs) in Finland or Evidence-Based Medicine Guidelines (EBM Guidelines) globally, are based on established and proven practices reflecting a rational and scientific view on health care delivery. In the spirit of evidence-based medicine, the purpose of the guidelines is to provide a “synthesis of the best available research evidence” (Mead, 2000, p. 110) on issues such as prevention, diagnosis, prognosis and therapy. Clinical guidelines range from very strict to indicative advice and they can be found in almost every area of health care delivery (research, self-care, education, etc.). When a guideline, a phenomenon of evidence-based medicine, is defined in a form of concrete set of steps with a specific course of action in mind, an alternative term protocol is sometimes used. While a guideline, as its name states, emphasizes guidance and even advisory nature of practice, a protocol is typically more formally and precisely defined. Protocols often contain a more refined set of instructions, or even rules, to be executed and monitored in a controlled fashion. In the context of decision support, these protocols are sometimes realized using a protocol representation language (such as Asbru) or pseudocode (see example in the figure 5.1).

```
plan Hyperbilirubinemia
  intentions
    avoid intermediate-state: (bilirubin = transfusion)
  conditions
    abort-condition: (possibility-of-hemolytic-disease = yes)
  plan-body type = unordered, wait-for-optional-subplans = yes
  wait-for Diagnostics-and-Treatment-hyperbilirubinemia
    Check-for-rapid-TSB-increase
    Check-for-jaundice-after-2-weeks
    Check-for-jaundice-after-3-weeks
    Diagnostics-and-Treatment-hyperbilirubinemia
```

Figure 5.1. Portion of Asbru protocol for the Management of Hyperbilirubinemia in the Healthy Term Newborn (Roomans et al., 2002).

An algorithm, however, can be seen as a slightly different concept. While a protocol defines steps to be taken in order to achieve a specific goal, an

algorithm is commonly a more mathematical or mechanistic; a step towards more computerized set of rules. Examples of algorithms in the health care setting include: Body Mass Index (BMI) calculator and a binary decision tree for defining aetiology of a chest pain (Focsa, 2006). In literature, the concepts of algorithm and protocol overlap. For example, Strauss (2005, p. 35) uses in her article a combination of protocol algorithm to describe a method for sepsis treatment. An illustrative example of an algorithm from the Medical Algorithms project³⁶ is presented in the figure 5.2.

Overview :

Orient et al used a decision rule to evaluate men with abdominal pain. The rule was slightly modified by one developed by Wasson et al. The authors are from the University of Arizona.

The decision rule was developed in ambulatory men from the VA System.

Parameters:
 (1) pain duration
 (2) epigastric pain
 (3) age
 (4) pain features
 (5) effect of pain on sleep
 (6) abdominal and pelvic physical examination findings
 (7) occult blood in stool
 (8) vomiting
 (9) weight loss
 (10) past history

Parameter	Finding	Points
pain duration	pain for at least 6 months, OR at least 10 previous occurrence of pain	-3
	pain for less than 6 months AND less than 10 previous episodes	0
Epigastric pain and tenderness	only finding	-2
	absent or other findings present	0
Age	>= 60 years of age	+4
	< 60 years of age	0
pain features	pain is constant OR pain is unrelieved by food or medication	+4
	pain inconstant AND relieved by food or medication	0
pain has affected sleep	yes	+3
	no	0
abdominal and pelvic exam findings	mass, rigidity, rebound, distention, absent bowel sounds or an abnormal liver	+3
	negative examination	0
stool testing for occult blood	positive	+3
	negative	0
Vomiting since pain began	yes	+2
	no	0
change in weight	unintentional weight loss >= 10 pounds	+1
	weight gain or no change or unintentional weight loss < 10 pounds or intentional loss	0
History	cancer, diverticular disease, pancreatitis, gallstones, or inflammatory bowel disease	+6
	negative history	0

where:
 Removal of the gallbladder would seem to reduce the significance of a history of gallbladder disease.
 The time interval for weight loss is unspecified.

total score =
 = SUM(points for all parameters) - 5

Interpretation:
 A score < 0 indicates a low likelihood of serious disease.

Limitations:
 Patients with peptic ulcer disease may be classified as low risk.
 Diseases outside of the abdomen and pelvis may present with abdominal pain. The score may indicate a low risk for serious abdominal disease yet the patient have a serious disease elsewhere.

Figure 5.2. Decision rule of Orient et al. for men with abdominal pain. Copyright (c) 2010, Institute for Algorithmic Medicine, Houston, TX, USA.

³⁶ <http://www.medal.org> (accessed: 25.3.2011)

Making a distinction between algorithms, protocols and guidelines is not always easy. While some of the guidelines can be extremely detailed, there are protocols that are defined on a much more abstract level. Guidelines, protocols and algorithms may also overlap, for example when a reference to one is made from another (from guideline to protocol, from algorithm to protocol, and so on).

One kind of a super-structure for guidelines, protocols and even algorithms in health care setting is an (Integrated) Care Pathway. These pathways define a general outline of anticipated care, placed within a specific timeframe such as a patient visit (cf. Middleton et al., 2001). The pathways are in place in order to help health care professionals and patients to move through the clinical experience to a positive outcome. When Care Pathways are applied, there is often more room for clinical freedom than with protocols and algorithms that can be seen as ones representing a more mechanistic view on care (figure 5.3).

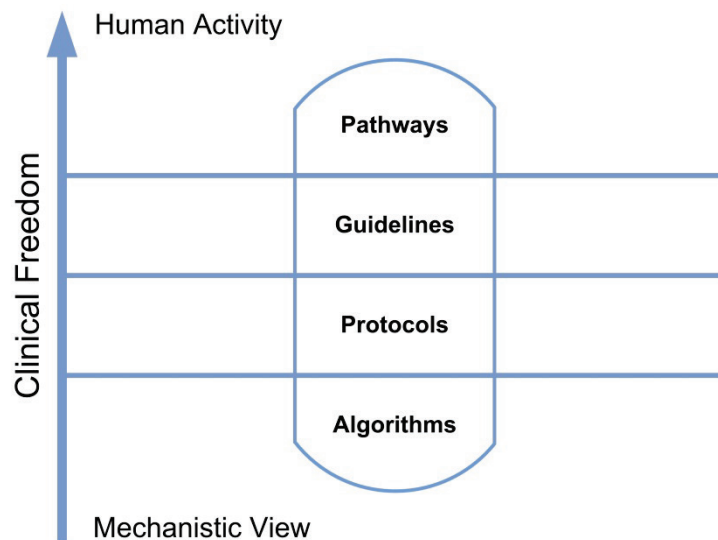


Figure 5.3. Pathways, guidelines, protocols and algorithms (author).

Clinical freedom (or clinical autonomy) is a term that signifies health care professional’s autonomy and control over one’s decisions and work activities (on the level of practice) for the benefit of a patient (Hampton, 1997). The term is closely linked with concepts like clinical judgment and experience, creating an image of a practically wise doctor who provides advice and treatment “on the basis of intuition, experience, and attention to particulars” (Parker, 2005, p. 28). Clinical freedom can also be seen as a metaphor for situation awareness and even for insight; viewpoints which can be both lacking in the narrower scope of

more mechanistic alternatives. Partially from this viewpoint, there has been some debate for and against protocols and evidence-based medicine in general (cf. Berg, 1997; Hampton, 1997, p. 129). While protocols and guidelines can be considered to some extent as means of bureaucracy and control, similarly to best practices in other lines of business, they are widely used tools that bring evidence into medical practice, complementing individualistic factors (and moral values) of different human actors on issues such as perceived quality, cultural characteristics and value-of-life.

Best practices in the form of different guidelines, protocols and algorithms to be used by the patients in their own care, or in that of their close ones, are also becoming a commonplace practice in the wake of different Personal Health Information Management (PHIM) solutions. For example, in the EBMeDS³⁷, the implemented medical scripts have three distinct target groups: physician, nurse and citizen. The purpose of this classification is to indicate to what degree the scripts are suitable for use by different group(s). In the case of the patients, the scripts could be used as an integral part of a PDSS or a PHR system; a solution that could support the use of published scripts, that often include medical terms and other domain specific jargon, by laypeople.

Customarily, all instructions provided to the patient are reviewed by the health care professional prior to their use in order to ensure their timeliness and applicability. In general, these instructions are gone through with the patient, for example, at the doctor's (or nurse's) appointment in order to ensure that the patients have understood how to employ them properly. Amongst others, the instructions may contain information on how to treat their ailments or diseases (incl. medication), how to prepare for an operation and what to do after an operation in order to ensure a better recovery (cf. Arnell, 2006).

Recently, in the clinical domain a viewpoint that emphasizes the role of the patient in the health care processes has emerged. The viewpoint focuses on the processes from the patient's point of view, highlighting issues such as potential problems and areas of improvement (cf. Trebble et al., 2010; Howard et al., 2006). Introduction of this viewpoint has also led into definition of different patient journey modelling endeavours, such as the adaptation of the Systems Development Life Cycle (SDLC) approach presented by Curry et al. (2007).

Nowadays, health related instructions originate often from other sources than from face-to-face meetings with the health care professionals. Since more and more different personal health and medical monitoring devices are used in health care by patients themselves, information on the health outcomes from using such devices are provided on manufacturer's web pages as well. Similarly, Internet

³⁷ <http://www.mrex.fi/EBMeDS/> (accessed 27.4.2011)

and different forms of social media (virtual communities, portals, etc.) have also claimed a strong position as a preferred source of patient instructions (cf. Sillence et al., 2007, p. 397).

5.2 Consumer-Centric eHealth Solutions of Today

Technologically, during the last five years the ICT industry has provided individuals better tools for “empowerment” in the context of health care and well-being, or means for controlling their health decisions and actions. The Internet in itself has brought not just health related information, but also health care and well-being services to the grasp of the technology literate. For example, Kaelber et al. (2008) argue that approximately 70 million people in the United States alone have access to some form of PHR. Similar technological advance can be seen in the Europe as well since more and more EHR solutions are becoming accessible to citizens via Internet and new media. For example, in Finland a possibility to access (a part of) one’s public health records are implemented as a part of the KanTa³⁸ services. At the same time the ICT service providers such as Microsoft are implementing their own consumer-centric PHR solutions that can be used in personal health information management.

The motivations behind this kind of development are rather evident; while the ICT sector aims for new markets in sector that has proven to be difficult to penetrate, the public health care sector strives to motivate individuals to take better care of themselves (and their relatives) in order to be able to better allocate their limited funding. The latter perspective has, for its part, given birth to a multi-layered phenomenon often referred as “empowerment”. While the concept in the context of health care and well-being services is often seen as a synonym to “self-service”, it is actually connected to issues such as awareness, power, influence and autonomy (cf. Rappaport, 1987; Anderson & Funnell, 2010). Especially from this viewpoint, the narrow interpretation of the concept is rather troublesome since it carries a notion that individuals are automatically willing to take the burden of their health management upon their shoulders.

While the consumer-centric PHR and EHR solutions of today give patients means for taking active part in health care processes, the current development of the solutions seems to imply that they should take more responsibility over their (incl. their families) health care and related information management. Somewhat similar paradigm change from object to subject of activity occurred on a smaller scale when the online banking (or Internet banking) was introduced around the 1980s. At the time, a growing number of individuals took some of the activities

³⁸ <http://www.kanta.fi/en/> (accessed 9.10.2013)

that had traditionally belonged to the banking sector and tellers as their personal responsibility. However, what is fundamentally different from information systems development perspective is that online banking is more tightly regulated; as is the case with the overall banking sector (Corvoisier & Gropp, 2001). In the health care sector, the online service providers are more diverse; for example, the myPHR³⁹ web site lists around 26 free and 48 for purchase online services that can be used for health services or health information management.

Partly due to this fragmentation of potential service providers and partly due to the imprecise nature of what can be regarded as “health” or “well-being”, the electronic health care services are often heterogeneous by nature and provided by divers service providers. From the best practices point of view, this means that controlling the source, validity and timeliness of the practice in question can be difficult. While in the 1970’s and 1980’s individuals “empowered” by books of medicine or pharmaceutical drug guides, and so on, were able to make more or less accurate references to a printed, published and even reviewed sources, the “empowered” individuals today often come to the doctor’s office armed with miscellaneous prints from a wide variety of sources available online (cf. Akekar & Bichile, 2004; section 3.6). The problematic nature of this phenomenon was also brought up by a domain specialist during a networking session late in 2011.

“It is exceedingly difficult to give the patients time that they deserve. Firstly, we [doctors] have these information systems that demand our attention during and after a patient visit. I think that goes with the profession nowadays and we can do very little about it. Secondly, there are all kinds of web sites, portals and whatsoever that provide patients information about their health and ailments. I have seen patients who come to the reception literally burdened with printouts related to their, sometimes self-diagnosed, ailment and they expect that I rifle through the information and explain to them what information is relevant and what is not. All this in half an hour or less, and sometimes I haven’t even started to examine the patient!”

With the previous remark in mind, the situation is even worse in the light of patient throughput. For example, in the UK the average GP consultation was 7 minutes in 2011 (Aviva, 2010) while it was by some estimates 10 minutes in 2005 (BBC News, 2005). As it seems that efficiency has become an overriding concern, it is no small wonder that there are results indicating that the mean time before interrupting the patient was 16.5 seconds, ranging between 3 to 145 seconds (Dyche & Swiderski, 2004, p. 269).

³⁹ <http://www.myphr.com/> (accessed 9.10.2013)

Continuing with the online banking metaphor, what we see in today's health care sector solutions is not just empowerment, or placing responsibility over one's health on the individuals themselves, but consumerism as well (cf. Robinson, 2005; chapter 3). However, the first steps of consumerism we see in today's eHealth are far from those of online banking where transactions can be completed successfully, even on a global scale, with few simple mouse clicks.

5.3 Computerization of Best Practices in Health Care

Giving a computerized interpretation to a health care best practice (i.e. algorithm, protocol or guideline) is a challenge. It is rarely possible to translate health care practices into computer algorithms in such a way that they are universally applicable. Even with a simplest algorithm, there is a risk that when computerized and integrated into a DSS, it becomes too rigid and limits user's workflow (cf. Bates et al., 2003). Furthermore, our assumptions on the very nature of health create unique challenges to computerization; health is not a simple and precise science and patients rarely fit to any exact pattern or disease, but they present different stages of an illness, different combinations of symptoms, and they have different capabilities for recovery (Coiera, 2003, p. 184).

When written in a computerized format, or as computer programs, and embedded into intelligent systems such as DSSs, health care algorithms, protocols and guidelines become manifestations of industry "best practices" much in a same way as in other lines of business, such as in manufacturing or in finance. However, at the same time the very aspects that differentiate health care from other lines of industry, especially those of manufacturing and assembly, are potentially "lost in translation". For example, in the health care setting, professionals have a right and duty to employ clinical freedom in their judgment for the benefit of a patient (Hampton, 1997, p. 128). In the light of best practices, this can result in applying *in situ* (e.g. provisional) practices instead of the *de jure* (e.g. formal) ones in order to engender clinician reflexivity.

For taking health care domain specific aspects such as clinical freedom, patient autonomy and preferences, and the current clinical state into account, Haynes, Devereaux & Guyatt (2002) propose a new prescriptive model for evidence-based clinical decisions (figure 5.4).

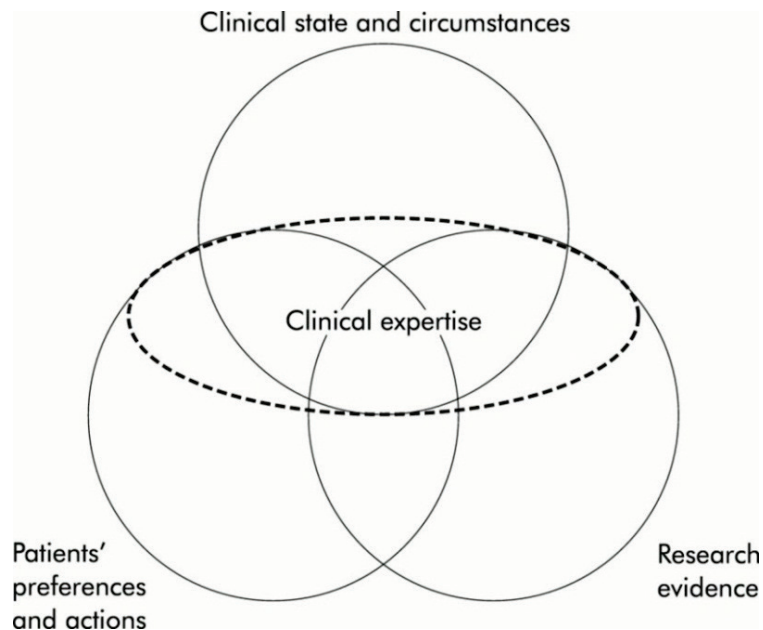


Figure 5.4. An updated model for evidence-based clinical decisions (Haynes et al., 2002, p. 37).

Purpose of this reviewed model is to highlight the role of the individual practitioner in the decision making situation as an expert who can balance different factors (i.e. research evidence, patient preferences, etc.) in order to achieve a successful result that will satisfy the patient and the clinician (ibid., pp. 37-38).

Creating a computerized practice that would highlight the role of the individual practitioner, allowing a required degree of freedom for both, the health care professional and the patient, is by no means a trivial task. For example, if the computerized best practice does not give room for a reasonable use of in situ practices, there is a risk of conflict that would potentially impede the workflow of the patient. In the academic literature, Bates et al. (2003, p. 525) emphasize the need for creating this kind of balance between the physician's workflow and the use of DSSs.

A similar conflict may occur if the computerized practice violates the patient's individualistic values, or those that can be regarded as a cultural norm, potentially resulting in a total patient non-adherence. In the changing world of today where cultural background of a patient cannot be determined on the basis

of one's residence or country of origin, the significance of clinical expertise (and social skills) are further emphasized. In order to avoid conflicts in the patient-physician relationship, the clinician, or another person with sufficient clinical expertise (such as a mediator), needs to act in a role of a facilitator, interpreting different guidelines and adapting to the current situation of the individual. These kinds of interpretive viewpoints to facilitation in health care setting are depicted in Harvey, et al. (2002), where the activities of the facilitator categorized as "enabling others" are closest to the ones pursued here (ibid., p. 581-582).

Bringing these kinds of "soft" aspects that are an inseparable part of care into the different intelligent systems is challenging – even with the technology of the near future. Replacing human factor with "an automaton" requires implementation of human characteristics such as care and compassion, even camaraderie into the solutions. At the moment, it seems unforeseeable that such will become available as discussed in the section 6.2.

Patient-physician relationship

Regardless of the recent advances and the future trends in the consumer-centricity, and in the patient-centred medicine, the relationship between the patient and the physician has been traditionally characterized as a paternalistic one. A paternalistic relationship is based on trust and as such it is assumed that the physician is a beneficent one (Beisecker & Beisecker, 1993, p. 41). In this kind of relationship, the physician controls the health care process and has a moral authority and discretion (Childress & Siegler, 1984). In a paternalistic relationship the patient may have little room for affecting on how the actual care is provided.

Another metaphor used by Beisecker & Beisecker (1993) for a relationship is consumerism in which it is assumed that the doctor is self-centred (ibid., p. 41). Unlike in a paternalistic relationship, consumerism can be regarded as a relationship where the patient has equal power, or even more power than the physician. In consumerism trust is replaced with legal accountability and individual's health care preferences may override the principles and the best practices of a good medical practice especially if the patients are able to comparison shop and change doctors as they see fit.

Scott & Lenert (2000) add to the discussion a metaphor of a deliberative patient-physician relationship. In this kind of relationship, the physician abandons objectivity and strives to influence the patient's values and beliefs on health outcomes. In this kind of relationship, the physician acts as a teacher or as a friend who may suggest to the patient what avenues to pursue in one's care. As a comparison, Scott & Lenert (2000) also present a collaborative relationship

where the physician attempts to elicit the patient's values and actively assists in selecting the most appropriate care from patient's viewpoint.

This kind of collaborative patient-physician relationship is close to an informed one where the physician acts as a domain expert and has a duty to provide all the necessary facts to the patient (ibid., p. 785). The primary difference between these two is the role of the physician as a decision catalyst. In collaborative relationship the physician not only educates but also guides the patient through the decision making process (ibid., p. 785). In this, the role is more active and an essential part in assessing, exploring and determining how the patient's values are reflected on the actual decision.

Patient decision making

When a best practice is computerized, it can become more mechanistic; void of "soft" aspects such as care, compassion and values. As such, when integrated into a PDSS, the practice can be seen as inherently deliberative; it steers individual's health related decision mechanistically, without consideration to individual's preferences. Furthermore, our tendency to treat computers and new technologies as real people and objects of trust (Reeves & Nass, 1996) may change our perception about the artefact, placing it into a paternalistic position as well. In theory, this may lead to a situation in which we place our trust on the artefact as we would on an actual physician (Lahtiranta & Kimppa, 2008).

In contrast to physicians, patients make explicit health related decisions relatively infrequently. Most of the decisions are made with a little or no preparation or repetition, and they are often related to everyday life (such as what to eat or when to exercise). In addition, patient decisions are often guided by misconceptions, such as folklore, prior beliefs and anecdotal knowledge (Ubel, 2006). In the health care setting, individuals are also prone to emotional misinterpretations, for example when facing difficult medical decisions, or decisions that will have an effect to their perceived quality of life (Ubel et al., 2003).

Rooting out potential negative effects of patient's emotions, misinterpretations and lack of clinical knowledge is not a trivial task. In a face-to-face situation individual practitioners may employ different strategies, such as taking advantage of time in order to allow patient's strong emotions to dissipate (Ubel, 2006, p. 180-181). In the case of intelligent systems, employing these kinds of strategies that require social acumen, and balancing human factors against best practices that base on hard realities of the evidence-based medicine, is challenging.

5.4 Recommendations

Health care is a knowledge intensive field and in its core is the individual. The individual is not always the same; in the same role, and the situation in which best practices are to be applied varies significantly. Cultural aspects, personal values and preferences, experience of the attending physician, etc. have an impact on the situation into which the practice is applied. Similarly, the practice itself and the level of detail it encloses, changes the way it is to be applied. When a best practice is computerized and integrated into an intelligent system such as PDSS, a special focus on its applicability should be paid.

As established, in any clinical encounter achieving an inclusive picture of the individual's current health status is of the essence. The health care professionals typically have different information sources at their disposal (incl. the patient), and they may employ different strategies when creating a hypothesis on the course of action to follow. In the case of intelligent systems, these functions are often lacking; there is no health care professional who verifies the result or the recommendation provided by the artefact (i.e. the output). In addition, the decision support rationale of the artefact may be vague to the user who often acquires the result by following a simple decision path, such as yes/no choices or stepwise definition of the current ailment (e.g. location, symptom, severity, etc.).

Basically, the defined decision path and the underlying interaction mechanism also define the degree of freedom the patient has. Especially in the case of more mechanistic practices there is rarely room for vagueness or interpretation and the patient choice is limited to the available options they must use in order to acquire a result from the artefact. Furthermore, there are rarely any kinds of mechanisms in place that ensure patient adherence. On the practical level, the patients may create their own adaptations of the practices, solely on the basis of their preferences, beliefs and (anecdotal) knowledge.

In order to help patients to make better health related decisions by using intelligent systems, intervention and mediation mechanisms should be implemented into the intelligent systems that help in ensuring applicability of the computerized best practice. Effectively, this means that if misinterpretation of the results may potentially lead to negative health effects, the system should discontinue its analysis and help the individual to seek help of a professional who could properly analyse the current situation.

This kind of functionality requires role-based implementation. As in the case of the EBMeDS⁴⁰ database, the implemented medical scripts have been categorized

⁴⁰ <http://www.mrex.fi/EBMeDS/> (accessed: 27.4.2011)

by three distinct target groups in order to indicate to what degree the scripts are suitable for different user groups. With a functional role-based implementation, the intelligent systems could be programmed to break out of their decision making routines when a potential health risk to a “non-conforming” user group emerges.

Understanding in which role the decision support system and the underlying best practice(s) are used could also be of assistance when additional mediation mechanisms are implemented. For example, in the case of a citizen who is often a layperson in terms of used vocabulary and concepts, a “translated” version void of domain specific jargon could be provided instead (c.f. section 4.3). However, this alone is not a sufficient measure for ensuring that individuals understand what kinds of artefacts and information they are using in health related decision making. In order to partially support this, complementary measures should be taken in ensuring that relevant information is not “lost in translation” and therefore missing from the decision making.

In addition to providing ‘translated’ versions of intelligent systems and best practices, individuals’ health literacy skills should be improved. Health literacy which refers to “citizen’s ability to recognize their needs for health information, to search for that information, to assess the validity of the information gained, and to apply that information” (Ek, 2008, p. 242), should be identified as one of the key arts to be taught in elementary schools, for example as an integral part of health education classes. In relation to the children, and underage Internet users in general, the technology literate parents should be taught how to mediate (e.g. facilitate, see section 1.4) the use of different electronic health and well-being services. This does not only mean that the minors are educated on the potential risks (and opportunities) of the services, but they should be taught how to perform self-control and self-regulation in their use. In terms of parents who are not adequately technology-literate to perform such function, kindergartens could provide a potential setting for updating education as children in the OECD countries start using the Internet at a very early age (see e.g. Haddon & Livingstone, 2012; Holloway et al., 2013).

In addition to creating mediation mechanisms, such as ones focusing on the challenges of the language, the significance and role of a mediator should be acknowledged. In practical terms, this could mean that in addition to the identified roles of the patient and health care professionals, the intelligent systems and the underlying decision support rationales, such as scripts, should be able to be executed from the viewpoint of a mediator. For example, the systems could steer the health and technology literate individual with a degree of craft in medicine to acquire such information on the patient’s current health status that would be normally outside of the particular individual’s capabilities (such as, blood glucose level, resting heart rate, etc.).

5.5 Conclusions

In terms of social interaction, there is no substitute for a face-to-face meeting and the traditional patient-physician interaction. No matter how advanced the employed intelligent systems are there are no mechanisms in place that can carry the emotional undertones of the physical world. Similarly, the “soft” aspects that are inseparable part of care are, as a rule, missing from the intelligent systems.

It can be argued that intelligent systems have a potential to change individual’s perception about the patient-physician relationship, and the underlying balance of power, therefore affecting individual decision making. In this lies also a potential to change the underlying values and attitudes of the individuals using such systems. With a proven health impact, intelligent systems can be success stories on shared decision making and empowerment. To support this development, there is little room for systems that fail to position themselves between the patient and the physician, in terms of patient expectations and trust.

Even though these are trying times for different intelligent systems, computerized practices are part of today’s health care landscape. They can be seen as tools for the mediator and aids that support aspirations of a willing individual to become active in terms of one’s health. These practices, when integrated into different solutions, can also help in bridging the gap between the clinical domain and expertise, and the laypeople’s beliefs, fears and (anecdotal) knowledge. In this lies the fundamental question: to what degree should people be encouraged (or discouraged) to use such systems in their own “diagnoses”?

There is no simple answer to this question. Each solution needs careful consideration particularly in terms of the influence; how to ensure that the decision support solution is not too deliberative, steering individual health related decision making without consideration of personal preferences and values, and clinical evidence. From this perspective, it could be concluded that what we need is personalized patient decision support and mediation; intelligent systems with the touch of a human expert.

The following chapter is revised and extended from:

Lahtiranta, J. & Kimppa, K. (2006), "The Use of Extremely Anthropomorphized Artefacts in Medicine", *International Review of Information Ethics*, Vol. 5, pp. 13-18.

6. Anthropomorphic Artefacts of ICT in Health Care and Medicine

In the field of health care and medicine, different artefacts that imitate human appearance and anatomy have been used for a long time. Most of us probably remember the human-like self-assembly manikins used for describing human anatomy from biology lessons at the elementary school. Probably the most famous human-like manikin in the world is the Resusci® Anne CPR training manikin⁴¹, which has been used for the past 50 years for training of resuscitation skills. The first versions of the manikin which appearance is based on the body of a dead girl (figure 6.1) found in River Seine, Paris (Rosen, 2008, p. 160), were rather crude and cumbersome in comparison to those of today that go into significant lengths in mimicking human-like behaviour.



Figure 6.1. L'Inconnue de la Seine, "the unknown woman of the Seine", picture of the dead girl used in modeling the face of Anne CPR training manikin (Wikipedia Commons).

⁴¹ <http://www.laerdal.com/> (accessed: 19.12.2011)

It is commonly known that we have a natural tendency to attribute human characteristics and emotional states to inanimate objects, animals and systems. Formally, this tendency is called anthropomorphism, a term that originates from Greek words for man (anthros) and form/structure (morphe) (Yiannoudes, 2007). Artifacts that have human-like characteristics, such as facial features of a training manikin, are called anthropomorphic; a term that stems from our natural tendency to see a reflection of ourselves in the surrounding world.

With these definitions in mind, a research domain that investigates the underlying reasons for our tendency to anthropomorphize different “things” revolves around the Theory of Mind (ToM) phenomenon that got widespread attention after the famous publication on primatology by Premack & Woodruff (1978). The publication gave rise to the modern phase of work on the phenomenon that has come to designate a particular domain of research. At that period time, the domain expanded to cover a wide range of disciplines, such as philosophy, cognitive science and developmental psychology (Carruthers & Smith, 1996). In the field of psychology, the domain commonly refers to research that “investigates our folk psychological concepts for imputing mental states to others and ourselves: what we know, think, want, feel, etc.” (Perner, 1999, p. 205).

In the following, the focus is on potential effects of anthropomorphism and imputing mental states on inanimate objects. The focus is on the field of health care and medicine where anthropomorphic artefacts, such as robots, are used increasingly. As a display of this particular increase, the International Federation of Robotics (IFR) reported that in 2011, approximately 2.5 million service robots for personal and domestic use were sold in the U.S., indicating an increase of 15% in comparison to 2010 (IFR, 2013). In the field of entertainment robots, 841,000 units were counted in 2011, 12% more than in 2010 (ibid.).

6.1 Anthropomorphism, the Good or the Bad?

Since the introduction of the Resusci® Anne CPR training manikin, anthropomorphic characteristics of different training manikins have developed significantly and the current training manikins possess surprisingly human-like features. In addition to training manikins, different anthropomorphic artefacts are used increasingly in the field of health care and medicine. Their use is particularly abundant in training and teaching of medical skills, for example, in dentistry (Graham, 2010, p. 40).

Arguments for and against the use of anthropomorphic features in artefacts can be made; for example, authors such as Cassell et al. (1999) and Gong (2002) speak on behalf of introducing human-like features into an ICT-artefact arguing

that it ensures better user acceptance and creates a positive user experience. In a more recent work, Duffy (2003, p. 177) highlights the importance of intentional use of anthropomorphic features in facilitating social interaction.

As a contrast to these arguments, Schneiderman (1989) takes an opposite view on the use of anthropomorphic features arguing that their use may have a negative impact on our perceptions and emotional reactions, especially in the case of children. Another well-cited reference is Nass & Moon (2000, p. 82) who demonstrate through experimentation how humans express “mindless responses”, such as overuse of human social categories (e.g. gender) and engaging in overlearned social behaviour (e.g. reciprocity) towards computers that are perceived as social actors.

Regardless of arguments for or against the use of human-like features in ICT-artefacts, it is inherent to humans to attribute human characteristics and cognitive or emotional states to different things. Every day we encounter anthropomorphic artefacts, characters of fiction, etc. in different situations, such as in entertainment, advertising and even in literature. One of the well-known examples of anthropomorphism in literature is the piece of Jewish folklore about The Golem of Prague in which the Rabbi Judah Loew ben Bezalel created an animated human-like creature (figure 6.2) from clay (Kieval, 1997).



Figure 6.2. “Rabbi Loew and Golem”, ink and pen illustration for Old Czech Tales by Mikoláš Aleš, 1899, (<http://www.mikolasales.org>, accessed: 25.2.2011).

A more modern example on the use of anthropomorphic features and anthropomorphism in general can be found in the animated movies such as the “Madagascar” by the DreamWorks Animation SKG (2005) and in the case of robotic pets such as the “Yume Neko”, a robot cat by Sega Toys⁴². In academic literature, these kinds of robots that rely on human tendency to anthropomorphize are described as “socially evocative” (Fong et al., 2002, p. 145).

In the field of ICT, there has been already in the 1960’s clear cases of computer programs being anthropomorphized. One of the most famous examples being the ELIZA, a computer program by Joseph Weizenbaum (Weizenbaum, 1966), which parodied a Rogerian therapist. Since then, human-like features have been used increasingly in the field. For example, the history of interactive conversational agents is rich with examples of human-like avatars and computerized secretaries, starting from the vision brought to life in the famous Apple Computer’s concept video “The Knowledge Navigator” in 1987 (cf. Marti, 2005, p.121-124).

In the field of health care and medicine, use of human-like features has found its way to teaching, robotics and user interfaces, creating new channels, and even completely new means, for patient-physician interaction (figure 6.3).



Figure 6.3. Examples of the use of anthropomorphism in telemedicine.

In the first example, a remote controlled robot is used to visually examine the patient. With this solution, the physicians are capable of interacting with the patient, whether they are in another part of the hospital, or even in another part of the world (BBC News, 2005). The robot is controlled remotely with a joystick and both parties are able to see each other. In the second example, medical students are trained how to deliver a baby by using robot dummies. The dummies are equipped with mechanical organs, synthetic blood and mechanical breathing systems (Fox News Network, 2006).

⁴² <http://www.segatoys.co.jp/yumepet/neko-venus/> (accessed: 20.3.2012)

In the last example a robot nurse called “Pearl” assists elderly people in their everyday activities (Reddy, 2006, pp. 24-25). A more recent example is the use of a human-like robot in training and teaching of pharmacy students. The robot, SimMan 3G, can be programmed to have a range of medical conditions and the students are able to examine simulated blood pressure, and heart and lung function of the robot (Ray et al., 2012, p. 2).

While these are just few examples on the use of anthropomorphized ICT-artefacts in health care and medicine they give rise to some concern towards the use of artefacts, for example, in the patient-physician relationship. The on-going development from human-to-human to human-to-computer, and finally to computer-to-human “relationship” can alter fundamentally the way care is provided in the near future; how the patient and physician interact with each other and how the patient-physician relationship is formulated. What we know today about anthropomorphism in human-computer interaction is that it has some effect on human behaviour and decision making.

For example, in some cases a human-like (or social) interface can be used to invoke trust in the user (Bickmore & Picard, 2004). It is also demonstrated in numerous psychological studies that people treat technology (computers, television and new media) as real people and places (Reeves & Nass, 1996). Similar results were recently reported by Breazeal (2010, 10:37) who compared the use of a robot, a computer application and a simple pen-and-paper log to each other in terms of trust and “working together” (i.e. working alliance).

Considering the use of technology in the field of health care and medicine today, and the potential avenues of tomorrow, the question on the potential impact of the anthropomorphized artefacts is a current one and requires close attention. One particular area of investigation is mediation, and the use of an ICT-artefact in the role of the mediator.

6.2 Anthropomorphism, Ubiquitous Applications and Care

Similarly to social interactions in general, there is a wide variation in our responses to the use of anthropomorphism in different contexts of use. Some of us are more prone to its effects while others are seemingly immune to it. Partially due to our individuality, it is difficult to define what can be regarded as appropriate or convenient degree of using anthropomorphic features in the case of different ICT-artefacts (Duffy, 2002). On the far ends of this scale are the artefacts stripped of all human characteristics, including those used in the style

of writing (cf. Schneider, 1989), and artefacts that mimic human-like appearance and behaviour as much as technologically viable.

In the field of health care and medicine, there is a need for the whole scale from “human to machine”. For example, in the clinical decision making the users typically need information on laboratory results in a concise and explicit form (cf. Wright et al., 1998). In training and teaching of medical skills, use of extremely anthropomorphized manikins can be of the essence. Between these two examples, there is a wide range of different ICT-artefacts with varying degrees of human-like features for users in different roles, including patients and their trustees (such as the mediator).

In a situation, when users interact with applications on a desktop screen, they are usually aware of the nature of the interaction and parties involved. However, as the desktop metaphor slowly dissolves as technologies mature, and interaction with (and via) technology usually involves “humans and machines”, the user may become obscured by the ubiquitous technology. For example, in the case of intelligent environments and embodied machines where the real world has become an interface (Nijholt, 2003) the possibility of confusing human actors to their computerized counterparts can be a real problem in the near future especially if the artefacts employ human-like characteristics (such as, natural-sounding speech) in their interaction.

Another near future technology trend to be followed is augmented reality (AR). In the technology, the physical world is augmented with computer generated sensory input such as sounds or graphics. From this perspective, more than a decade old definition by Azuma (1997) is sufficiently comprehensive one. According to the definition (ibid., p. 2) augmented reality has three characteristics: 1) it combines real and virtual, 2) it is interactive and real time and 3) it is registered in 3-D. In the case of AR, the real world becomes the interface and distinguishing human actors from computer-generated ones can be more challenging than in the case of “traditional” interface technologies.

In the health care sector, areas where AR could be employed include endoscopic surgery and imaging (Moline, 1997, p. 7). The latter aspect was also highlighted in the Augmented Reality Event of 2010 (June 2-3, Santa Clara, U.S.) where the use of technology in visualization was presented. The presented examples included superimposing facial bone structure on the face of a moving patient and spinal structure on the patient’s spine (Cameron, 2010). Applicability of the technology has also been investigated in relation to virtual presence (in other words, a presence mediated with ICT-artefacts). Examples in this area include treatment of eating disorders and body image disorders, and psychotherapy in general (Wallach et al., 2011, p. 129).

Especially in training of medical skills, intermingling of virtual and physical (actors and artefacts) can pose a problem in the near future. While there is a trend towards development of more and more detailed anthropomorphic artefacts, creation of a fully mechanized (biomimetic) replica of a human patient will probably elude us for years to come. One consequence of this is that if students of medicine are trained with anthropomorphic artefacts they become accustomed to the “quirks” and limitations of today’s technology. At some point when they apply their teachings on a living subject instead of an artefact, the transition from the “world of the non-living” to the one “of living” may not occur without some friction.

If we look into potential developments in the field of developing near-human capabilities, it is estimated that some kind of self-awareness can be achieved around the year 2029 (Buttazzo, 2001). Similar estimates are presented by Kurzweil (2005) who has estimated that the first computer to pass the Turing test will be implemented at the same era (p. 263). In his book that was published in 1988, Austrian futurist Hans Moravec estimated human intelligence to be “common within fifty years” (p. 6), placing his estimates somewhere before the year 2038. However, counter arguments opposing the aforementioned views have been presented (cf. Burkhardt, 2011, p. 99) emphasizing the complex nature of human mind and arguing that human intelligence cannot be reduced to computing power or built on silicone.

Considering the characteristics of teaching or training medical skills, it should be noted that none of these estimates shed light into issues, such as creating nervous systems or similar required in simulating pain or discomfort, that are in the crux of simulating patient experience. In Japan, these avenues are already explored as the robot labelled as “Simroid” (figure 6.4) is equipped with a sensor network in teeth that could be used for indicating pain over the course of a dental treatment (Mail Online, 2007; Graham, 2010, p. 40).



Figure 6.4. The “Simroid”, a robot that ‘feels pain’ (from: Mail Online, 2007)

While these technological future projections are stimulating in many areas, and the replication of biological form and function has advanced greatly, the relationship between artefact, user and environment has more dimensions than the appearance. In this, one of the key elements is perceived familiarity. It effectively defines the state and quality of the interaction and applicability of the artefact into different uses, of which training and teaching of medical skills is one and mediation is another.

6.3 Familiarity and Anthropomorphized Artefacts

As in other trades where a personal and face-to-face contact between the provider and the beneficiary is required, training often involves use of more immediate and “hands-on” teaching methods, such as teaching with the use of manikins. For practical purposes these manikins are often anthropomorphized as far as viable; considering the scenarios and purposes they are used to simulate. For example, in the case of non-surgical airway management procedures (cf. Jordan et al., 2007), an anthropomorphic head or a torso (incl. relevant organs) of a training manikin can be sufficient⁴³.

If we look into the field of robotics, anthropomorphic features of a robot head can be evaluated using a three-dimensional design space (figure 6.5) where heads are evaluated according their abstract, iconic, or human properties (Duffy, 2003).

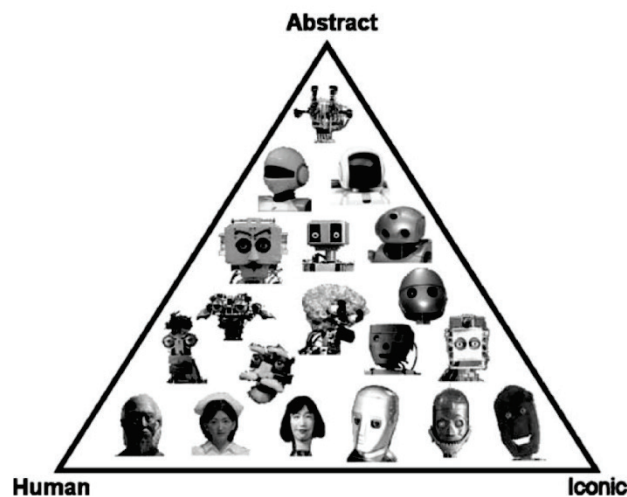


Figure 6.5. Anthropomorphic design space for robot heads (ibid., p. 182).

The design space defined by Duffy (2003) specifies an illustrative map for designing robot features and defining how closely these correlate to human physiognomy. Features in the iconic dimension employ a very minimum set of human characteristics often found in comics and cartoons. The abstract dimension refers to functional or mechanistic design. Naturally, the human dimension describes features with a close resemblance to a human counterpart.

⁴³ AirSim and Truman products at <http://www.trucorp.co.uk/> (accessed: 22.3.2012)

In training and teaching of medical skills, appearances of the manikins belong often to the human dimension for practical reasons. For example, in the case of teaching non-surgical airway management procedures (see above) the used manikin should have a close resemblance to the human physiognomy in order to provide the most effective training experience in terms of used artefact. If the manikin used in training would have too iconic or even abstract features, it would probably have a negative impact on the training goals. It is rarely feasible to create abstract manikins if the purpose of the training is to prepare students for a real-life experience. From these starting points and due to the limited availability of real-world patients to practice upon, the “Stan D. Ardman”, human patient simulator was created (cf. Kinney, 1999).

In terms of extremely anthropomorphized artefacts, there is a difference in the perception of human-like and almost human-like artefacts. Already in the 1970 Masahiro Mori coined the famous term “Uncanny Valley” depicting the possible relationship between “an objects appearance or motion and how people perceive the object” (Gee et al., 2005). Mori himself (1970) characterized the valley in a mathematical term of “negative familiarity” and used a prosthetic hand as an example of this effect (ibid., 34-35):

“[...] recently prosthetic hands have improved greatly, and we cannot distinguish them from real hands at a glance. Some prosthetic hands attempt to simulate veins, muscles, tendons, finger nails, and finger prints, and their color resembles human pigmentation. So maybe the prosthetic arm has achieved a degree of human verisimilitude on par with false teeth. But this kind of prosthetic hand is too real and when we notice it is prosthetic, we have a sense of strangeness. So if we shake the hand, we are surprised by the lack of soft tissue and cold temperature. In this case, there is no longer a sense of familiarity. It is uncanny. In mathematical terms, strangeness can be represented by negative familiarity, so the prosthetic hand is at the bottom of the valley. So in this case, the appearance is quite human like, but the familiarity is negative. This is the uncanny valley.”

While the term was coined in 1970, the effect itself is much older and it has been illustrated already in 1888 by Thomas Edison in the context of his Talking Doll invention (Duffy & Joue, 2004). In the field of humanoid robotics, the artefacts that are perceived as almost human-like but are “a bit off” are perceived as peculiar or even absurd and they belong to this category. Considering that a close resemblance, or even an exact match, is a necessity for most of human-like artefacts in the field of health care and medicine, it can be argued that crossing the “valley” is of the essence (or at least, avoiding it).

In addition to the physical appearance of the artefact, the familiarity of a robot can be analysed by using the core set of features defined by Duffy and Joue (2005). These features are (ibid., p. 2-3):

- Control, the ability to influence the robot, or our environment, through it;
- Predictability, not too simplistic, predictability of the robot that enables us to “bond” with it;
- Dependency, to what degree the robot plays on our needs (utilitarian or satisfaction needs).

When a robot is integrated into the field of medicine (for example, as a surgical robot), the function and role of the robot are close to those of a tool. However, in the health care setting and especially in the context of the consumer health care products and services, the social setting may change the framework into which we base our familiarity. For example, instead of efficiency (such as in the case of a surgical robot) we might assume, in the milieu of homo sociologicus commonly associated with Emile Durkheim (c.f. Elster, 1989, p. 98), that the predictability of an anthropomorphic artefact is defined by the social norms and conventions, dominant in our culture. In contrast to homo economicus, which states that human behaviour is principally driven by instrumental rationality, Durkheim’s alternative view proposes social norms as the driving factor (ibid.). These kinds of issues are commonly researched in relation to the field of “social robotics”; autonomous artefacts that are intended for human-computer interaction on human terms (e.g. using human-like social-behaviour and roles). In the field, the importance of social norms and conventions specifically in relation to human-robot interaction has already been identified and researchers are already looking into the use of norm-based biological models and mimicking in enhancing artefacts capabilities in providing culturally acceptable responses (cf. Cowley, 2008).

Similarly our assumptions in control may shift if the current trend continues and ICT-artefacts (especially robots) become more capable of a rich social interaction, for example by using human-like voice and socially rich dialogue in addition to other anthropomorphic features. We are already seeing examples on this development towards rich social interaction as Japanese researchers unveiled in 2010 a humanoid robot called “Geminoid F” (Guizzo, 2010) that is capable of mimicking facial expressions (smile, frown, etc.) of a woman in her twenties (figure 6.6).



Figure 6.6. The Geminoid F (pictures by Osaka University)

Especially if an ICT-artefact is used as a cooperative partner (cf. Breazeal et al., 2004) and even regarded to be a solution of mediation, the social interaction capabilities of an anthropomorphic ICT-artefact can be seen as a double-edged sword. A natural, human-like experience may lead to better user experience and even to a better learning experience. On the other hand, a too familiar ICT-artefact capable of socially rich interaction may result in misconceptions about the current situation, and even add a new layer to interaction potentially concealing the actual actor. The beneficiary may place false assumptions on who (or what) controls the situation and where the actual responsibilities lie. Even though it is likely that the artefacts of the near future still lack the required emotional intelligence; they are not aware of our intentions or motivations, nor are they capable of analysing the current situation from different perspectives, the recent developments in the field of social robotics give rise to concerns regarding the use of ICT-artefacts in mediation, for example, as cooperative partners in a working alliance.

6.4 Optimal Anthropomorphism in Health Care and Medicine?

In the context of health care and medicine, it is difficult to define what can be regarded optimal or even appropriate degree of using anthropomorphic features in different artefacts (Duffy, 2002). From purely didactic perspective, it could be argued that optimally anthropomorphized artefact in training and teaching of medical skills is one that is extremely anthropomorphized; a “biomimetic replica” of a human-being, or at least of the relevant anatomy. However, in the health care setting and particularly in the case of services and products intended for the consumers, the situation may be different.

In order to analyse different uses of anthropomorphic artefacts, and in order to differentiate teaching from other uses of human-like technology, issues such as components and fidelity should be discussed.

Components and fidelity

Creation and use of anthropomorphic artefacts is basically simulation; the purpose is to mimic (relevant) human-like features and behaviour. This view of the use of anthropomorphic artefacts is highlighted especially in training and teaching of medical skills, and in the context of conducting business in walks of life where the artefact can be regarded as a cooperative or “sociable partner” in similar fashion to human-robot interaction (Breazeal, 2004, p. 181). In the WordNet® Lexical database⁴⁴ the term “simulation” has following definitions:

Simulation:

1. The act of imitating the behaviour of some situation or some process by means of something suitably analogous [...];
2. The technique of representing the real world by a computer program;
3. Representation of something (sometimes on a smaller scale);
4. The act of giving a false appearance.

In the field of simulation, fidelity has been a subject of academic research for a long time. Already in the 1970s the field was rich with different approaches to simulation fidelity (cf. Hays, 1980, p. 7). Using a simplified breakdown of fidelity concepts (Kinkade & Wheaton, 1972, p. 679) it is possible to narrow different approaches to three basic components:

⁴⁴ <http://wordnet.princeton.edu/> (accessed: 11.10.2012)

- Equipment fidelity. The degree to which the simulator duplicates the look and feel;
- Environmental fidelity. The degree to which the simulator duplicates the sensory stimulation (excluding control feel);
- Psychological fidelity. The degree to which the simulator is perceived by the trainee as being a duplicate of the equipment and the situation.

In the case of equipment fidelity, the look and feel dimension includes aspects such as the degree to which the location of controls in the simulator correspond to those of the real operational equipment, and how the control feel (such as steering) corresponds to the conditions in the real world. The environmental fidelity emphasizes issues such as how the displayed external visual world is similar to the real world, and how the simulator responds to the external conditions, such as weather. The psychological fidelity indicates the perceived realism; how much the simulator itself and the simulated conditions create an illusion of a real world situation. As a related concept, a term physiological fidelity is sometimes used to depict the degree of somatic reactions the simulation has been able to produce in a trainee (Bennell & Jones, 2005, p. 30). Specific use cases in this area include ability to render complex decision in use of force scenarios, and ability to engage in intricate responses under time pressure (ibid.).

Equipment fidelity captures most of the salient points related to analysing the exterior features and aspects of the anthropomorphic artefact in question. When necessary, use of the component can be complemented with design space characterizations, such as the one used in the context of robot heads where different features are positioned on a scale of human, iconic and abstract (Duffy, 2003; figure 6.5). Similarly, the discussion revolving the concept of the “Uncanny Valley” (Gee et al., 2005) in terms of appearance and motion can be seen as ones contributing to this component. Especially in training and teaching of medical skills, artefacts that seem almost human-like but are “a bit off” can be seen as ones having negative effects in terms of equipment fidelity, and therefore they may be limiting from a purely pedagogical perspective.

Considering that with the technology of today it is not possible to create a “biomimetic replica” of a human-being, the most advanced anthropomorphic artefacts probably fall into the “Uncanny Valley”. This creates a philosophical contradiction between the pedagogical requirements and technology. For example in nursing education, it is argued that due to the “exceedingly complex care environment, nursing students must be educated with the most realistic technologies available” (Weaver, 2011, p. 40). The use of high fidelity patient simulation in clinical nursing education has been identified as essential component and a “valuable adjunct” to traditional education in other sources (cf. Nehring & Faaidd, 2008, p. 116).

As defined by Kinkade and Wheaton (1972), environmental fidelity focuses primarily on the similarity of the external (visual) world. In addition to realism of the surrounding world, the environmental fidelity takes into account the degree on which effects of the environment can be simulated. In the field of health care and medicine, the latter aspect becomes of the essence especially when the feedback mechanism between the artefact and the real world is considered, for example in the form of simulated response to care or medication.

To capture these kinds of nuances, the control aspect presented by Duffy and Joue (2005) raises to attention. Effectively, in training environmental fidelity is about the ability to influence the artefact, or our environment through it. In the case of health (and well-being) services, the control aspect can be linked to issues such as perceived autonomy of the actual beneficiary. If the beneficiary has limited means to influence the artefact, or outcome of a service through its use, it may have a negative effect on the component.

Probably the most challenging fidelity component defined by Kinkade & Wheaton (1972) is the psychological fidelity. In the field of simulation, the component focuses on the perceived similarity to a real-world situation. While this aspect is important in relation to teaching and training, it is also linked to complex issues such as predictability and dependency (Duffy & Joue, 2005) that can be seen as complementing to the component, adding issues related more directly to the interaction with the artefact into the mix.

Necessary fidelity vs. optimal anthropomorphism

One way to approach the question of optimal anthropomorphism in the context of health care and medicine is to consider necessity; what level of fidelity can be regarded as necessary in the light of different tasks as actors. Especially in the field of medical training, this has been a question that many have asked (Pettitt et al., 2009). Using the components above and the “Uncanny Valley” concept originally defined by Mori (Gee et al., 2005), it is possible to give one interpretation to the matter. Even though the tasks (e.g. conducting business and teaching) are not totally comparable as such, and the fidelity scale is not absolute, it is possible to provide suggestive indication on what can be regarded as necessary fidelity in the case of each identified component (figure 6.7).

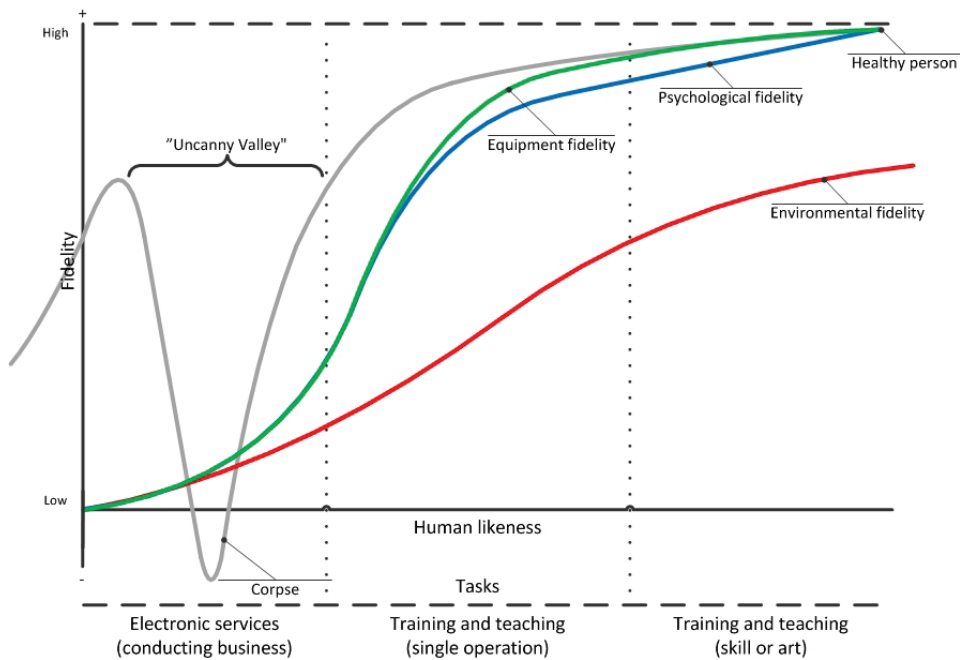


Figure 6.7. Fidelity, components and tasks (a non-mathematical illustration).

Case: training and teaching

The underlying rationale in the figure 6.7 above is that in training and teaching of medical skills, the completeness of the artefact's physical form (i.e. equipment fidelity) is of the essence if the used artefact is intended to be anthropomorphic. For example, accurate simulation of relevant bodily functions, such as pulse, blood pressure, lung and breath sounds, etc. can be commonly regarded as key features in an anthropomorphic artefact especially in scenarios where the simulated patient may improve, stabilize or die.

However, in the case of training and teaching of a singular task or operation, the necessary equipment fidelity can range from low to moderate if the anthropomorphic features are limited to a chosen physiognomy. For example, in the case of teaching non-surgical airway management techniques the anthropomorphic features may be limited to a head and a portion of upper torso; to body parts that include the most relevant organs. This interpretation of using low to moderate fidelity artefacts in teaching singular operations, and using higher fidelity artefacts in teaching a skill or an art; complex subject matters and competencies, is in line with the real-world use of medical simulators (cf. Seropian et al., 2004). Wider range in equipment fidelity also gives room to

using other anthropomorphic artefacts besides manikins (such as computer programs that simulate human-like behaviour).

In training and teaching of medical skills, attaining psychological fidelity can be regarded as a core requirement regardless of the artefacts equipment fidelity. However, depending on the task, the skills of the trainee and the trainer (when applicable), the necessary fidelity may vary and the necessary skill transfer may be obtained with simple cardboard models (Maran & Glavin, 2003, pp. 23-24). In the case of anthropomorphic artefacts and training of medical skills, that often require fine motor skills, higher psychological fidelity is needed in order to avoid the “Uncanny Valley” phenomenon. If the artefact is considered as too strange or alien, it may have a negative impact on the teaching experience. What differentiates the degree of fidelity in the case of teaching a singular skill from that of a skill or complex subject matter is related to equipment fidelity. If the artefact’s physiognomy is limited, it may have an effect on attaining high psychological fidelity and necessary skill transfer especially if the external factors, such as working environment (cf. Gaba & DeAnda, 1988) do not support the intended simulation.

Comparably lower environmental fidelity in the figure 6.7 is based on the nature of the component which focuses on simulating the external (visual) world and its effects. In the case of anthropomorphic artefacts, the significance of the component rises, not due to the simulation of the external world, but on its effects to the simulated patient, for example in the form of adverse effects to care or medication.

Case: electronic services

Electronic services or more fundamentally, conducting business and interacting with the beneficiary or the chosen mediator in the health (and well-being) sector, is different in terms of fidelity. While higher fidelity in training and teaching of medical skills with an anthropomorphic artefact can be seen justified in many cases, it is difficult to create sound grounds for arguments stating that electronic services and conducting business in the field requires high fidelity in any of the presented components.

Outside training and teaching, use of anthropomorphic features is rarely related to simulation of a patient or some (adverse) health related event. Use of anthropomorphic features is more often related to creating a positive user experience. Especially in the case of conducting business, the anthropomorphic artefact can be also be in a role of a collaborative partner (cf. Fong et al., 2002) instead that of a training tool (or “object”), or anthropomorphic features can be used merely as a visualization technique, such as in the case of avatars where they are representations of user’s character or alter ego (cf. Hemp, 2006).

If the artefact is used in such fashion that it can be regarded as a partner (to a reasonable degree) and it is used in the context of health care, it may be even beneficial to pursue low fidelity especially in the context of psychological fidelity and equipment fidelity due to our tendency to treat new technologies as real people and places (Reeves & Nass, 1996). Another alternative to potentially lessen this kind of “illusion of life” is to complement anthropomorphic features with iconic or even abstract ones in similar fashion to the design space characterization, defined by Duffy (2003).

Our inherent tendency to treat technology as people can be especially challenging in the context health care where the service provider (such as, a physician or a nurse) is effectively in a position of power. Especially in a paternalistic relationship the service provider is the dominant authority and good medical practice takes priority over patient’s wishes (Beisecker & Beisecker, 1993, p. 45). In a situation in which an anthropomorphic artefact substitutes the human expert and the process goes unnoticed from the patient, there is a risk that perceived familiarity (Duffy & Joue, 2005) with the artefact becomes obscured; individuals become dependent of the artefact, expect human-like behaviour from it, and instead of controlling the artefact it “controls us” or at least influences our behaviour.

With this risk in mind, it can be argued that low fidelity across the components, even in relation to the “Uncanny Valley” phenomenon might be sufficient – or closer to optimal than moderate or high fidelity unless it has a negative effect on the user experience. In such case, it might be beneficial to consider alternative methods for ensuring that the individuals understand the true nature of the parties they are involved with (e.g. “human or machine”). In this kind of work, the role of regulators and ethicists is of the essence. Public-private collaboration groups, such as the one operated and financed by the Markle Foundation has worked extensively in the field of networked personal health information and expanding their work in relation to individual participation and control (Markle Foundation, 2013, p. 4) could be extended to cover the aspects related to the use of anthropomorphic ICT-artefacts.

6.5 Recommendations

It is true that it takes more than a human face on a screen to create an illusion of life and intelligence. Individually, it may require use of human-like verbal cues or body language to facilitate social interaction associated with human behaviour; or just a bit of imagination. However, with the examples presented in this chapter, it may not require vivid imagination to consider a robot closely simulating a new-born baby (figure 6.3) as one would its human counterpart. At

least in theory, the situation may be quite the opposite: with highly anthropomorphic artefacts that feel familiar and are similar to us in anatomy and motion, it is possible that users actively remind themselves that they are interacting with an ICT-artefact not with a human.

Teaching and training

As established, there can be various benefits in using anthropomorphic artefacts of high fidelity in teaching and training medical skills. However, from the perspective of a trainee such as a medical student, the benefits are not so evident. In the context of training medical skills it should be noted that a high psychological fidelity can also be seen as a “double-edged sword”; anthropomorphic artefacts are in effect “standardized patients” (cf. Barrows, 1993, p. 443), such as a, “30-year old moderately overweight Caucasian male patient experiencing abdominal pain”, and it is unforeseeable that the technological advance of the near future will be able to depict “quirks” of a live patient. However, there are recent advances in the field of robotics that enable robots to act more human than ever before. For example, Hasegawa Lab of Tokyo Institute of Technology has recently reported of a robot that can “learn” from its past experiences and to create estimates on the future patterns (Yin, 2011). Similar advances were reported in 2011 by IBM in the field developing “cognitive” processors (Ojanperä, 2011).

Until the technology advances and can be used for richer and more flexible scenario modelling in a wider range of areas of clinical expertise, anthropomorphic artefacts should not be used as the sole means of knowledge transfer. Considering the delicate nature of providing care, use of anthropomorphic artefacts should be seen as methodological add-on or as a “value-added component” in teaching and their use should be complemented with supervised actual care, and the transition from simulated patients to actual ones should be executed in informed and controlled manner.

Conducting business

In conducting business the potential value of using anthropomorphic artefacts is more difficult to pinpoint. There is no clear evidence that anthropomorphic features provide a better user experience, or that the individuals expect human-like behaviour or appearance from the artefacts even though it is argued that our interactions with computers are fundamentally social (Nass et al., 1994). In theory, the situation may be quite the opposite and the use of anthropomorphic features may even obscure individual’s perceptions about the involved artefacts and actors.

Especially in the health (and well-being) sector, trust has a paramount importance. Unless there is a trust between the service provider and the beneficiary, it is possible that the provided care or instructions, intended outcome of the process will not be realized to their full extent. In the case of beneficiaries, this may lead to issues such as non-adherence, or even to a total negligence. As a phenomenon of wired world of today, Weaver et al. (2009) report that use of internet health information has led to non-adherence and patients have used online information to “refuse or discontinue treatment recommended by a doctor or a dentist” (p. 1373). From these starting points the use of anthropomorphic features should be considered, or alternative mechanisms that indicate to all involved parties what kind of actors and artefacts are present in the process should be devised (where applicable).

The use of anthropomorphic artefacts is also a delicate matter in the case of mediators. If the mediator operates in a similar setting anthropomorphic artefacts (for example, as an avatar amongst computer generated characters), misinterpretations on the nature of the interaction may occur. A similarly obscuring setting could be a chat; synchronous conversation mediated by a computer network. If ICT-artefacts employ natural language in their interaction, a possibility for a misinterpretation is similarly present. In this kind of situation one mechanism that could indicate to all involved parties the true nature of actors and artefacts is a consistent breach against rules and norms of social interaction (such as, use of neutral language void of personal pronoun, or use of body language void of characteristics associated with a natural body language).

In recent literature, obscuring effects of human-like behaviour of ICT-artefacts has been brought up by Salem et al. (2013). The authors (*ibid.*) found out that that communicative non-verbal behaviour affected human perception and mental models during interaction with an anthropomorphic ICT-artefact. In the light of these recent findings, it can be hypothesized that the perceived difference between human actors and anthropomorphic ICT-artefacts should be evident enough in order help beneficiaries to have a better possibility to maintain a coherent picture of the on-going interaction.

6.6 Conclusions

It is difficult to make definite statements for or against the use of anthropomorphic artefacts in the field of health care and medicine. It is even more difficult to state whether our inherent trait to anthropomorphize inanimate objects, animals and systems has, without doubt, a negative effect on our use of different ICT-artefacts and services. The field is still new and the use of highly anthropomorphized ICT-artefacts is relatively rare, partially due to immaturity of the technology (section 6.4). It needs experimental research in the field of ICT

and behavioural sciences in order to understand antecedents and consequences of using anthropomorphism in the field of health and well-being.

On the basis of research conducted in the field, we can predict that anthropomorphic artefacts with a high fidelity may have a positive effect on knowledge transfer in relation to teaching medical skills and arts (cf. Weaver, 2011). Considering the nature of the taught subjects and current state of the related technology, learning should be complemented with alternative or “traditional” methods. It follows from this that anthropomorphic artefacts of today could be seen as methodological add-on or as a “value-added component” in teaching. This is in line with the current research since there is not clear indication on the impact of using anthropomorphic ICT-artefacts in teaching (cf. Ray et al., 2012) and after that, in actual patient care (Diener & Hobbs, 2012, p. 37).

Due to its variety, conducting business is probably the most controversial area for the use of anthropomorphic ICT-artefacts. There is no clear indication that anthropomorphic artefacts provide a better user experience, or that the individuals will be better able to conduct their business with such artefacts. However, there is some indication that individuals may feel “psychologically closer” to robots that use human-like voice of the same gender as the individual they are interacting with (Eyssel, et al., 2012, p. 126). Due to our natural tendencies to misplace trust on new technologies and ICT, it can argued that due to potential obscuring effect, the beneficiaries should be informed of the true nature of artefacts and actors they are interacting with. For similar reasons, the use of anthropomorphic artefacts as a cooperative partner should be implemented in a way that the beneficiaries are at all times reasonably informed about the true nature of the participants.

The same principle applies to mediators and mediation which can be seen as a very particular layer of tool-mediated activity since it potentially adds a layer to the interaction. Clear and consistent boundaries should be set in order to make a clear distinction between different forms of interaction (such has human-to-computer-to-human). In other words, the used technology should not be too anthropomorphized or its use may lead to false assumptions on the nature of interaction. Continuing this line of thought, interactions that fall to the “Uncanny Valley” (or are “a bit off”) are also prone to misinterpretations. They can be regarded as distorted much in a same fashion to a poor connection in a teleconsultation where the distortions in media may have a negative effect on the provided care. In theory, this kind of distortion that originates from the (disturbingly) anthropomorphic features of an artefact can have other implications as well, such as lower adherence to medical advice, or even misapprehension.

Bot regulators and ethicists are often criticized for being late with their recommendations on how to apply ICT in the field of health care and medicine. Therefore it is important to make a proactive approach to the matter presented in this chapter and investigate what are potential implications of using anthropomorphic technologies and anthropomorphism in relation to the delicate matter that is our health. The field of human-robot interaction may provide a rich field for this kind of research due to following reasons: a) the use of anthropomorphic robots is not yet a commonplace practice, b) robots typically incorporate more human-like features than a simple display, and c) robots have a potential clientele amongst health care professionals, beneficiaries, and mediators.

The following chapter is revised and extended from:

Lahtiranta, J. & Kimppa, K. (2005), "Some Ethical Problems Related to the Near-Future Use of Telemedicine in the Armed Forces", in: Collste, G., Hanson, S.O., Rogerson, S. & Ward Bynym, T. (Eds.) *Ethicomp 2005: Looking Back to the Future*, September 12-15, 2005. Linköping, Sweden.

7. Telemedicine and Armed Forces – Ethical Questions and Challenges

Telemedicine, as an application of clinical medicine where diagnosis, monitoring and treatment of patients is enabled with the use of Information and Communication Technology (ICT), is a commonplace practice today. Different solutions are widely employed in different institutions worldwide, and they have found their way to the pockets of a layperson. Just to name few, these applications include smart personal health assistants for certain specific disorders, such as diabetes, and different health monitoring systems (for practical examples, see European Commission, 2003 and chapter 4). As in practically every area related to the use of ICT, the solutions in the field of telemedicine are becoming smaller, smarter and more integrated.

Globally, armed forces of different countries have employed different solutions of ICT in the delivery of health care from the early days of maritime service. For example, ship-to-shore telemedicine has been widely used by both civilian and military seafaring since the establishment of Morse-code (International Telecommunication Union, 1997, p. 13). However, regardless of the advances in the field of using telemedicine in the armed forces (cf. European Space Agency, 2004; Lewis, 2010), the use of different applications on an individual or a small unit level can be regarded as a coming trend. For example, Lam and Poropatich (2008, p. 946) report that prior to creation of NATO Telemedicine Expert Panel in 2000, only few nations had deployed telemedicine systems to support military field operations.

Like in other walks of life, the barriers preventing a wide-scaled adoption of telemedicine are often multiform by nature in the field of armed forces. In addition to commonly accepted societal barriers, such as culture, financing and (global) economy, the field has more unique barriers as well. For example, system size, weight and power constraints (i.e. SWaP constraints, cf. Pursley, 2010) typically differ from the solutions used, for example, in the home care. Similarly, the network architecture in many theatres of conflict is often lacking and a satellite connection is, in practice, the only viable option for creating a broadband connection to the health care professionals residing outside the immediate area of deployment.

At the moment, there are different military modernization programs being implemented world-wide. Some of these programs go beyond updating the military hardware, modernizing the personal equipment of an individual warfighter. In these programs, ICT is gradually harnessed to bring different applications and systems of telemedicine to personal or small unit level. For

example, in the visionary Future Force Warrior (FFW) advanced technology demonstration project, introduced Warfighter Physiological Status Monitoring System (WPSM), a solution that can monitor physiological indicators (such as blood pressure and hydration) of the individual (Trivedi, 2007, pp. 596-597; Wesensten et al., 2005, p. 103). It is estimated that the solution provides “one of the truly revolutionary breakthroughs in individual soldier enhancement” (Friedl & Allan, p. 36). (For more examples on military modernization programs, see Hellstén et al., 2003, pp. 29-40.)

While one of the central objectives of these modernization programs is to ensure health and safety of the warfighters, the programs aim for enhancing human performance as well, for example via enhanced mobility and situation awareness, thereof optimizing the overall operational effectiveness of deployed units. For example, the Defense Advanced Research Projects Agency (DARPA) is currently researching on military exoskeletons (cf. figure 7.1), a system that can be used for enhancing warfighter’s physical abilities (Guizzo & Goldstein, 2005, p. 52).



Figure 7.1. The HULC Exoskeleton by Lockheed Martin⁴⁵.

Optimization of the warfighter’s performance has not always been limited only to the military hardware and software. Throughout the history, various chemical substances (methylphenidate, dextroamphetamine, etc.) have been used for a similar purpose (cf. Jones, 1985; Rasmussen, 2008, p.54-58).

⁴⁵ <http://www.lockheedmartin.com/> (accessed: 12.10.2012)

Performance optimization, future telemedicine and different military modernization programs create interesting challenges arising from their unethical (and unsanctioned) use in a theatre of war. In the following, the focus is on these emerging issues and on their impact on a) individual warfighters, and b) health care personnel operating in the field. Analysis on whether or not these issues will come to light is outside the scope of this chapter. However, since the focus is on emerging aspects, they deserve the attention now prior to an actual widespread implementation.

The discussion begins with a short introduction to some of the well-known agreements of war, continuing with examples how they have been violated in spirit and in practice. The examples reflect the time of the reported incidents in terms of relevance; what technology was in the focus of development at that time and what kind of emerging aspects came to life. As a consequence, the examples are related to the use of drugs, chemical weapons and warfare agents. In the latter part of the chapter, the focus is shifted to technologies that are positioned similarly today, creating a bridge between yesterday and tomorrow.

While most of the examples in this chapter that highlight potentially unethical use of technology, debatable use of drugs, chemical weapons and warfare agents in the armed forces originate from U.S. military, the purpose of this chapter is not to pinpoint any country as more prone to misuse or malpractice. The rationale behind the chosen examples is that of practicality; there is more publicly available information on the subject in relation to the U.S. armed forces than, for example, in relation to armed forces of China or Russia.

7.1 On Agreements of War

Probably the most notable international agreements of war are the Geneva Conventions and the Hague Convention⁴⁶. In addition to the aforementioned ones, there are certain sets of protocols, such as the “Protocol for the Prohibition of the Use in War of Asphyxiating, Poisonous or other Gases, and of Bacteriological Methods of Warfare” (also known as the Geneva Protocol), that prohibits the first use of chemical and biological weapons.

While the Geneva Protocol focuses on the use of specific armaments such as “asphyxiating, poisonous or other gases” (cf. Shindler & Toman, 1988, pp. 116), the aforementioned conventions (incl. their amendments) focus more on the role and treatment of an individual, such as in the case of a wounded or sick warfighter. For example, Article 3 of the Geneva Conventions known as “Convention (II) for the Amelioration of the Condition of Wounded, Sick and

⁴⁶ cf. http://avalon.law.yale.edu/subject_menus/lawwar.asp (accessed: 11.1.2012)

Shipwrecked Members of Armed Forces at Sea (Geneva, August 12th, 1949)”⁴⁷ states the following:

“Art 3. In the case of armed conflict not of an international character occurring in the territory of one of the High Contracting Parties, each Party to the conflict shall be bound to apply, as a minimum, the following provisions:

Persons taking no active part in the hostilities, including members of armed forces who have laid down their arms and those placed hors de combat by sickness, wounds, detention, or any other cause, shall in all circumstances be treated humanely, without any adverse distinction founded on race, colour, religion or faith, sex, birth or wealth, or any other similar criteria. [...]

The wounded, sick and shipwrecked shall be collected and cared for. An impartial humanitarian body, such as the International Committee of the Red Cross, may offer its services to the Parties to the conflict. “

In terms of how the actual care should be rendered, there seems to be no specific universal agreements of war; the ethical principles of beneficence, patient autonomy, self-determination, etc. that set a framework for ethical conduct in practice of medicine apply in war and in peace. This notion is visible, for example, in the Commentaries related to the Additional Protocols of June 8th, 1977 to the Geneva Conventions of August 12th, 1949, it is stated that “the wounded and sick must be given such care as their condition requires” (Pilloud et al., 1987, p. 147). All in all, the Geneva Conventions capture in their iterations (1864 to 1929) four basic principles that should be taken into attention when care is provided. These principles are a) actual provision of care (as in contrast to negligence), b) respect, c) protection and d) humane treatment without adverse distinctions such as sex or race (See Art. 3 above and Vollmar, 2003 p. 754-755).

However, it is easy to fathom that during the time of war the health professionals are sometimes faced with a conflict between their moral duties and principles of the Hippocratic Oath, and their service commitments (cf. Rosner, 2010, p. 134) for example when prioritizing the treatment between civilians, prisoners of war and a member of friendly troops. For example, it is reported that the U.S. military medical system failed to protect the detainee’s human rights in Iraq, Afghanistan and Guantanamo Bay for example, due to collaboration with abusive guards (see summary in Miles, 2004). The confirmed and reliably reported abuses included, amongst others, those of “beatings, burns, shocks, bodily suspensions, asphyxia, threats against detainees and their relatives, sexual

⁴⁷ <http://www.icrc.org/ihl.nsf/FULL/370?OpenDocument> (accessed: 11.1.2012)

humiliation, isolation, prolonged hooding and shackling, and exposure to heat, cold, and loud noise” (ibid. p. 726).

7.2 Debatable use of Drugs, Chemical Weapons and Warfare Agents in the Armed Forces

At least from the early days of the World War II where murderous and torturous experiments were conducted by Nazi doctors in the concentration camps (Shuster, 1997, p. 1436) to the debatable use of investigational new drugs (e.g. experimental drug which is not approved for distribution) such as pyridostigmine bromide in the Gulf War (FitzPatrick & Zwanziger, 2003) there has been incidents where individual’s autonomy has been violated in order to serve the purposes of experimental science or common good. In the case of the Gulf War, investigational new drugs were administered to the U.S. troops as part of the Nerve Agent Protection Packs in anticipation of possible exposure from Iraqi chemical weapons (ibid.).

Another well-known example of debatable administration of drugs to the military personnel is the case of Major Sonnie G. Bates of the U.S. Air Force who disobeyed a direct order to take a vaccination against anthrax (Katz, 2001). In his publicly distributed memorandum⁴⁸, Major Bates stated:

“I believe the anthrax vaccine is unsafe. It is linked to a large number of illnesses among people in my unit. Within a few weeks after I reported for duty I became aware that approximately 5 % of my squadron were suffering from unusual illnesses that resembled those described as Gulf War Illness. They all had two things in common; they all had the anthrax vaccine and were healthy before receiving the vaccine. These people were suffering from symptoms such as severe skin rashes, chronic bone and joint pain, autoimmune disorders, thyroid damage, seizures, memory loss, neurological problems, chronic fatigue, vertigo, and internal and external lesions. I had never seen illness of this like and magnitude before and neither had my peers and those senior to me. To date there has been no medical explanation for the widespread illnesses listed in the attachment.”

Probably the most notorious example of unwilling participation to medical experiments in the armed forces dates back to an era of 1962-1973. During that time, the U.S. military executed the infamous Shipboard Hazard and Defense (SHAD) project in which over 5.800 military personnel (mostly Navy personnel and Marines) were subjected to chemical or biological warfare agents, thought at the time harmless (Page, 2007). In this case, it took almost 30 years until the

⁴⁸ http://www.mvrd.org/avn/sonnie/law/bates_21feb00.htm (accessed: 22.10.2010)

existence of these tests was publicly announced. In 2000, the Department of Defense (DoD) undertook the task of providing information on the tests at the request by the Veteran Affairs (ibid.). In 1940s similar uninformed large scale experiments were performed on nearly 2.000 U.S. naval personnel on the effects of mustard gas (Amoroso & Wenger, 2003, p. 568).

Outside the United States, reported cases of coercion, debatable use of drugs, chemical weapons and warfare agents are more difficult to find. For example, there is relatively little data on Soviet chemical weapons testing (Page, 2007, Appendix A, p. 84). However, there are reported acute poisonings related to the use of sarin, soman or VX in Russian production facilities (ibid.). Page (2007, Appendix A, p. 83) also reports a case of testing sarin in the United Kingdom in 1950s where “largest experimental use of “ the agent on humans appears to have occurred at Porton Down, resulting in the death of a test subject after 45 minutes.

Part of the debatable use of drugs is related to pharmacological optimization of the individual warfighter’s performance on a battlefield. For example, reducing fear, anxiety or development of a posttraumatic stress disorder, belong to this category. In history, the U.S. Army experimented with mind altering drugs from early 1950s to 1970s, funding 13 research contracts and conducting in-house studies on the effects of the lysergic acid diethylamide, LSD (Amoroso & Wenger, 2003, p. 570). The research focused on the soldier’s ability to perform one’s duties under the influence of the narcotic substance, and on the use of substance as part of interrogations in order to gain sensitive information (ibid.).

During the Second World War, the German army tested the use of methamphetamine called Pervitin during the war on Poland where a group of military doctors received large amounts of the drug to be tested under fighting conditions (Iversen, 2006, p. 71-72). The use of amphetamine by armed forces increased rapidly during and after the Second World War and during the period of 1966-1969, the total consumption of the drug was 225 million tablets by the U.S. armed forces alone, exceeding the combined consumption of the U.S. and U.K. forces during the Second World War (ibid. p. 72).

After the Second World War, the use of amphetamine has continued in the armed forces. For example, in the U.S. armed services, especially in the Air Force, the use of amphetamine has been sanctioned by some components under supervision since 1960 until 1991 when it was banned after the Operation Desert Storm (Cornum et al., 1997, p. 52-53). In their article Cornum et al. (ibid.) also conclude that due to their value to mission accomplishment the ban on amphetamines should be lifted, since there has been no reported negative effects (at that time).

Voluntary drug use has also been a problem for the enlisted men in the recent history. For example, in 1971 drug use amongst the servicemen in Vietnam reached “epidemic proportions” (Robin et al., 1974, p. 236). However, in a more recent study the level of voluntary drug use is reported significantly lower amongst the U.S. military personnel when compared to civilian population. According to Bray et al. (1991) the drug use amongst the military personnel is one-third that among all civilians.

7.3 Coercion and Armed Forces

Excluding the use of coercion as a military tactic (cf. Byman & Waxman, 2002) and focusing on the practice of medicine, coercion has always had a special role in the research of ethics in the field. For example, the Nuremberg Code, one of the most famous collections of research ethics principles, highlights voluntary consent and lack of coercion in its opening paragraph (Shuster, 1997, p. 1436):

“The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected; and the effects upon his health or person which may possibly come from his participation in the experiment. The duty and responsibility for ascertaining the quality of the consent rests upon each individual who initiates, directs or engages in the experiment. It is a personal duty and responsibility which may not be delegated to another with impunity.”

The Code was formulated in 1947 by American judges sitting in judgment of Nazi doctors after the World War II (ibid.). It encompasses a set of ten principles that in addition to coercion, addresses issues such as avoiding suffering and injury, and the degree of risk to be taken. In the light of the presented examples, it is easy to see how the experiments on drugs, chemical weapons and warfare agents in the armed forces test the limits of the Nuremberg Code, in some cases blatantly breaking against it. One of the documented cases of coercion and research using human subjects occurred during the Vietnam War in the U.S. Army. At that time, a group of volunteers at the U.S. Army Quartermaster Research Development Command were coerced to give their consent to testing,

or they would be assigned to a unit in Vietnam (Amoroso & Wenger, 2003, pp. 571-572).

Analysing the underlying rationale behind these kinds of activities is difficult. While in some cases the motivation is valid in principle, such as protecting individuals against a warfare agent that has been employed during a conflict, the true enabler for this kind of behaviour remains vague. To a degree, it is the military as an organization that provides a breeding ground for this kind of behaviour, which is in its very core, abusive and destructive.

Similarly to (certain) boarding schools and prisons, members of the armed forces live in, what can be regarded as, a “total institution”; their lives are dependent and controlled by the authorities of the organization. Due to the nature of the lives they have chosen, the individual warfighters are more prone to coercion than civilians (Howe & Beam, 2003, p. 847). Another aspect in the lives of the warfighters that makes them more prone to coercion, when compared to most civilian professions, is the intertwined nature of their life and that of their fellows. During an active engagement, the lives of the warfighters often depend on the decisions of another. For example, on a matter whether to take certain drug or not, warfighters may experience strong pressure from their peers (ibid., p. 841). Especially certain elite units, such as Ranges and Special Forces are prone to this kind of unit pressure (Amoroso & Wenger, 2003, p. 590). The effects of the unit pressure and the nature of the social cohesion in a total institution was also reported in the research performed by Harinen (2012) who reported that the loyalty towards a fellow warfighter may surpass the duties towards the formal organization (p. 104).

7.4 The Near Future of Telemedicine in the Armed Forces?

It is difficult to analyse the future directions of the military telemedicine solely on the basis of publicly available material. However, enriching the non-classified material with the trends related to different military modernization programs (cf. Vääänen et al., 2009), and with the on-going changes in the operational theatres around the globe, it is possible to define possible directions for the future development.

Considering the nature of conflicts today, it is easy to understand why the nature of the warfighting in the diverse urban environments of today is referred to with the term “Complex Warfighting” (cf. Fletcher, 2007, p. 37). The term accurately encompasses the nature of today’s battlespace and the overall theatre of operations for peacekeeping missions. Even though some of the characteristics are the same as in the conflicts of the past, their emphasis and proportions have

changed. For example, in the case of terrain the size and complexity of urban terrains has increased over the last years and will continue to do so as the world population continues to rise.

In his analysis on the complex warfighting and battlespaces of the near future, the former Australian Army officer David Kilcullen (2004) depicts the changing terrain by dividing it into three dimensions, physical, human and information. Summarizing Kilcullen's (ibid.) interpretations, the dimensions are in principle:

- Complex physical terrain. This is the physical environment of the operational theatre, consisting of urbanized areas, littoral regions, etc. that typically comprises mosaics of open spaces (such as manoeuvre corridors and compartments), and patches of terrain that prevents movement and restricts observations;
- Complex human terrain. The terrain encapsulates the human element of the operational theatre. It comprises numerous different population groups (such as political groups, tribes or clans) that coexist in the same physical space, sharing intertwined dynamics with each other;
- Complex information terrain. As a phenomenon of the Information Age, the role of this environment has increased and will continue to do so. It encompasses multiple sources of transmissions and information that the operating force is unable to completely control.

These characteristics of the theatre of operations create an asymmetrical environment where the elements of influence, such as different population groups, are often non-contiguous and the "front line" is hard to accurately describe (cf. Fletcher, 2007). One consequence of this is that there is rarely any kind of secure or safe place within the theatre, for example due to guerrilla warfare in urban environments (Hoffman, 2006).

In addition to the changes in the physical, human and information terrains, the nature of the health needs of the deployed forces have changed as well. While there will be a need to treat catastrophic wounds, such as in the case of Improvised Explosive Devices (IEDs) like roadside bombs, the greatest stress to the health care personnel operating in the area will come from treating non-hostile injuries and diseases. It is estimated that these two will cause most casualties to the deployed forces (Fletcher, 2007, p. 38).

This kind of complex terrain with interacting physical, informational and human elements, the health care services and related logistics require agility unlike anything seen in the conflicts of the past. One way to answer to this demand is to execute integrated campaigns tailored for the theatre at hand. Key elements in such campaigns are combined interagency task forces; groups of strategic assets that tailored and scaled to meet the demands of a specific mission (cf. Bogdanos,

2005). From the perspective of health care delivery, this not only means incorporating deployable health assets into the mix, but also training individual warfighters to act as combat first aiders and medics who are aware of the unique characteristics of the current operating theatre (cf. Fletcher, 2007).

In order to cope in the complex terrain of the contemporary conflicts, and the ones of tomorrow, the army command and control depends on the situational awareness that can be effectively mediated to a necessary level (such as, to small unit leaders). This concept does not only mean precision navigation or efficient communication between different troop elements, it encompasses a more comprehensive operational picture. All relevant data originating from forward scouts, satellites, unmanned drones, etc. are collected, enriched and distributed in order to provide a maximal networked effect. In the Joint Vision 2020, a military doctrine of the United States, this kind of view to information as a key-enabler to military dominance is referred with the term information superiority (cf. Wielhouwer, 2005, p. 86).

In the current military modernization programs worldwide, improving situational awareness is one of the primary focus areas of research and development activities. For example programs like *Infanterist der Zukunft* (Germany), *Combatiente Futuro* (Spain) and *Fantassin à Equipements et Liaisons Intégrées* (France) all look into this area (cf. Vääänen et al., 2009). From the perspective of telemedicine, this development revolves around monitoring physiological status of an individual warfighter, such as in the case of *Warfighter Physiological Status Monitor Subsystem (WPSM)* of the *Future Force Warrior* project (Trivedi, 2007, pp. 596-597; Wesensten et al., 2005, p. 103). Similar development can be seen, for example, in the *Soldato Futuro* program (Italy). The command and control systems of the program include the *Galileo Avionica* physiological sensor which allows “the commander of the infantry section to monitor each soldier's health conditions through its command and control system” (army-technology.com, 2010a). Depending on the level of detail and type of the collected and relayed data, these kinds of solutions can also be seen as ones supporting telediagnosis, determining the nature of the disease or ailment from a distance.

Primarily from the perspective of the health care providers in the service of the armed forces, the near future of telemedicine will probably highlight the need for bringing the knowledge of the critical medical specialist to the use of combat first aiders and medics without the need for far-forward-deployed medical facilities. These kinds of solutions include teleconsultation, telediagnosis and teleoperation, such as the ones used in robot-assisted telesurgery (i.e. remote surgery) as described in Marescaux et al. (2001). The concept of robot assisted telesurgery has already been experimented in relation to unmanned extraction vehicles (Brett et al., 2008).

Similarly to the private sector, teleconsultation services are already provided for the deployed soldiers and health care professionals in teledermatology consultations (cf. McManus et al., 2008). In the near future, as the telemonitoring and communication capabilities improve, it is possible that teleconsultation solutions will be enabled on a small unit level. For example, by means of augmented reality by using a head-mounted display such as the M1 Personal Viewer or the Microvision Nomad heads-up display (cf. Colbert & Tack, 2005, pp. 9-10). These kinds of head-mounted displays are already researched in the context of different military modernization programs. For example, in the Future Infantry Soldier Technology (FIST) program (U.K.), the helmet display is integrated into the warfighter's helmet (army-technology.com, 2010b).

Deployed troops, especially in the peace keeping missions, consist of units from different nationalities. In order to provide responsive health care services on a short notice, service interoperability is of the essence. From this perspective, the challenges faced by the military telemedicine are not so different from those of the health care sector in general. In order to provide integrated health care services in the conflict areas, it is potentially an issue of paramount importance that the information generated at different states of care is available throughout the patient trajectory; from the combat first aiders and medics to forward surgical teams and theatre medical care, and when necessary all the way to medical centres outside the theatre of operations (figure 7.2).



Figure 7.2. Complexity of military medicine, example (Lam, 2007).

Addressing this need does not only mean adherence to technical interoperability standards, it requires implementing solutions for addressing the individual's relevant health records (allergies, blood type, etc.) in the case of an emergency. One way to address this need is to employ solutions such as Battlefield Medical Information System – Tactical (BMIS-T). The mobile solution enables transfer of relevant medical information on a personal transferable medium and architecture for accessing the stored information (Morris et al., 2006). Naturally, solving interoperability issues in this kind of complex terrain has other benefits as well (disease surveillance, outbreak early warning, etc.).

In the current military modernization programs, the envisioned early detection programs focus on detecting nuclear, biological and chemical (NBC) hazards. These are developed, for example, in the relation to the U.K. military modernization program (see FIST above) where the applications are implemented as a part of the Battlefield Information System Applications (BISA) architecture (army-technology.com, 2010b). However, the current status of the development work remains vague as CBRNe World reported on 2007 that the NBC BISA has been cancelled forthwith due to “technical difficulties in pre-existing software” (p. 1). Even in late 2013, there is no (publicly) reported progress on the matter⁴⁹.

As a conclusion, it can be postulated that in the near future the military modernization programs, and general development in the field of ICT and medicine, will bring the following solutions to the field of telemedicine: 1) remote monitoring of the individual warfighter's physiological condition, 2) improved teleconsultation possibilities for the health care personnel (incl. combat first aiders and medics), 3) new tools for teleoperations (incl. telesurgery) and 4) new solutions for integral health care provisioning throughout the patient trajectory.

7.5 Potential Threats and Risks

As we have established, unethical or at least debatable, use of drugs, chemical weapons and warfare agents has occurred in the recent history of the armed forces. Of course, this does not automatically indicate that this kind of misuse or malpractice occurs today in the armed forces. However, in order to highlight possibilities for misuse and malpractice, the following speculative scenarios that base on history and potential near future development directions indicated in the military modernization programs, are devised.

⁴⁹ Personal correspondence with SciSys U.K. Ltd. (18.9.2013).

Case 1: Battlefield medical evacuation

The individual warfighter's personal body armour is changing. In contrast to the bulky ballistic vests of today, the new body armours of the near future are more robust, they cover larger sections of the wearer's body, and they are integrated to complex sensor networks such as personal health monitoring systems (see examples above). The materials used for producing personal body armours change as well and the Kevlar brand fibre used since 1960s is replaced by materials such as Vectran™, carbon fibre and liquid crystal polymer fibre (cf. Sullivan, 2010).

If we look further into patent applications and accepted patents in the field of protective vests (Griffin, 1997; Ford, 2002; van Albert et al., 2010), the envisioned sensor networks are capable of detecting hits (incl. magnitude and location). Combining this information to the warfighter's physiological status monitoring will provide a rather accurate estimate on the current health status of the warfighter.

Battlefield evacuation has always been a complex matter and the crucial factor between life and death. Locating evacuees and delivering appropriate care on time are challenges that will remain in the near future as well. However, technology will help in such endeavours, for example via positioning technologies (cf. Fletcher, 2007, p. 40), in the form of unmanned extraction vehicles (Brett et al., 2008) and even in the form of battlefield extraction robots (Gilbert & Beebe, 2010 p. 6).

In today's complex terrain, the challenges of evacuation are multiform by nature. The deployed resources (vehicles, personnel, etc.) are often prone to different threats and even in the simplest "swoop and scoop" operations they easily become targets of opportunity. Like any successful battlefield operation, evacuation is not just a matter of equipment, personnel and proven methods; the element of luck is often also involved.

From the perspective of demographics, the real "killer" in the battlefield is haemorrhage. In combat, from 83 % to 87 % of so-called "potentially survivable" deaths are caused by haemorrhage (Blackbourne, 2010). All in all, military medicine has gained substantial amount of empirical data on different wound profiles and patterns, and catastrophic wounds during conflicts (cf. Manring et al., 2009; Hollerman et al., 1990).

From these starting points, it is easy to picture a situation in which the probabilistic logic overrides the duty of care and professional ethics in general (cf. Kelly, 2010), in the battlefield conditions. In this speculative scenario, this kind of situation may occur when the information on individual warfighter's

health status (incl. reports on sustained wounds originating from the personal body armour) and current location in the battlefield do not exceed the threshold where battlefield evacuation is deemed as a viable option.

Case 2: Human performance enhancement and modification

Enhancing the performance of an individual warfighter is one of the central themes in military modernization programs. In the current programs, the enhancement efforts focus primarily on the sense of sight (such as, night-sight and aiming). Outside the individual modernization programs, the research activities focus on improving physical aspects (i.e. strength and endurance) as well. In this area, the research on exoskeletons is abundant (cf. Brown et al., 2003; Altmann & Gubrud, 2004a, p. 273; Guizzo & Goldstein, 2005; Walsh et al., 2006).

In history, the research on human performance enhancement has been conducted on other areas besides the augmenting physical aspects. One of the areas in which research has been executed is pharmacological optimization, namely in the field of battling harmful effects of sleep deprivation. As an alternative to the use of amphetamine (cf. Cornum et al., 1997), the U.S. military has studied (Whitmore et al., 2006) the use of Modafinil, an analeptic drug commonly associated with the treatment of narcolepsy and attention deficit hyperactivity disorder (i.e. ADHD).

More forward thinking human performance enhancement and modification scenarios in the context of armed forces are presented in a report by the Pentagon's Office of Defense Research and Engineering (Williams et al., 2008). The report provides an insight on how performance enhancement is entering military practice (if not necessarily endorsed by the authorities). For example, in the case of battling the consequences of sleep deprivation different cognitive supplements are already used by the members of the military (ibid., pp. 33-35).

Interestingly, the report also draws its own speculative scenarios on what kind of military applications brain plasticity research could unfold, and how brain-computer interface could be used a) in linking auxiliary equipment to direct human actions, and b) in enhancing sensory input to enhance the performance of a warfighter (ibid.). In other sources, applications of military nanotechnology are also described as potential future avenues in enhancing human performance (Altmann & Gubrud, 2004a, pp. 272-274).

In the area of human performance enhancement and modification, the future concepts include release of drugs for therapy, and “influencing performance and mood”, for example by using implants to reduce reaction time (Altmann & Gubrud, 2004b p. 36). The authors also envision the use of implants of

nanoscopic scale for the purposes of identification, espionage and communication in the armed forces (ibid.).

While especially the use of nanotechnology in the armed forces can be seen as a technology of the near future, it is one of the potential areas in conflict with preventive arms control (ibid., pp. 36-38; Altmann, 2006). Considering the theoretical and practical work in the area, it is possible to create a speculative scenario in which the individual's autonomy over health related affairs is challenged; or even abolished.

In this scenario, the health status of an individual warfighter triggers administration of a pharmacological substance directly to the bloodstream from an implant without consent. The scenario is even more worrying if the pharmacological substance is one affecting the mood or other personal traits of the individual, and the substance is released by a remote command from the military command and control.

While the accuracy of these two speculative scenarios will remain to be seen, the potential threats and risks to the individual warfighter exist regardless of the actual implementation of devices and systems of described above. The possibilities for these threats and risks to emerge increases especially if a) there are proven results that certain pharmacological substances can be used for enhancing human performance (for example, in the case of sleep deprivation), or b) if major global conflicts occur that draw the most technologically advanced countries into an open warfare involving ground troops.

7.6 Recommendations

As established, the history of armed forces contains numerous cautionary examples on unethical, or at least debatable, use of drugs, chemical weapons and warfare agents. In some of these examples individual autonomy, personal independence and privacy are blatantly disregarded. At the same time, the mutual respect one expects to find in any professional setting, be it armed forces or health care, is heavily undermined.

Military as a career and armed forces as an operational environment are different when compared to "civilian life". Members of the armed forces live in a total institution, an environment controlled by authorities of the organization, and where obeying rules is the highest priority of the culture. Similar control emerges also from within the society where its members, even their lives, often depend on the decisions of another. The society and the inherent working conditions create a special kind of social cohesion and pressure that has a strong impact on the behaviour of its members.

Protecting individual warfighters

Creating protective mechanisms for individual warfighters in the turmoil of current technological and pharmacological progression is a very real challenge even in the today's world where most conflicts are local, involving only a fraction of the military resources committed to the global crises of the past. Even so, protective mechanisms that extend to individual level should be made or there is a very real risk that the mistakes of the past repeat.

Preventive arms control treaties, such as the "Convention on the Prohibition of the Development, Production, Stockpiling and Use of Chemical Weapons and on their Destruction" signed in 1993, and the work by organizations such as the "Organisation for the Prohibition of Chemical Weapons"⁵⁰, are steps in the right direction. However, when it comes to emerging technologies and unforeseeable legislative, ethical, and even medical risks, the path is a long and a winding one.

To protect individual warfighters, their superiors and health care personnel operating in the complex terrain of the contemporary conflicts, at least twofold protective mechanisms should be considered. Firstly, multilateral conventions that address the issues revolving around human performance enhancement and modification should be created. The focal point of the discussion should be on nanotechnology and pharmacological implants, not necessarily the external augmentations, such as exoskeletons.

Secondly, countries involved in military modernization programs should open a discussion on who controls the individual warfighter's health status in the time of crisis, and owns the related information. Considering these issues solely from a Scandinavian mind-set brings the individual into the centre and, in most cases, as a principal actor. However, military organizations and cultures differ from one to another highlighting the intricate nature of this fundamental aspect.

Creating a functional whole of legislative and ethical frameworks and complementing it with ICT-artefacts needs balancing and foresight. One possible avenue to follow emerges from enveloping individual's health related decisions behind a "veil of anonymity". In practice, this would mean that no one, besides the beneficiary, would have an automatic and all-inclusive access to health related information on such level that information could be tracked to the level of an individual warfighter without valid justification and consent. However, in this we must acknowledge the potential effects of peer pressure (section 7.3).

⁵⁰ <http://www.opcw.org/> (accessed: 12.10.2012)

On a more fundamental level, this kind of principle should be employed as a part of code of conduct in the institution and enforced accordingly regardless of a potential conflict on the level of authority (e.g. between the beneficiary and their superiors). Without this kind of formality and backing, it is possible that this kind of change could encounter strong resistance from different echelons as it potentially alters familiar operations procedures and disrupts the accustomed balance of power.

Technologically, this kind of principle could be partially implemented using similar encapsulation mechanisms as described in the section 2.4 providing that these mechanisms would not compromise the health of the beneficiary in a life-threatening situation. However, it must be admitted that this kind of approach is a short-sighted, and even a banal one, in relation to the currently changing political and technological landscape.

The mediator and life in the armed forces

Primarily due to the intertwined nature of the lives of warfighters and their peers, the role of a mediator can be seen as having a polarized effect on the health and well-being of the individual warfighter. While the benefits of the role are often linked to better health outcomes, the downsides are not. Theoretically, individual's health and well-being can even be compromised if the control over personal medical devices is given to their peers in a conflict situation. The risk is probably even more evident if these devices can be used for performance enhancement or pharmacological optimization. In this kind of situation, the role of the mediator and the formal role of the trusted individual within the total institution (such as, a combat first aider) become intertwined and a conflict of responsibilities could emerge.

For example, in the case of using investigational new drugs such as in the case of pyridostigmine bromide (FitzPatrick & Zwanziger, 2003), strong peer pressure could have led to a situation where the mediator had ignored the actual beneficiary's refusal to take the drug, therefore violating principles of benevolence and consent. The recent findings of Harinen (2012) also support this line of thought; in some cases the loyalty towards the fellow warfighters can surpass the duties towards the formal organization. In this hypothetical situation, the conflict of responsibilities could occur if the majority of the peers and the beneficiary are at odds on the matter of taking the investigational drug; the strong peer pressure could influence the mediator to act against the will of the beneficiary (in a situation where the beneficiary is not able to make the decision by him- or herself).

On the other hand, there is room for a mediator in the total institutions in similar fashion to other walks of life; providing that one acts outside the confines and

influence of the institution. Another line could be drawn to conflict situations. It should be considered whether a warfighter can act as a mediator to one's peers during an active engagement. In this situation, individual's own decision making in terms of health should not be superseded by a peer, a commanding officer, or anyone who can be regarded as a layperson in terms of medicine, and even in case of an expert, the Hippocratic principles of benevolence and beneficence should be honoured. However, it must be recognized that in an extreme situation, drawing a line between one's duties and moral values may not be so easy to make.

One way forward could be establishing a remote telemonitoring unit, for example on in-theatre level (see figure 7.2), where a health care professional could act as a mediator. In theory, this could enable mediator to operate on a more trustworthy level, without having immediate self-interests at stake. The same principle could be applied to other close-knit teams (such as in fire brigade) where one's condition could have an immediate effect on the performance (and safety) of the other team members.

7.7 Conclusions

The history of armed forces is raked by cautious examples on unethical, or at least debatable, use of drugs, warfare agents and chemical agents. The examples discussed here are merely a take on incidents that have occurred within the field. It can be safely assumed that some of the incidents that have occurred in the past will never see the light of day. The reasons for this probably range from political to those bordering conspiracy theories of fiction. A practical example of this is the North Korea of today; it is probable that the international community will never know what kind of incidents (if any) take place in the most reclusive country in the world.

In order to protect individual warfighters from potential abuse, protection mechanisms should be devised. Some of these can be based on multilateral conventions and agreements, while other mechanisms are more personal in nature. As discussed in the previous section, one example of the latter is the use of a mediator, or a similar trustee that supervises the use of performance enhancement or pharmacological optimization. Even though there is room for the role in a total institution, the actual implementation of the role should be carefully considered due to the potential effect of the peer pressure. Technology can provide some assistance in solving the matter, for example by hiding the health decisions of an individual warfighter behind a "veil of anonymity", and by placing the mediator outside the confines and influence of the institution. However, especially in the immediate area of deployment, or in areas where communication capabilities are limited, these options are rapidly exhausted and

the only viable option is to place a peer in the role (or opt out). This does not mean that these technological means are unsuitable as a whole; their applicability to other total institutions is still an option to be investigated upon.

Before there are external control mechanisms, such as conventions and treaties in place that provide some protection to individuals from unethical and questionable use of emerging technologies, all practically oriented activities within the field of human performance enhancement and alteration should be ceased. In addition, practices related to the use of information originating from individual's personal health status should be subordinated solely to the use of health care professionals, not by that individual's peers or superiors. However, this is an idealistic notion and achieving this on a global scale is, without a doubt, a challenge.

8. Conclusions

Over the course of six chapters, this dissertation presented different perspectives to the near future of the ICT-mediated health and well-being services. In the core of the investigation was the beneficiary; the individual who derives advantages from the services, often resulting in a better health and a longer life. The conceptual origins and the underlying worldview set the stage for the beneficiary who was regarded as the principal actor in terms of one's health and well-being. In line with this approach, health and well-being were not perceived as an absence of illness, but as a constant shift between two: absolute health and absolute illness (salutogenic, as described in Antonovsky, 1979).

Even though this kind of beneficiary-centricity is an on-going global trend, the staging put the research into a slightly provocative position in terms of "traditional" (and often prevalent) paternalistic views to service provisioning, and to technology-centricity that has become a driving factor in many service deployments in the field. Regardless of this juxtaposition, the beneficiary-centric approach should have been seen, if not as a substitute, at least something that complements the way health and well-being services are organized today. To emphasize this aspect, the approach was used to highlight transitions from one end of a scale to another; from care to prevention, liability to responsibility and health centres to homes. In other words, aspects that commonly share the same label, empowerment.

In these kinds of transitions that potentially change the nature of the whole health and well-being industry, the exact positions of the service providers and the users are hard to pinpoint. In order to open up the discussion on the new and emerging services, and to promote the values embedded in the underlying worldview, the following observations were made.

The paradigm shift

A shift from paternalistic (or profession-centric) patient-physician relationship to a more beneficiary-centric one does not necessarily come of one's own accord to everyone. It is probable that there will always be individuals who simply decide not to become active, or "empowered" in terms of their health related affairs. Similarly, it is likely that there will be individuals, digital orphans, who do not have the skills or capabilities to conduct their health related affairs online (i.e. using an ICT-artefact). To support these kinds of groups of people in their use of health and well-being services that are becoming more and more wired every day different measures could be taken.

In addition to mediation which is discussed as a separate topic later on, distinct mechanisms that keep different (minority) groups with some technology literacy within the reach of the information society could be devised. One of these mechanisms is enhanced familiarity, which encompasses an idea of implementing ICT-artefacts using familiar constructs, mechanisms and communication models. Especially in relation to retired elderly people who no longer gain up-to-date information on new technologies and their use, enhanced familiarity could be an aspect that helps the individuals to maintain the acquired level of ability with the technology.

Taking enhanced familiarity into account when implementing ICT-artefacts is primarily a usability issue, and a technological one. It addresses some of the user-side challenges related to the use of artefacts in the field of health and well-being. In order to take a more comprehensive view to the user-side challenges, the investigation should be expanded from technological aspects to the underlying service provisioning mechanisms. The “traditional” provisioning mechanisms primarily base on the patient-physician relationship, where the role of the physician is the dominant one and the one with responsibilities. However, as the field gradually changes highlighting the significance of the beneficiary, the traditional outlook on service provisioning is not sufficient.

In terms of service provisioning, this means that alternative interpretations to the relationship, and especially to the role of the patient, emerge. While the role of the patient will always be present in the field of health and well-being and it will always be a central one, other roles, namely those of the consumer, customer and citizen, will come to the foreground. This change will have an impact on service provisioning, on the overall care pathways, and it will place demands on the use of technology. In terms of service provisioning, the emergence of new roles (and the overall commercialization of the field) will probably force service providers and health policy makers to address how diagnosis and care, articulation and execution, are separated to individual instances in a fashion that the beneficiary has more power in terms of choosing the service provider. This discussion is already taking place in the European Union as cross-border care will be enabled between the member states in the European Union (directive 2011/24/EU).

The effects of this change will not be limited only to the service provisioning. In addition to that of the beneficiary, the overall care pathways should be re-evaluated in order to take into account the changing nature of the service providers as well. Since the beneficiary should have more leverage in terms of service provisioning, the service provider may come from public or private sector, or in principle, from the third sector (i.e. associations and societies) as well. In order to cope with this kind of situation the service providers, especially in the public sector where the situation has been relatively stagnated until late, could benefit from re-evaluation of their current position in the market. In

applying (electronic) service models from other lines of industry and analysing the current situation in terms of value proposition, revenue model and marketing strategy could be of the essence.

Another issue that could be of use in understanding the current situation and taking the changing roles of the beneficiary into account comes from Citizen Pathways. These kinds of voluntary practices that run in conjunction with clinical processes and are implemented with the changing roles of the beneficiary in mind could help in understanding the overall picture; how offered services are aligned in relation to each other, including the ones positioned outside the clinical domain. Naturally, when implemented these practices could offer a practical tool, and a guide, for mediators for managing issues that can be regarded as the mediator's responsibility and an area of specialty.

Demands on technology

The on-going beneficiary-centric paradigm change places demands on the technology as well. In order to support mediation and to enable changes in the underlying service provisioning, the employed technology should provide an integration point in the fragmented health service landscape. On a conceptual level, this means that the employed solution should be able to encapsulate information and provide a mechanism of trust for the beneficiary. This could mean that the access to beneficiary's personal health and well-being information could be defined individually for each mediator and for each service provider. Naturally, this kind of encapsulation should not pose a threat to the beneficiary's health (for example, if access to medication information is limited).

In terms of trust, the near future of technological development will hold interesting opportunities and challenges in the form of anthropomorphic ICT-artefacts. Considering that there seems to be a tendency towards more and more human-like artefacts especially in the field of robotics, and we have a natural tendency to attribute human characteristics and emotional states to inanimate objects, animals and systems, use of anthropomorphic characteristics calls for careful consideration. If these kinds of artefacts become a commonplace practice in the field of electronic health and well-being services, the human-like characteristics should not create an illusion of life potentially creating misconceptions on where the responsibilities lie. For example, a human-like ICT-artefact does not, regardless of its anthropomorphic appearance, bear the same responsibilities as a human actor would.

The same risk regarding an illusion of life applies to the field of teaching and training of medical skills as well. Even though use of high fidelity artefacts can be justified for example when singular tasks, such as non-surgical airway management techniques, are trained, the use of human-like features should not

be used in extremis or without complementing teaching methods. Considering that with the technology of today it is not possible to create a “biomimetic replica” of a human-being, a sole use of anthropomorphic artefacts in training can be seen as a “double-edged sword”; anthropomorphic artefacts are in effect “standardized patients”, such as “30-year old moderately overweight Caucasian male patient experiencing abdominal pain”. However, since there are no extremely anthropomorphized artefacts in the market, this analysis is intended as a speculative one.

Continuing with the theme of technology, another area that holds much promise as an enabler of beneficiary-centricity is Personal Health Information Management. In this area personal information repositories and decision support aids, that base on the on the notion of the beneficiary as the aggregation point, potentially hold a key for solving some of the integration problems that are a bane for the whole industry. These kinds of artefacts, such as the envisioned Coper, should not only integrate information from different sources, they should a) encompass functions that combine public and private information in the form of contextualized information, and b) provide means for integrating individual service transactions as a coherent trajectory in relation to a specific health event or ailment. Naturally, these kinds of artefacts should also support mediation.

At this point, it should be acknowledged that combining public and private information comes with a price. In practice, contextualizing information means that information should be accessible, not only by the artefacts at the beneficiary’s side, but also those on the service provider’s side as well. This can have serious security implications that need addressing. Only after a careful analysis, we know whether the price for this kind of highly personalised information and related services is too steep.

Contextualized information is also of the essence when the function of different decision support aids is considered. In the field of health care, these aids often base on best practices that are formulated on different levels of abstraction with different degrees of (clinical) freedom in mind. Computerization of these practices and using them in different artefacts, such as in the envisioned Coper, is not a trivial matter. In principle, computerization of these kinds of practices could benefit from a role-based implementation. This kind of implementation could combine health information, best practices and their context of use (such as, in the role of a mediator or a parent). With this kind of combination, the applicability of the best practice to the current situation could be understood better. With the roles in mind, the linguistic aspect of the decision support aid could also be taken into account. For example, instead of clinical jargon, a ‘translated’ version of the aid and its results could be offered to a layperson. In Finland, there are already products in development that enable these kinds of

translations⁵¹. Hopefully, when completed, they will be integrated into different EHR solutions in the near future.

As it is in almost every line of business, the use of technology in the field of health care poses some ethical risks and challenges. One of the most complex domains where these kinds of risks potentially have immediate impact on the health, and on the autonomy, of the ‘beneficiary’ is the armed forces. In this area emerging issues such as human performance enhancement, prioritisation of evacuation and even mediation can create severe ethical risks that should be resolved before the use of related technology is even considered. Addressing these kinds of challenges in a pre-emptive manner is an endeavour that could benefit from multilateral conventions, such as in the case of chemical weapons, and from transparency especially in relation to modernization programs which, admittedly, might not be a viable option in the chosen domain.

Mediation and the mediator

In order to complement some shortcomings of technology and underlying service provisioning, the role of a mediator was presented on a conceptual level. This initiated a discourse on the role that continued throughout the dissertation and provided a thread that weaved different angles to the field of ICT-mediated health and well-being services as a whole. Principally, the role was depicted as a contributing enabler to the on-going trends on the field, and as a mechanism of trust. A more detailed inspection to the role revealed aspects that, when put together, could bring a form to a vision that is beneficiary-centricity.

Basically, the mediator is a use-side role. It is based on a notion of a benevolent, technology-literate individual who acts on the behalf of the beneficiary in the field of health and well-being. The primary function of the role is to lend a hand when ICT-artefacts or the electronic services in the field seem alien or unfamiliar; or when one is unable to use them for some reason. Depending on the situation, there can be one or more this kind of auxiliary users and the role can be linked to other, more formal, ones. In order to act in this role, the individual should possess certain skills. In addition to domain-specific skills that may vary from case to case, the only skills that can be seen as a prerequisite for mediation are some degree of a) people skills (ability to answer questions, give advice and to deal with emotionally charged situations, ability to act with discretion, etc.), b) communication and observation skills, c) understanding of medical jargon and concepts, and d) technological literacy.

Partially, following from this diversity and specificity, it is not easy to “step into the shoes” of a mediator. On ethical level, the individual acting in the role

⁵¹ Presentation by Michael Stormbom / Lingsoft Ltd. on September 20, 2013.

should also be impartial, especially in terms of health service provisioning, and have the best interest of the beneficiary in mind. It can be argued, that there is certain business potential in the role. A stand-alone “mediator service”, or extending services of a (private) home care company, could be a welcome addition to the field, and a differing factor for a SME due to its novelty. For example, a subscription-based, high quality counselling service that could address the personal and emotional problems in the way of using the ICT-mediated health and well-being services could not only bring new business opportunities to the field, but they could also be seen as ones contributing to lifelong learning after working life. Alternatively, this kind of service could be implemented as an ancillary service to a premium concierge service where primary care is often offered with a 24/7 access.

It should be kept in mind that there is a potential risk for a conflict of interests in a business model based on empowerment and supporting lifelong learning. Even though in health care the Hippocratic principles of benevolence and beneficence are a priority, a business model that “helps beneficiaries to help themselves” would eventually undermine the client base. On the other hand, this philosophical dilemma applies to the field as a whole regardless of sectors; in an ideal world health care services would put themselves out of business as prevention and self-care would keep everyone in a sufficient health.

Expansion of service models and provisioning mechanisms in the field has underlined the fact that the role of a patient is not always a sufficient unit of analysis when the relationship between the service provider and the beneficiary is investigated. Other interpretations on the role of the beneficiary, such as consumer, customer and citizen, often provide a ground for a richer analysis on the relationship that has changed over the time (and still is) changing. This analysis enriches the analysis on the role of the mediator particularly in transition points; when the role of the beneficiary changes from one to another within or without a health service provider’s process. In these kinds of situations mediation can provide means for “breaking through” the health care provider’s professional jargon and bureaucracy potentially associated with the service provisioning.

In this, the similarities and differences between a case manager and a mediator become more evident. Both roles are principally integrative by nature and they both work in favour of the beneficiary. However, there are some fundamental differences as well that become evident when the changing role of the beneficiary is examined in more detail. The role of a case manager is often limited to the role of the patient, and sometimes even to a singular process such as to a discharge from a hospital after a specific operation. The role of a mediator is not so clear cut and the work often expands to other fields outside a specific patient trajectory or medical condition. This kind of highly personal and

integrative work could benefit from ICT-artefacts, such as the discussed Coper, and electronic services that base on the notion of mediation and shared decision making, and rely on a strong ethical background.

One particular area where a need for openness and adherence to ethical principles is particularly evident is human-computer interaction. As the technology becomes more immersed into everyday life and used in different areas without a second thought, the true nature of the artefacts may become obscured. This is particularly true in the field of anthropomorphized ICT-artefacts where the features (voice, appearance, etc.) of the used artefact are intentionally human-like. In order to provide unambiguous answers to questions like “who” uses a particular artefact for “what” and where the responsibilities in terms of decision making lie, the true nature of the used ICT-artefacts should be explicitly presented.

The use of anthropomorphic features can also be a usability question. For example, if the artefact is used in mediation, in clinical decision making or in patient care and the human-like features are perceived as a distraction in similar fashion to a poor connection in teleconsultation, it may have a negative effect on issues such as adherence to medical advice. This is particularly true if the artefact falls to the “Uncanny Valley”, and the features are “a bit off”. In this kind of situation the interacting human, such as the beneficiary, is not necessarily able to point out the reason for distraction and filter out its negative effects. In order to reduce these kinds of theorized problems originating from ICT-artefacts that have features that are close to a human counterpart, additional measures for making clear and consistent boundaries on human and non-human should be set. These could include use of neutral language void of personal pronoun, or use of body language void of characteristics associated with a natural body language.

Besides technology, the envisioned means that could support mediation included Citizen Pathways, voluntary practices that run in conjunction to clinical processes. When implemented, these pathways could help mediators in managing the overall course of events ensuring that the impact of a clinical event, such as a kneecap surgery, on the level of everyday life is taken into account and controlled. Areas in which the envisioned pathways could support mediation include insurance, deductions and contacting other parties affected by the consequences of the operation (such as, workplace and hobbies). In theory, these pathways could also be used for delegation of tasks between different mediators (multi-mediation), and in clarification of the overall situation (alignment of different mediators).

In principle, Citizen Pathways work also as decision support aids. They help in analysing the current situation and the next step to be taken in relation to the

underlying clinical situation, or current health status of the beneficiary. When formalized and taken into a widespread use, similar pathways are often referred as best practices. Best practices, clinical guidelines, protocols and algorithms often form a foundation for different computerized decision support aids, such as for Clinical Decision Support Systems. One problem with these kinds of solutions is that they rarely take the role of a mediator, or any kind of intermediary (such as, case manager), into account in their function. In order to support mediation, the underlying decision support rationales should be defined and computerized with the role of the mediator in mind.

In the field of electronic health and well-being services, role of a mediator has its shortcomings. Particularly in the case of total institutions, such as armed forces, and similar closely-knit units, the position of the role in terms of group dynamics and hierarchy should be carefully considered. In theory, a mediator with a wrong alignment in relation to the beneficiary may lead to a situation where the well-being, objectives and even the free will can be negatively influenced by the social cohesion and pressure of the peers. Even though there are some primarily ethical and certain technical challenges, related to the role, it has a potential of becoming an enabler in terms of beneficiary-centric health and well-being. Considering the current trends in the field, this kind of role is a welcome addition.

As a whole, mediation and the mediator are pieces that are virtually missing from today's health care service provisioning. Without them, it is practically impossible to activate beneficiaries as a health resource throughout the population. Even though there will always be groups of individuals outside the information society of today, mediation and the mediator hold a key for lowering this number. Economically, these two aspects should be considered as a viable mechanism for lowering health care costs that can be 8-12 % higher amongst less active patients when compared to the more active and knowledgeable ones (Barlow-Oregon, 2013). In today's economic climate, this translates as a significant saving and resources to be allocated where the need is greatest.

Summary

In order to link the research questions to the key findings of this dissertation, the following observations are made.

- 1. How to support aspirations of a willing individual to become an active subject and a principal actor in terms of their health and well-being, and that of their close ones?*

It is possible to support these aspirations on two levels; services and technology. On the level of services, new kind of beneficiary-centric provisioning and service models are needed. This calls for the services that take different roles of the beneficiary into account, and promote individual choosing in the form of a) citizen pathways and b) services where articulation and execution are segregated. On the level of technology, new kinds of solutions, such as “The Coper”, that enable personal health information management are needed. This calls upon solutions that integrated services on the level of the beneficiary, creating a coherent trajectory of health related events and other relevant activities (such as reimbursement) across sectorial borders. In this approach, coherency is also linked to comprehension; information in itself is not a value unless it is understood in the context of one’s health. This implies that information that is contextualized, for example in the form of taxonomical translations, and its use is supported on the level of personal decision making is of the essence. A final measure discussed in this dissertation which aims to support aspirations of a willing individual is mediation and the role of the mediator, missing pieces in the field of health and well-being services.

a. Would mediation support these aspirations (when present) in the context of ICT-mediated health and well-being services?

Mediation and the mediator are the missing pieces that have a potential to bring the digital orphans, and individuals with lacking technological literacy skills to the folds of the contemporary health and well-being services that are becoming more and more electronic by nature. Mediation and mediators can also be seen as factors that complement the shortcomings of the electronic services for example, if the technology has become too unfamiliar and forbidding. In this, seeing the mediator as a medium for lifelong learning is of importance. On a broader context, mediation and the mediator are facilitators that help the beneficiary to take the missing steps in their health related efforts, or take them on beneficiary’s behalf.

b. How could that mediation, if desirable, itself be supported?

Mediation is a complex matter. First of all, the role of the mediator needs acknowledgement on the level of service provisioning. This implies that the beneficiary should be able to appoint one, and the mediator should be able to act in the role. This does not only mean that health care should be seen as a collaborative process that involves other actors besides the service provider and the beneficiary, it also means that issues such as legislation, financing and privacy must be in line with each other. Technologically, mediation calls for mechanisms, such as encapsulation of information that can be employed in order to support the beneficiary, and in some cases anonymity that hides health decision on individual level. As the beneficiaries differ from each other in terms

of health and ailment, and the beneficiaries must be able to cope with these differences, different decision support systems and computerized best practices are to be a tool of the trade, especially in the near future.

On the business side, widespread acknowledgement and adoption of mediation would create new business providing that mediation as a business is aligned properly in terms of health services and beneficiaries. This also calls for revised reimbursement practices especially in the countries where health services are regarded as a basic service provided by the society.

2. What kind of challenges and opportunities emerging technologies bring to the contemporary health and well-being services (especially in the OECD countries)?

Few things, if any, are as delicate as health. In an ideal world, the technology can be seen as an enabler for beneficiary-centric health care and a way towards empowerment. In this lie opportunities for the beneficiary and for the society as a whole. If technology could be harnessed to lessen the economic pressure set on public health sector by enabling willing individuals to take care of their health related affairs, and those of their close ones, the economic impact could be considerable, even though the economic discourse has not been in the centre of this dissertation. On a more down-to-earth level the technology could be harnessed for the service of cross-border health care in the form of language technologies that are context-sensitive and take the user of the information into account.

The technology could be also harnessed for enabling home-based care in the form of computerized best practices and solutions of decision support. It is also possible that technology will provide new and more effective means for knowledge transfer and a better user experience in the form of anthropomorphic artefacts. However, in all these potential avenues lie challenges as well; to what degree the individuals should be encouraged to do their own “diagnoses”, and how human-like artefacts could be discerned from actual humans. These challenges are also relevant when mediation is considered as the user of technology is not necessarily the beneficiary and the context of use may not be a home-like environment but a total institution or a similar closed society. It must be also acknowledged that issues such as trust, privacy, security and ethical use of health related information are all aspects that pose potential challenges to the field of electronic health and well-being services.

Notes on the Methodology

The research presented in the six chapters formed the bulk of this dissertation. These articles were revised and extended from original articles for two reasons. One, the field of health and well-being changes so rapidly that parts of the research had become obsolete. Two, mediation as a theme was not evident in the original articles; in some parts the theme was missing or the discussion was unfocused. The underlying approach, that was already present in the original articles focused on the beneficiary and was coupled with different individual-centric approaches. While these approaches were not promoted as such, their influence could be seen in the articles as the beneficiary was chosen as the principal agent in the research.

Due to the exploratory nature of the dissertation that targets the near future, the work did not follow stylistic patterns or taxonomy of any methodology on a detailed level. However, in terms of demarcation and choosing the locus of research, the work was influenced by case study methodology. The choice of a discursive and narrative approach was made in order to highlight the complexity of the target, and to promote “softer” aspects of health and well-being (morality, quality of life, etc.). The approach also gave room for reporting findings from different projects, each employing a different set of methodological tools and techniques. Due to the differences in the objectives of the projects, each chapter provided a unique insight to the chosen target.

In addition to the use of different approaches in the chapters, mediation and the role of a mediator was brought up and used as a lens in the examination. By taking this role into account, alongside that of a beneficiary, it was possible to pinpoint and address some of the essential changes in the field that would have otherwise been given less attention. The chosen approach, use of a beneficiary as the locus of research, and the role of a mediator as an intertwining theme, offered a way to approach some of the emerging aspects in the near future of the field. This approach, however, had some drawbacks that come to light when the rigor of the research is balanced against the relevance.

Most of the research presented in the six chapters was performed in practically-oriented projects with an emphasis on conceptualization. Hopefully, in terms of relevance, the presented findings reflected the nature of the research and the highlighted issues were truly current ones. In terms of rigor, the chosen approach was probably not the most robust one especially if the formality of research is examined and compared against works that base on a quantitative framework. Metaphorically, this drawback can be seen as a “casting flaw” that originated from the fact that most of the research was conducted in different externally funded projects.

Each project had a different setting and a research group, and different control mechanisms in terms of expected results. For its part, this led to a somewhat fragmented research this was taken account when the original articles were partially rewritten. On the other hand, the research was always practically oriented and served the needs of the participating companies. Therefore applicability of research was always a prime factor. From this viewpoint, the findings will stand their ground against scrutiny.

Future avenues

The work on mediation and on the role of the mediator will continue in different projects over the next years. One of the avenues to be pursued is related to the extension of the original MyWellbeing project that was an important source for the dissertation. From this perspective, the national level project Pumppu (Pump in English) will be in the core of the near future work. The project that started in the turn of 2011-2012 will also look into the Citizen Pathways described in the chapter 4. As a related matter, there is also a need for research on the emerging roles of citizen, customer and consumer, and their interrelationships (including transitions from one to another) especially in relation to new business models (incl. revenue model and marketing methods).

As a closing remark, it can be argued that there is a need and room for mechanisms in the field of ICT-mediated health and well-being services that will enable individuals to take a more active role in terms of their health and well-being, and when needed, that of their close ones. Hopefully this dissertation and the related future work will open up new avenues in this field and support a paradigm shift, and a global trend, from paternalistic and technology-centric service provisioning towards a beneficiary-centric one. This change has born out of necessities of the overall health care system and it will hold keys for addressing multiple challenges in it including those of a shared responsibilities; how to harness the resources of the beneficiary, or the mediator, to carry some of the burden that is weighing down the overall health care system.

References

Abrahan, S. & Chengalur-Smith, I. (2010), "An overview of socialengineering malware: Trends, tactics, and implications", *Technology in Society*, Vol. 32(3), pp. 183-196.

Accenture (2012), "*Clinical Transformation: New Business Models for a New Era in Health Care*", <http://patientadherence.com/?p=755> (accessed: 20.9.2013).

ACM/IEEE-CS (2013), "*Software Engineering Code of Ethics and Professional Practice*", <http://www.acm.org/about/se-code> (accessed: 9.9.2013).

Adams, S.A. and de Bont, A.A. (2007), "Information Rx: prescribing good consumerism and responsible citizenship", *Health Care Analysis*, Vol. 15, pp. 273–290.

Adema, W. & Ladaique, M. (2009), "How expensive is the welfare state?: gross and net indicators in the OECD Social Expenditure Database (SOCX)", *OECD Social, Employment and Migration Working Papers*, No. 92, OECD Publishing.

Agencia peruana de noticias. (2009), "Law on Health Insurance published today", *Agencia peruana de noticias (andina)*, <http://www.andina.com.pe/Ingles/Noticia.aspx?id=mSOVQJu0hxY=> (accessed: 28.9.2010).

Ahlzén, R. (2011), "Illness as unhomelike being-in-the-world? Phenomenology and medical practice", *Medical health care and philosophy*, Vol.14, pp. 323-331.

Akekar, S.M. & Bichile, L.S. (2004), "Doctor patient relationship: changing dynamics in the information age", *Journal of Postgraduate Medicine*, Vol. 50(2), pp. 120-122.

Alanen, S.I., Johannala-Kemppainen, R., Ijäs, J.J., Kaila, M., Klockars, M., Mäkelä, M. & Välimäki, M.A. (2007), "Evaluation of current care effectiveness: a survey of hypertension guideline implementation in Finnish health centres", *Scandinavian Journal of Primary Care*, Vol. 25(4), pp. 232-236.

Alavi, M. and Leidner, D.E. (2005), "Review: knowledge management and knowledge management systems: conceptual foundations and research issues" in

- Nonaka, I. (Ed.) *Knowledge Management: Critical Perspectives on Business and Management*, Routledge, New York, pp. 163-202.
- van Albert, S.A., Bruney, P.F., Matthews, R. & Kunstmanas, L. (2010), "Ballistic impact detection system", U.S. Patent No. 7,660,692, U.S.
- Altmann, J. (2006), "Military Nanotechnology: Potential Applications and Preventive Arms Control", Routledge, New York, U.S.
- Altmann, J. & Gubrud, M.A. (2004a), "Military, arms control, and security aspects of nanotechnology", in: Baird, D., Nordmann, A. & Schummer, J. (Eds.), *Discovering the Nanoscale*, IOS Press, Amsterdam, The Netherlands.
- Altmann, J. & Gubrud, M.A. (2004b), "Anticipating military nanotechnology", *IEEE Technology and Society Magazine*, Vol. 23 (4), pp. 33-40.
- Amoroso, P.J. & Wenger, L.L. (2003), "The human volunteer in military biomedical research", in: Beam, T.E., Sparacino, L.R. & Beam, T.E. (Eds.), *Military Medical Ethics, Volume 2*, Bethesda, Maryland, U.S., pp. 563-660.
- Anderson, R.M. & Funnell, M.M. (2010), "Patient empowerment: myths and misconceptions", *Patient Education and Counseling*, Vol. 79, pp. 277-282.
- Annas, G.J. (1991), "Sounding board: the health care proxy and the living will", *The New England Journal of Medicine*, Vol. 324(17), pp. 1210-1213.
- Antonovsky, A. (1979), "Health, Stress and Coping", Jossey-Bass Publishers, San Francisco.
- Army-technology.com (2010a), "Soldato Futuro – Future Soldier System, Italy", <http://www.army-technology.com/projects/italiansoldiersystem/> (accessed 25.11.2010).
- Army-technology.com (2010b), "Soldato FIST - Future Infantry Soldier Technology, United Kingdom", <http://www.army-technology.com/projects/fist/> (accessed 28.11.2010).
- Arnell, T. (2006), "Preoperative patient instructions", *The Sages Manual*, Part 1, pp. 20-24.
- Arnstein, S.R. (1969), "A ladder of citizen participation", *Journal of the American Planning Association*, Vol. 35(4), pp. 216-224.

Aronkyytö, T., Hallipelto, A. & Kangasharju A. (2010), "Uusi terveydenhuollon rahoitus- ja ohjausjärjestelmä" (Finnish), *Sitran selvityksiä*, Vol. 24.

Askim, J., Fimreite, A.L., Moseley, A. & Holm Pedersen, L. (2011), "One stop shops: An emerging instrument for joining up the 21st century welfare state", *Public Administration*, Vol.89(4), pp. 1451–1468.

Aujoulat, A., d'Hoore, W. & Deccache, A. (2007), "Patient empowerment in theory and practice: polysemy or cacophony?", *Patient Education and Counseling*, Vol. 66, pp. 13-20.

Avery, G. (2000), "Outsourcing public health laboratory services: a blueprint for determining whether to privatize and how", *Public Administration Review*, Vol. 60(4), pp. 330-337.

Aviva (2010), "Time pressures means GPs aren't tackling key health issues", <http://www.aviva.co.uk/media-centre/story/8700/time-pressures-means-gps-arent-tackling-key-health/> (accessed: 9.10.2013).

Axisa, F., Schmitt, P.M., Gehin, C., Delhomme, G., McAdams, E. & Dittmar, A. (2005), "Flexible technologies and smart clothing for citizen medicine, home healthcare, and disease prevention", *IEEE Transactions on Information Technology in Biomedicine*, Vol. 9(3), pp. 325-336.

Azuma, R.T. (1997), "A survey of augmented reality", *Presence: Teleoperators and Virtual Environments*, Vol. 6(4), pp. 355–385.

Bakardjieva, M. (2005), "Internet society: the Internet in everyday life", Sage Publications, London, UK.

Balint, J.B. & Shelton, W. (1996), "Regaining the initiative, forging a new model of the patient-physician relationship", *Journal of the American Medical Association*, Vol. 275(11), pp. 887-891.

Banks, P. (2004), "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.

Bardram, J.E. (2004), "The personal medical unit - a ubiquitous computing infrastructure for personal pervasive healthcare". In Adlam, T., Wactlar, H., & Korhonen, I. (Eds.), *UbiHealth 2004: The 3rd International Workshop on Ubiquitous Computing for Pervasive Healthcare Applications*, Nottingham, UK.

- Barlow-Oregon, J. (2013), “Health care costs more for least ‘activated’”, <http://www.futurity.org/health-care-costs-more-for-least-%E2%80%98activated%E2%80%99/> (accessed 23.9.2013).
- Barrows, H.S. (1993), “An overview of the uses of standardized patients for teaching and evaluating medical skill”, *Academic Medicine*, Vol. 68(6), pp. 443-451.
- Bates, D.W., Kuperman, G.J., Wang, S., Gandhi, T., Kittler, A., Volk, L., Spurr, C., Khorasani, R., Tanasijevic, M. & Middleton, B. (2003), “Ten commandments for effective clinical decision support: making the practice of evidence-based medicine a reality”, *Journal of American Medical Association*, Vol. 10(6), pp. 523-530.
- Battaglio, R.P. & Legge, J.S. (2008), “Citizen support for hospital privatization: a hierarchical cross-national analysis”, *Public Organization Review*, Vol. 8(1), pp. 17-36.
- BBC News (2005), “Robo-docs boost London hospitals”, *BBC News*, 18th May, 2005, <http://news.bbc.co.uk/2/hi/health/4555555.stm> (accessed: 25.2.2011).
- BBC News (2005), “UK GPs top European pay league”, <http://news.bbc.co.uk/2/hi/health/4205616.stm>, (accessed: 9.10.2013).
- Beam, T.E. & Howe, E.G. (2003), “A look toward the future”, in: Beam, T.E., Sparacino, L.R. & Beam, T.E. (Eds.), *Military Medical Ethics, Volume 2*, Bethesda, Maryland, U.S., pp. 831-850.
- Becher, E.C. & Chassin, M.R. (2001), “Improving the quality of health care: who will lead?”, *Health Affairs*, Vol. 20(5), pp. 164-179.
- Beisecker, A.E. & Beisecker, T.D. (1993), “Using metaphors to characterize doctor-patient relationships: paternalism versus consumerism”, *Health Communication*, Vol. 5(1), pp. 41-58.
- Benson, T. (2010), “*Principles of Health Interoperability HL7 and SNOMED*”, Springer Verlag, London, UK.
- van Bommel, J.H. (1997), “Introduction and Overview”, in: van Bommel, J.H. & Musen, M.A. (Eds.), *Handbook of Medical Informatics*, pp. 3-18, Springer-Verlag.

- Bennell, C. & Jones, N. J. (2005), "*The Effectiveness of Use of Force Simulation Training Final Report*", Psychology Department, Carleton University, Ottawa, Canada.
- Berg, M. (1997), "Problems and promises of the protocol", *Social Science & Medicine*, Vol. 44, pp. 1081-1088.
- Bessant, J. & Rush, H. (1995), "Building bridges for innovation: the role of consultants in technology transfer", *Research Policy*, Vol. 24, p. 97-114.
- Best, M. & Neuhauser, D. (2006), "Walter A Shewhart, 1924, and the Hawthorne factory", *Quality and Safety in Health Care*, Vol. 15, pp. 142-143.
- Biagi, F., Cavapozzi, D. & Miniaci, R. (2007), "Technology, skills and retirement", *Marco Fanno Working Papers*, No. 42. <http://www.decon.unipd.it/assets/pdf/wp/20070042.pdf> (accessed: 12.3.2010).
- Bickmore, T.W. & Picard, R.W. (2004), "Towards caring machines", in: *Proceedings of CHI 2004*, April 24-29, 2004, Vienna, Austria, pp. 1489-1492.
- Bigelow, J.H., Fonkych, K., Fung, C. & Wang, J. (2005), "*Analysis of healthcare interventions that change patient trajectories*", Rand Corporation Monograph.
- Blackbourne, L.H. (2010), "Combat damage control resuscitation: today and tomorrow", *HFM-182 Symposium on "Use of Advanced Technologies and new Procedures in Medical Field Operations"*, April 19-21, 2010, Germany.
- Boardman, R. & Sasse, M. (2004), "Stuff goes into the computer and doesn't come out: a cross-tool study of personal information management". In Boardman, R. & Sasse, M.A. (Eds.), *Proceedings of the ACM SIGCHI Conference of Human Factors in Computing Systems in Vienna, Austria, April 24-29, 2004*. ACM Press, New York, pp. 583-590.
- Bogdanos, M.F. (2005), "Joint interagency vooperation: the first step", *Joint Force Quarterly*, 37, pp. 10-18.
- Botsis, T., Demiris, G., Pedersen, S. & Hartvigsen, G. (2008), "Home telecare technologies for the elderly", *Journal of Telemedicine and Telecare*, Vol. 14, pp. 333-337.
- Boulos, M.N.K., Lou, R.C., Anastasiou, A., Nugent, C.D., Alexandersson, J., Zimmermann, G., Cortes, U. & Casas, R. (2009), "Connectivity for healthcare and well-being management: examples of six European projects", *International*

Journal of Environmental Research and Public Health, Vol. 6(7), pp. 1947-1971.

Boyd, D. (2008), "Facebook's privacy trainwreck", *Convergence*, Vol. 14.(1), pp. 13-20.

Bozios, T., Lekakos, G. & Skoularidou, V. (2001), "Advanced techniques for personalized advertising in a digital TV environment: The imedia system", *Proceedings of the 2001 eBusiness and eWork Conference*, Venice, Italy, pp. 1025-1031.

Bray, R.M., Marsden, M.E. & Peterson, M.R. (1991), "Standardized comparisons of the use of alcohol, drugs, and cigarettes among military personnel and civilians", *American Journal of Public Health*, Vol. 81(7), pp. 865-869.

Breazeal, C. (2004), "Social Interactions in HRI: the robot view", *IEEE Transactions of Systems, Man and Cybernetics – Part C: Applications and Reviews*, Vol. 34(3), pp. 181-186.

Breazeal, C. (2010), "The Rise of Personal Robots", *TED Talks*, February 2011, http://www.ted.com/talks/cynthia_breazeal_the_rise_of_personal_robots.html (accessed 1.9.2011).

Breazeal, C., Brooks, C., Gray, J., Hoffman, G., Kidd, C., Lee, H., Lieberman, J., Lockerd, A. & Mulanda, D. (2004), "Humanoid robots as cooperative partners for people", *International Journal of Humanoid Robotics*, Vol. 1(2), pp. 1-34.

Brennan, P.F., Downs, S. & Gasper, G. (2010), "Project HealthDesign: Rethinking the power and potential of personal health records", *Journal of Biomedical Informatics*, Vol. 43(5), pp. S3-S5.

Bresnick, J. (2013), "EHR replacement gone wrong: Who owns patient data?", *EHR Intelligence*, July 23, 2013, <http://ehrintelligence.com/2013/07/23/ehr-replacement-gone-wrong-who-owns-patient-data/> (accessed: 11.9.2013).

Brett, M.H., Doarn, C.R., Rosen, J., Hannaford, B. & Broderick, T.J. (2008), "Evaluation of unmanned airborne vehicles and mobile robotic telesurgery in an extreme environment", *Telemedicine and e-Health*, Vol. 14(6), pp. 539-545.

Bridges, L. (2008), "The changing face of malware", *Network Security*, Vol. 1, pp. 17-20.

Broos, A. & Roe, K. (2006), "The digital divide in the playstation generation: Self-efficacy, locus of control and ICT adoption among adolescents", *Poetics*, Vol. 34, pp. 306-317.

van den Broek, G., Cavallo, F. & Vehrman, C. (2010), "*AALLIANCE Ambient Assisted Living Roadmap*", IOS Press BW, Amsterdam, Netherlands.

Brown, I. & Adams, A.A. (2007), "The ethical challenges of ubiquitous healthcare", *International Review of Information Ethics*, Vol. 8, pp. 53-60.

Brown, K., Stainer, K., Stewart, J., Clacy, R. & Parker, S. (2008), "Older people with complex long-term health conditions. Their views on the community matron service: a qualitative study", *Quality in Primary Care*, Vol. 16(6), pp. 409-417.

Brown, M., Tsagarakis, N. & Caldwell, D.G. (2003), "Exoskeletons for human force augmentation", *Industrial Robot: An International Journal*, Vol. 30(6), pp. 592-602.

Brown, S.A. (2008), "Household technology adoption, use, and impacts: past, present, and future", *Information Systems Frontiers*, Vol. 10(4), pp. 397-402.

Burkhardt, C. (2011), "The trajectory to the "Technological Singularity", In: Bisset, A., Bynum, T.W., Light, A., Lauener, A. & Rogerson, S. (Eds.), *Ethicomp 2011: The Social Impact of Social Computing*, pp. 94-100.

Buttazzo, G. (2001), "Artificial consciousness: utopia or real possibility?", *Computer*, Vol. 34(7), pp. 24-30.

Byman, D. & Waxman, M. (2002), "*The Dynamics of Coercion: American Foreign Policy and the Limits of Military Might*", Cambridge University Press, New York, U.S.

Bødker, S. & Andersen, P.B. (2005), "Complex mediation", *Human-computer interaction*, Vol.20, pp. 353-402.

California Health Care Foundation, (2010), "Consumers and health information technology: a national survey" <http://www.chcf.org/~media/MEDIA%20LIBRARY%20Files/PDF/C/PDF%20ConsumersHealthInfoTechnologyNationalSurvey.pdf> (accessed: 9.9.2013).

Callon, M., Méadel, C. & Rebeharisoa, V. (2002), "The economy of qualities", *Economy and society*, Vol.31(2), pp. 194-217.

Cameron, C. (2010), "How augmented reality helps doctors save lives", *Read Write Web*, 2nd June, 2010, http://www.readriteweb.com/archives/how_augmented_reality_helps_doctors_save_lives.php (accessed: 10.3.2011).

Carpentier, N., Pomey, M., Contreras, R. & Olazabal, I. (2008), "Social care interface in early-stage dementia: practitioners' perspectives on the links between formal and informal networks", *Journal of Aging and Health*, Vol.20(6), pp. 710-738.

Carruthers, P. & Smith, P.K. (1996), "Introduction" in Carruthers, P. & Smith, P.K. (Eds.) *Theories of Theories of Mind*, pp. 1-10, Cambridge University Press, New York, U.S.

Case Management Society of America (2012), <http://www.cmsa.org/Home/CMSA/WhatisaCaseManager/tabid/224/Default.aspx> (accessed: 12.9.2012).

Cassell, J. Bickmore, T., Billingham, M., Campbell, L., Chang, K., Vihjalmsson, H. & Yan, H. (1999), "Embodiment in conversational interfaces: Rea", in: *Proceedings of the SIGCHI Conference on Human factors in Computing Systems: the CHI is the Limit*, ACM, New York, US.

CBRNe World (2007), "BISA begin again", *CBRNe World*, Autumn 2007, p. 1.

Chang, M.K., Cheung, W. & Tang, M. (2013), "Building trust online: Interactions among trust building mechanisms", *Information & Management*, Vol. 50(7), pp. 439-445.

Challis, D. (1999), "Assesment and Care Management: Developments Since the Community Care Reforms", In: Henwood, M. & Wistow, G. (Eds.), *With Respect to Old Age, Research Volume 3*, The Stationery Office, London, UK, pp. 69-86.

Charles, C., Gafni, A. & Whelan, T. (1999), "Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model", *Social Science & Medicine*, Vol. 49, pp. 651-661.

Chaytor, R., Brown, E., Wareham, T. (2006), "Privacy advisors for personal information management", In: *SIGIR Workshop on Personal Information Management*, Seattle, Washington, pp. 28-31.

Chen, I., Phee, S.J., Luo, Z. & Lim, C.K. (2011), "Personalized biomedical devices & systems for healthcare applications", *Frontiers of Mechanical Engineering*, Vol. 6(1), pp. 3-12.

Childress, J.F., & Siegler, M. (1984), "Metaphors and models of doctor-patient relationship: their implications for autonomy", *Theoretical Medicine*, Vol. 5, pp. 17-30.

Cohen, S.B., Grote, K.D., Pietraszek, W.E. & Laflamme, F. (2010), "Increasing Consumerism in Healthcare Through Intelligent Information Technology", *The American Journal of Managed Care*, Vol. 16(12, Spec No), pp. SP37-SP43.

Coiera, E. (2003), *Guide to Health Informatics*, 2nd Edition, Arnold, London.

Coiera, E., Aarts, J. & Kulikowski, C. (2012), "The dangerous decade", *Journal of the American Medical Informatics Association*, Vol. 19(1), pp. 2-5.

Colbert, H.J. & Tack, D.W. (2005), "Augmented reality for battlefield awareness", *Defence Research Report*, Defence Research and Development Canada, Toronto, may 2005.

Connell, J. (2006), "Medical tourism: sea, sun, sand and... surgery", *Tourism Management*, Vol. 27, pp. 1093-1100.

Cornum, R., Caldwell, J. & Cornum, K. (1997), "Stimulant use in extended flight operations", *Airpower Journal*, Spring 1997, pp. 53-58.

Corvoisier, S. & Gropp, R. (2001), "Contestability, technology and banking", *EFA 2002 Berlin Meetings Presented Paper*.

Coulter, A. & Jenkinson, C. (2005), "European patients' views on the responsiveness of health systems and healthcare providers", *European Journal of Public Health*, Vol. 15(4), pp. 355-360.

Cowley, S. J. (2008), "Social Robotics and the person problem", *Proceedings of AISB 2008 Convention. Aberdeen: The Society for the Study of Artificial Intelligence and Simulation of Behaviour*.

Crawford, W. (2006), "Personally controlled health records: the US landscape and the Indivo project", in: Kofod-Petersen, A. & Brasethvik, T. (Eds.), *Proceedings of the International Symposium on Electronic Personal Health Records 2006*, Trondheim, Norway, September 28, 2006, pp. 1-4.

Cress, M.E., Buchner, D.M., Prohaska, T., Rimmer, J., Brown, M., Macera, C., DePietro, L. & Chodzko-Zajko, W. (2006), "Best practices for physical activity programs and behavior counseling in older adult populations", *European Review of Aging and Physical Activity*, Vol. 3(1), pp. 34-42.

Cruz-Jesus, F., Oliveira, T. & Bacao, F. (2012), "Digital divide across the European Union", *Information & Management*, Vol. 46(6), pp. 278-291.

Curry, J.M., McGregor, C. & Tracy, S. (2007), "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.

Deber, R., Kraetschmer, N., Urowitz, S. & Sharpe, N. (2005), "Patient, consumer, client, or customer: what do people want to be called?", *Health Expectations*, Vol. 8(4), pp. 345-351.

DeLange, W. H. (1962), "Conceptions of patient role by patients and staff in a state mental hospital", *Comprehensive Psychiatry*, Vol. 3(3), pp. 174-180.

D'Mello, E. & Rozenblit, J. (2007), "Design for a patient-centric medical information system using XML web services", *Proceedings of the International Conference on Information Technology*. IEEE Computer Society, Washington, DC, pp. 562-567.

Denley, I. & Smith, S.W. (1999), "Privacy in clinical information systems in secondary care", *British Medical Journal*, Vol. 318, pp. 1328-1331.

Deville, J. (2013), "Leaky data: How Wonga makes lending decisions", *Charisma: Consumer Market Studies*, 20th May, 2013, <http://www.charisma-network.net/finance/leaky-data-how-wonga-makes-lending-decisions> (accessed: 12.9.2013).

Diener, E. & Hobbs, N. (2012), "Simulating care: technology-mediated learning in twenty-first century nursing education", *Nursing Forum*, Vol. 47(1), pp. 34-38.

Dixon, T. (1989), "Doctors, patients and relationships", *Canadian Family Physician*, Vol. 35.

Dolan, A. (2004), "Social Engineering", SANS Institute, http://www.sans.org/reading_room/whitepapers/engineering/social-engineering_1365 (accessed_ 19.8.2011).

Duffy, B.R. (2002), "Anthropomorphism and robotics", *The society for the study of artificial intelligence and the simulation of behaviour - AISB 2002*, Imperial College, England, April 3-5, 2002.

Duffy, B.R. (2003), "Anthropomorphism and the social robot", *Robotics and the social robot*, Vol. 42, pp. 177-190.

Duffy, B.R. & Joue, G. (2004), "I, robot being", *Intelligent Autonomous Systems Conference*, Amsterdam, The Netherlands, 2004.

Duffy, B.R. & Joue, G. (2005), "Why Humanoids", *4th Chapter Conference on Applied Cybernetics 2005*, September 7-8, 2005, City University, London, United Kingdom.

Dyche, L. & Swiderski, D. (2004), "The effect of physician solicitation approaches on ability to identify patient concerns", *Journal of General Internal Medicine*, Vol. 20(3), pp. 267-270.

Dykes, P.C., Cook, R., Currie, L.M., Tsuru, S. & Weber, P. (2009), "Integrating personal health information management systems into clinical practice", in: Saranto, K., Brennan, P.F. & Casey, A. (Eds.), *Personal Health Information Management, Tools and Strategies for Citizen's Engagement, Proceedings of the Post-Congress Workshop of the 10th International Nursing Informatics Conference*, pp. 68-82.

Eisenberg, M.B. (2008), "Information literacy: essential skills for the information age", *Journal of Library and Information Technology*, Vol. 28(2), pp. 39-47.

Ek, S. (2008), "Information mastering as a pathway to social equity in health". In: Suomi, R., Apiainen, S. (Eds.) *Promoting Health in Urban Living (WIS 2008)*, TUCS General Publication, Vol. 49, August 2008, pp. 241-249.

Elhauge, E. (2010), "The Fragmentation of U.S. Health Care: Causes and Solutions", Oxford University Press, U.S.

Eloniemi-Sulkava, U. (2009), "Muistisairaan ja hänen perheensä omaishoidon tukeminen", *Presentation in Omahoidon Tukeminen, 18.11.2009*, Helsinki.

Elster, J. (1989), "*The cement of society: a study of social order*", Cambridge University Press, New York, U.S.

Emanuel, E.J., & Emanuel, L.L. (1992), "Four models of the physician-patient relationship", *Journal of the American Medical Association*, Vol. 267(16), pp. 2221-2226.

Engel, J.F., Kollat, D.T. & Blackwell, R.D. (1968), "*Consumer Behavior*", Holt Rinehart & Winston, New York, U.S.

Engelhardt, H.T. Jr. (1996), "*The foundations of bioethics, 2nd Edition*", Oxford University Press, New York, U.S.

Engelhardt, G.V. & Greenhalgh-Stanley, N. (2010), "Home health care and the housing and living arrangements of the elderly", *Journal of Urban Economics*, Vol. 67-(2), pp. 226-238.

Engeström, Y. (2000), "Activity theory as a framework for analyzing and redesigning work", *Ergonomics*, Vol. 43(7), pp. 960-974.

European Commission (2003), "*Applications relating to health, fifth research and development framework programme 1998-2002, final report*", European Commission.

European Commission (2012), "E-Communications Household Survey", *Special Eurobarometer 381 / Wave EB76.4*.

European Parliament (2010), "*Corrigendum to Regulation (EC) No 1924/2006 of the European Parliament and of the Council of 20 December 2006 on nutrition and health claims made on foods (OJ L 404, 30.12.2006)*", <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32006R1924R%2801%29:EN:NOT> (accessed: 22.8.2011).

European Parliament (2014), "The Ubiquitous Digital Single Market", http://www.europarl.europa.eu/aboutparliament/en/displayFtu.html?ftuId=FTU_5.9.4.html (accessed: 7.3.2014).

European Policy Centre (2014), "Establishing the Digital Single Market: Policy recommendations", http://www.epc.eu/dsm/6/Policy_recommendations.pdf (accessed: 6.3.2014).

European Space Agency (2004), "*Italian army using telemedicine in Iraq*", European Space Agency, Telecommunications & Integrated Applications,

http://www.esa.int/esaTE/SEMh2R2VQUd_index_0.html (accessed: 11.10.2010).

European Union (2010), “*The Orphan Drugs Strategy*“, http://ec.europa.eu/health/ph_threats/non_com/rare_6_en.htm (accessed: 21.1.2010).

European Union (2012), *Digital Agenda Scoreboard*, “Life Online”, http://ec.europa.eu/digital-agenda/sites/digital-agenda/files/scoreboard_life_online.pdf (accessed: 27.8.2013).

Eurostat (2011), “*Europe in Figures – Eurostat Yearbook 2011*“, http://epp.eurostat.ec.europa.eu/cache/ITY_OFFPUB/KS-CD-11-001/EN/KS-CD-11-001-EN.PDF (accessed: 29.3.2012).

Eurostat (2012), “Internet use in households and by individuals in 2012”, *Statistics in focus*, 50/2012.

Eurostat (2013a), ”Individuals using the Internet for Internet banking”, <http://ec.europa.eu/eurostat/> (accessed: 28.8.2013).

Eurostat (2013b), ”Individuals - Internet use”, <http://ec.europa.eu/eurostat/> (accessed: 29.8.2013).

Eurostat (2013c), ”Individuals frequently using the Internet”, <http://ec.europa.eu/eurostat/> (accessed: 29.8.2013).

Eurostat (2013d), “Individuals using the Internet for seeking health information”, <http://ec.europa.eu/eurostat/> (accessed: 5.9.2013).

Evenett, S.J. & Hoekman, B.M. (2005), “Government procurement: market access, transparency, and multilateral trade rules”, *European Journal of Political Economy*, Vol. 21, pp. 163-183.

Eysssel, F., Kuchenbrandt, D., Bobinger, S., Ruiter de, L. & Hegel, F. (2012), “If you sound like me, you must be more human!: on the interplay of robot and user features on human-robot acceptance and anthropomorphism”, *HRI '12 Proceedings of the seventh annual ACM/IEEE international conference on Human-Robot Interaction*, pp. 125-126.

Expert Patients Programme (2013), “*Self care reduces costs and improves health - the evidence*”, <http://www.expertpatients.co.uk/sites/default/files/files/Evidence%20for%20the%20Health.pdf> (accessed: 10.10.2013).

Fairweather, N.B. & Rogerson, S. (2001), "A moral approach to electronic patient records", *Medical Informatics & The Internet in Medicine*, Vol. 26(3), pp. 219-234.

Falk-Rafael, A.R. (2001), "Empowerment as a process of evolving consciousness: a model of empowered caring", *Advances in Nursing Science*, Vol. 24 (1), pp. 1-16.

Farrell, C.M. (2000), "Citizen participation in governance", *Public Money & Management*, Vol. 20, pp. 31-37.

Federal Trade Commission. (1986), "Fair Credit Billing Act", <http://www.ftc.gov/os/statutes/fcb/fcb.pdf> (accessed, 3.10.2010).

Finnish Government (2013), "Kuukauden termit", http://vnk.fi/toiminta/kielipalvelut/sanastot/pdf/Kuukauden_termit_2013.pdf (accessed, 6.9.2013).

Finnish Medical Association. (2005), "Ennalta ehkäisevä terveydenhuolto vaarantuu: omalääkärijärjestelmä uhkaa romuttua", *Bulletin of the Finnish Medical Association (Suomen Lääkäriliiton tiedote)*, 2.5.2005, http://www.laakariliitto.fi/uutiset/tiedote.html?opcode=show/news_id=1246/news_db=web_sll2005/type=2 (accessed: 15.6.2010).

FitzPatrick, W.J. & Zwaziger, L.L. (2003), "Defending against biochemical warfare: ethical issues involving the coercive use of investigational drugs and biologics in the military", *The Journal of Philosophy, Science & Law*, Vol. 3.

Fletcher, S. (2007), "Health support to complex warfighting: more than just 'deploy level three'", *Australian Army Journal*, Vol. IV(2), pp. 35-47.

Focsa, M. (2006), "EHR integration of medical algorithms", In: Reichert, A., Mihalas, G., Stoicu-Tivadar, L., Schulz, S. & Engelbrecht, R. (Eds.) *Integrating Biomedical Information: From eCell to ePatient - Proceedings of the European Federation for Medical Informatics Special Topic Conference*, pp. 392-394.

Fong, T., Nourbakhsh, I. & Dautenhahn, K. (2002), "A survey of socially interactive robots", *Robotics and Autonomous Systems*, vol. 42(3-4), pp. 143-166.

Fong, T., Thorpe, C. & Baur, C. (2002), "Robot as a partner: vehicle teleoperation with collaborative control", in: Schultz, A.C. & Parker, L.E. (Eds.), *Multi-Robot Systems: From Swarms to Intelligent Automata, Proceedings of the*

2002 *NRL Workshop on Multi-Robot Systems*, pp. 195-202, Kluwer Academic Publishers, Netherlands.

Ford, S. (2002), “*Bullet-proof vest with distress signaling system*”, U.S. Patent No. 6,349,201, U.S.

Fox, S. & Beijer, J. (2006), *Online banking 2006: surfing to the bank*, http://www.pewinternet.org/~media/Files/Reports/2006/PIP_Online_Banking_2006.pdf (accessed: 21.10.2009).

Fox, S. & Jones, S. (2013), “*51 % of U.S.adults bank online*”, Pew Internet & American Life Project.

Fox News Network (2006), “Pregnant robot teaching med students how to deliver baby”, *Fox News Network*, 17th April, 2006, <http://www.foxnews.com/story/0,2933,191971,00.html> (accessed: 25.2.2011).

Friedl, K.E. & Allan J.H. (2004), “USARIEM: physiological research for the warfighter”, *Army Medical Department Journal*, 4Q, pp. 33-43.

Friedman, C.P., Iakovids, I., Debenedetti, L. & Lorenzi, N.M. (2009), “Across the Atlantic cooperation to address international challenges in eHealth and health IT: Managing toward a common goal”, *International Journal of Medical Informatics*, Vol. 78, pp. 778-784.

Frosch, D.L., Bhatnagar, V., Tally, S., Hamori, C.J. & Kaplan, R.M. (2008), “Internet patient decision support - a randomized controlled trial comparing alternative approaches for men considering prostate cancer screening”, *Archives of Internal Medicine*, Vol. 168(4), pp. 363-369.

Frosch, D.L., Krueger, P.M., Hornik, R.C., Cronholm, P.F. & Barg, F.K. (2007), “Creating demand for prescription drugs: a content analysis of television direct-to-consumer advertising”, *Annals of Family Medicine*, Vol. 5(1), pp. 6-13.

Gaba, D.M. & DeAnda, A. (1988), “A comprehensive anesthesia simulation environment: re-creating the operating room for research and training”, *Anesthesiology*, Vol. 69, pp. 387-394.

Gafni, A. & Charles, C. (2009), “The physician-patient encounter: an agency relationship?”, in: Edwards, A. & Elwyn, G. (Eds.), “*Shared decision-making in health care: achieving evidence-based patient choice, 2nd Edition*”, Oxford University Press, New York, U.S., pp. 73-78.

Gaßner, K. & Conrad, M. (2010), “ICT enabled living for elderly: a status-quo analysis on products and the research landscape in the field of Ambient Assisted Living (AAL) in EU-27”, Institute for Innovation and Technology (IIT).

Gaventa, J. (2004), “Towards participatory governance: assessing the transformative possibilities”, in: Hickey, J. & Mohan, G. (Eds.) *Participation: from tyranny to transformation? Exploring new approaches to participation in development*, pp. 25-41, Zed Books, London.

Gee, F.C., Browne, W.N. & Kawamura, K. (2005), “Uncanny valley revisited”, *IEEE Workshop on Robots and Human Interactive Communication*, pp. 151-157.

Gilbert, G.R. & Beebe, M.K. (2010), “United States Department of Defense research in robotic unmanned systems for combat casualty care”, Army Medical Research and Materiel Command Fort Detrick MD Telemedicine and Advanced Tech Research Center.

Gilleard, C. & Higgs, P. (2002), “The third age: class, cohort or generation?”, *Ageing and Society*, Vol. 22, pp. 369-382.

van Ginneken, A.M. (2002), “The computerized patient record: balancing effort and benefit”, *International Journal of Medical Informatics*, Vol. 65, pp. 97-119.

Glaser, R., Lauterbach, C., Savio, D., Schnell, M., Karadal, S. & Weber, W. (2005), “Smart carpet: a textile-based large-area sensor network”, http://www.future-shape.com/publications_lauterbach/SmartFloor2005.pdf (accessed: 4.11.2009).

González-Valenzuela, S., Chen, M., Leung, V.C.M. (2011), “Mobility support for health monitoring at home using wearable sensors”, *IEEE Transactions on Information Technology in Biomedicine*, Vol. 15(4), pp. 539-549.

Goh, K.W., Kim, E., Lavanya, J., Kim, Y. & Soh, C.B. (2006), "Issues in implementing a knowledge-based ECG analyzer for personal mobile health monitoring", *Engineering in Medicine and Biology Society, 2006. EMBS '06. 28th Annual International Conference of the IEEE*, pp. 375-378.

Gong, L. (2002), “Towards a theory of social intelligence for interface agents”, *Workshop on Virtual Conversational Characters: Applications, Methods, and Research Challenges*, 29th November 2002, Melbourne, Australia.

Graham, I. (2010), “*Robot Technology*”, Evans Brothers, Ltd. London, U.K.

Gregor, P., Newell, A.F. & Zajicek, M. (2002), "Design for dynamic diversity – interfaces for older people", *Proceedings of the fifth international ACM conference on Assistive technologies*, pp. 151-156.

Griffin, J. (2002), "Developing world drugs", *Triple Helix*, No. 19, Spring 2002, pp. 14-15.

Griffith, Q.L. (1997), "*Impact sensing vest*", U.S. Patent No. 5,636,378, U.S.

Grol, R. & Grimshaw, J. (2003), "From best evidence to best practice: effective implementation of change in patients' care", *The Lancet*, Vol. 362, pp. 1225-1230.

Grumbach, C. & Mieth, K. (2008), "The consumer healthcare market: a new booming market to conquer", Finpro White Paper.

Guizzo, E. (2010), "Meet Geminoid F, a Smiling Female Android", *IEEE Spectrum*, <http://spectrum.ieee.org/automaton/robotics/humanoids/040310-geminoid-f-hiroshi-ishiguro-unveils-new-smiling-female-android> (accessed: 4.8.2011).

Guizzo, E. & Goldstein, H. (2005), "The rise of the body bots", *IEEE Spectrum*, Vol. 42, pp. 50-56.

Haddon, L. & Livingstone, S. (2012), "*EU kids online: national perspectives*", The London School of Economics and Political Science, London, UK.

Halevy, A. "Game-changing interoperability for healthcare: Bringing semantically harmonized clinical information into provider workflows from disparate health information technologies", *Emerging Technologies for a Smarter World (CEWIT), 2011 8th International Conference & Expo*, New York, 2-3 Nov. 2011.

Hampton, J.R. (1997), "Evidence-based medicine, practice variations and clinical freedom", *Journal of Evaluation in Clinical Practice*, Vol. 3(2), pp. 123-131.

Handschu, R., Scibor, M., Willaczek, B., Nüchel, M., Heckmann, J.G., Asshoff, D., Belohlavek, D., Erbguth, F. & Schwab, S. (2008), "Telemedicine in acute stroke: remote video-examination compared to simple telephone consultation", *Journal of Neurology*, Vol. 255(11), pp. 1792-1797.

Hargrave, A.M., Moratille, B., Vahtivouri, S., Venter, D., de Vries, R., Burdick, B., Coakley, C. & Richardson, J. (2008), *The Internet Literacy Handbook*, 3rd

Edition, http://www.coe.int/t/dghl/standardsetting/internetliteracy/hbk_EN.asp (accessed: 9.11.2009).

Harvey, G., Loftus-Hills, A., Rycroft-Malone, J., Titchen, A., Kitson, A., McCormack, B. & Seers, K. (2002), "Getting evidence into practice: the role and function of facilitation", *Journal of Advanced Nursing*, Vol. 37(6), pp. 577-588.

Harinen, O. (2012), "*Sotilaiden Epäviralliset Ryhmänormit Kolmessa Jalkaväkikompanjassa Koskeneessa Empiirisessä Tutkimuksessa (Knut Pipping, Roger Little, John Hockey)*" (Finnish), Doctoral Dissertation, Maanpuolustuskorkeakoulu, Käyttäytymistieteiden laitos, Vol. 1(3).

Harvard Business Review (2012), "*Megatrends in Global Health Care*", <http://hbr.org/web/extras/insight-center/health-care/globaltrends/13-slide> (accessed: 18.12.2012).

Haux, R., Ammenwerth, E., Herzog, W., & Knaup, P. (2002), "Health care in the information society. A prognosis for the year 2013", *International Journal of Medical Informatics*, Vol. 66, pp. 3-21.

Haynes, R.B., Deveraux, P.J. & Guyatt, G.H. (2002), "Clinical expertise in the era of evidence-based medicine and patient choice", *Evidence Based Medicine*, Vol. 7(2), pp. 36-28.

Hays, R.T. (1980), "Simulator fidelity: a concept paper", *Technical Report 490*, Research institute for the behavioral and social sciences, U.S. Army.

Health Canada (2009), *Consumers warned against buying fraudulent H1N1 flu virus products online*, http://www.hc-sc.gc.ca/ahc-asc/media/advisories-avis/_2009/2009_179-eng.php (accessed: 11.11.2009).

Heikkilä, T. (2007), "*Nuorten lääkärrien uravalintaan vaikuttavat tekijät*", Presentation in the Yleislääkäripäivät (Finnish), 29.11.2007.

Hellstén, M., Harriet, M. & Anttonen, H. (2003), "Älykkyyttä sotilaan kylmävaatetukseen, Älymatine projektin loppuraportti", *Kuitumateriaalitekniikka, raportti 7* (Finnish), Tampereen teknillinen yliopisto, 2003.

Hemp, P. (2006), "Avatar-based marketing", *Harvard Business Review*, Vol. 84(6), pp. 48-57.

Herr, H. (2009), “Exoskeletons and orthoses: classification, design challenges and future directions”, *Journal of Neuroengineering and Rehabilitation*, Vol. 6(21), pp. 1-9.

Hietala, H., Ikonen, V., Korhonen, I., Lähteenmäki, J., Maksimainen, A., Pakarinen, V., Pärkkä, J. & Saranummi, N. (2009), *FeelGood – Ecosystem of PHR based products and services*, Research Report, VTT.

Hobbes, T. (1651), “*Leviathan*”, Forgotten Books, 2008.

Hoffman, B. (2006), “Insurgency and counterinsurgency in Iraq”, *Studies in Conflict & Terrorism*, Vol. 29(2), pp. 103-121.

Holloway, D., Green, L. & Livingstone, S. (2013), “*Zero to eight. young children and their internet use*”, LSE, London: EU Kids Online.

Hollerman, J.J., Fackler, M.L., Coldwell, D.M. & Ben-Menachem, Y. (1990), “Gunshot wounds: 1. bullets, ballistics, and mechanisms of injury”, *American Journal of Roentgenology*, Vol. 155, pp. 685-690.

Hovorka, R., Chassin, L.J., Wilinska, M.E., Canonino, V., Akwi, J.A., Federici, M.O., Massi-Benedetti, M., Hutzli, I., Zaugg, C., Kaufman, H., Both, M., Vering, T., Schaller, H.C., Schaupp, L., Bodenlenz, M. & Pieber, T.R., (2004), “Closing the loop: the Adicol experience”, *Diabetes Technology & Therapeutics*, Vol. 6(3), pp. 307-318.

Howard, P., Jonkers-Schuitema, C., Furniss, L., Kyle, U., Muehlebach, S., Ödlund-Olin, A., Page, M. & Wheatley, C. (2006), “Managing the patient journey through enteral nutritional care”, *Clinical Nutrition*, Vol. 25, pp. 187-195.

Howells, J. (2006), “Intermediation and the role of intermediaries in innovation”, *Research Policy*, Vol. 35, pp. 715-728.

Hämäläinen, M., Iinatti, J. & Kohno, R. (2011), “Wireless Communications in Healthcare: Recent and Future Topics”, *ISABEL '11 Proceedings of the 4th International Symposium on Applied Sciences in Biomedical and Communication Technologies*, ACM, New York, U.S.

IFR (2013), “Service Robot Statistics”, <http://www.ifr.org/service-robots/statistics/>, (accessed: 16.9.2013).

Iivari, J., Hirschheim, R. & Klein, H.K. (2004), "Towards a distinctive body of knowledge for Information Systems experts: coding ISD process knowledge in two IS journals", *Information Systems Journal*, Vol. 14, pp. 313-342.

Iltalehti (2013), "Lääkärit pelkäävät: Tietojärjestelmät uhka potilasturvallisuudelle", 9.1.2013 (Finnish).

International Telecommunication Union (1993), "Telemedicine and Developing Countries, ITU-D Study Groups, Document 2/155 (rev. 2)", International Telecommunication Union.

Israel Ministry of Foreign Affairs. (1995), "National health insurance", http://www.mfa.gov.il/MFA/MFAArchive/1990_1999/1998/7/National%20Health%20Insurance (accessed: 28.9.2010).

ITEA (2006), "Technology literacy for all: a rationale and structure for the study of technology", 2nd Edition, International Technology Education Association, Reston, U.S.

Iversen, L. (2006), "Speed, Ecstasy, Ritalin: The Science of Amphetamines", Oxford University Press, New York, U.S.

Jaakkimainen, R.L., Schultz, S., Glazier, R.H., Abrahams, C. & Verma, S. (2012), "Tracking family medicine graduates. Where do they go, what services do they provide and whom do they see?", *BioMed Central Family Practice*, Vol. 13.

Jagatic, T.N., Johnson, N.A., Jakobsson, M. & Menczer, F. (2007), "Social phishing", *Communications of the ACM*, Vol. 50(10), pp. 94-100.

Jones, F.D. (1985), "Sanctioned use of drugs in combat", *Psychiatry*, Vol. 6. Plenum Publishing Corporation. pp. 489-494.

Jones, S. & Fox, S. (2009), *Generations online in 2009*, http://www.pewinternet.org/~media/Files/Reports/2009/PIP_Generations_2009.pdf (accessed: 16.10.2009).

Jordan, G.M., Silsby, J., Bayley, G. & Cook, T.M. (2007), "Evaluation of four manikins as simulators for teaching airway management procedures specified in the Difficult Airway Society guidelines, and other advanced airway skills", *Anaesthesia*, Vol. 62, pp. 708-712.

Joumard, I., André, C. & Nicq, C. (2010), "Health care systems: efficiency and institutions", *Economics Department Working Paper*, No. 769.

Jowett, B. (1892), "The Works of Plato", Oxford University Press, U.K.

Jääntti, S. (2008), "*Citizen's choices of health services: the three-stage model of choice concerning physician services in the public and private sectors*", doctoral dissertation, university of Kuopio.

Kaba, R. & Sooriakumaran, P. (2007), "The evolution of doctor-patient relationship", *International Journal of Surgery*, Vol. 5, pp. 57-65.

Kaelber, D.C., Jha, A.K., Johnston, D., Middleton, B., & Bates, D.W. (2008), "A research agenda for personal health records (PHRs)", *Journal of the American Medical Informatics Association*, Vol. 15 (6), pp. 729-736.

Kalb, P.E. (1999), "Health care fraud and abuse", *Journal of the American Medical Association*, Vol. 282(12), pp. 1163-1168.

Kaptelinin, V. (1996), "Computer-mediated activity: functional organs in social and developmental contexts", in: Nardi, B.A. (Ed.), *Context and Consciousness: Activity Theory and Human-computer Interaction*, pp. 45-69, Massachusetts Institute of Technology.

Kaptelinin, V., Kuutti, K. & Bannon, L. (1995), "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.

Kathol, R.G., Lattimer, C., Gold, W., Perez, R. & Gutteridge, D. (2011), "Creating clinical and economic "wins" through integrated case management: lessons for physicians and health system administrators", *The Journal of Ambulatory Care Management*, Vol. 34(3), pp. 140-151.

Katz, R.D. (2001), "Friendly fire: the mandatory military anthrax vaccination program", *Duke Law Journal*, Vol. 50(6), pp. 1835-1865.

Kaveny, C.M. (1999), "Commodifying the polyvalent good of health care", *Journal of Medicine and Philosophy*, Vol. 24(3), pp. 207-223.

Kelly, J. (2010), "Battlefield conditions: different environment but the same duty of care", *Nursin Ethics*, Vol. 17(5), pp. 636-645.

Khazanchi, D. & Munkvold, B.E. (2000), "Is information systems a science? An inquiry into the nature of the information systems discipline", *The DATA BASE for Advances in Information Systems*, Vol. 31(3), pp. 24-42.

Khazanchi, D. & Munkvold, B.E. (2003), "On the rhetoric and relevance of IS research paradigms: a conceptual framework and some propositions", *Proceedings of the 36th Hawaii International Conference on System Sciences (HICSS'03)*.

Kieval, H.J. (1997), "Pursuing The Golem of Prague: jewish culture and the invention of tradition", *Modern Judaism*, Vol. 17, pp. 1-23.

Kilcullen, D. (2004), "*Future Land Operation Concept, Complex Warfighting*", Department of Defence, Canberra.

Kim, D.J., Ferrin, D.L. & Rao, H.R. (2008), "A trust-based consumer decision-making model in electronic commerce: the role of trust, perceived risk, and their antecedents", *Decision Support Systems*, Vol. 44(2), pp. 544-564.

Kim, E.H., Stolyar, A., Lober, W.B., Herbaugh, A.L., Shinstrom, S.E., Zierler, B.K., Soh, C.B. & Kim, Y.(2009), "Challenges to using an electronic personal health record by a low-income elderly population", *Journal of Medical Internet Research*, Vo.11(4), e44.

Kinkade, R.G. & Wheaton, G.R. (1972), "Training device design", in: VanCott, H.P. & Kinkade, R.G. (Eds.), *Human Engineering Guide to Equipment Design, Revised Edition*, American Institutes for Research, Washington D.C., U.S., pp. 67-700.

Kinney, D. (1999), "Is it Standard Man, or Stan D. Ardman?", *Los Angeles Times*, 1st August, 1999, <http://articles.latimes.com/1999/aug/01/news/mn-61471> (accessed: 10.3.2011).

Kirk, J. (2007), "Microsoft falls victim to shady 'scareware'", *Infoworld*, February 20, 2007, <http://www.infoworld.com/d/security-central/microsoft-falls-victim-shady-scareware-605> (accessed 20.1.2010).

Kouri, P., Palmén, M., Reijonen, P. & Wuorisalo, J. (2010), "Käyttäjien tarpeet ja Pärjäimen käyttömahdollisuudet", in: Meristö, T., Muukkonen, P., Nurminen, M.I. & Tuohimaa, H. (Eds.), *Pärjään, OmaHyvinvointi-hankkeen loppuraportti*, pp. 10-18.

Krause, J.H. (2013), "Kickbacks, Self-Referrals, and False Claims: The Hazy Boundaries of Health-care Fraud", *Chest*, Vol. 144(3), pp. 1045-1050.

Krohn, R. (2007), "The consumer-centric personal health record – it's time", *Journal of Healthcare Information Management*, Vol. 21 No. 1, pp. 20-23.

Kuntaliitto (2012), ”*OECD Health Data 2012 taloustietoja*”, <http://www.kunnat.net/fi/tietopankit/tilastot/soster/oecd-health-data/Sivut/default.aspx>, (accessed: 19.9.2012).

Kurzweil, R. (2005), ”*The Singularity is Near: When Humans Transcend Biology*”, Penguin Group, U.S.

Laamanen, E., Ala-Kauhaluoma, M. & Nouko-Juvonen, S. (2002), ”Kuntien ja kolmannen sektorin projektiyhteistyö sosiaali- ja terveydenhuollossa: Kokemuksia ja kehittämisajatuksia”, *Acta*, Vol. 143 (Finnish).

Laamanen, R., Simonsen-Rehn, N., Suominen, S., Øvretveit, J. & Brommels, M. (2008), ”Outsourcing primary health care services – how politicians explain the grounds for their decisions”, *Health Policy*, Vol. 88, pp. 294-307.

Lahtiranta, J. (2008), ”Emerging roles in eHealth”, in: Suomi, R. & Apiainen, S. (Eds.), *Promoting Health in Urban Living (WIS 2008)*, TUCS General Publication, Vol. 49, pp. 141-152.

Lahtiranta, J. & Kimppa, K. (2008), ”Responsibility in electronic health: what muddles the picture”, in: Duquenoy, P., George, C., and Kimppa, K. (Eds.), *Ethical, Legal, and Social Issues in Medical Informatics*, Hershey, New York, pp.113-138.

Lahtiranta, J. & Koskinen, J. (2013), ”Electronic health services for cardiac patients: a salutogenic approach”, *Finnish Journal of eHealth and eWelfare*, Vol. 5(2-3).

Lahtiranta, J. & Nurminen, M.I. (2010), ”Pärjäimen ominaisuudet”, in: Meristö, T., Muukkonen, P., Nurminen, M.I. & Tuohimaa, H. (Eds.), *Pärjään, OmaHyvinvointi-hankkeen loppuraportti*, pp. 19-23.

Lain-Entralgo, P. (1969), ”*Doctor and patient*”, World University Library, London, U.K.

Lam, D.M. (2007), ”Telemedicine in the context of force protection”, *Force Health Protection (RTO-EN-HFM-137, AC/323(HFM-137)TP/67)*, Paris: NATO Research and Technology Organisation, March 2007, pp. 11-1–11-12.

Lam, D.M. & Poropatich, R.K. (2008), ”Telemedicine deployments within NATO military forces: a data analysis of current and projected capabilities”, *Telemedicine and eHealth*, Vol. 14(9), pp. 946-951.

- Laudon, K.C. & Traver, C.G. (2009), *E-Commerce: Business, Technology, Society, 5th Edition*, Prentice Hall, New Jersey.
- Lehto, J. (2000), "Saumaton palveluketju mosaiikkimaisessa järjestelmässä", in: Nouko-Juvonen, S., Ruotsalainen, P. & Kiikala, I. (Eds.), *Hyvinvointivaltion palveluketjut* (Finnish), Tammi, Helsinki, Finland, pp. 33-48.
- Leino-Kilpi, H. (2004), "Guest editorial: we need more nursing ethics research", *Journal of Advanced Nursing*, Vol. 45 No. 4, pp. 345-346.
- Lemire, F. (2013), "Generational malaise", *Canadian Family Physician*, Vol. 59(5), p. 588.
- Levitt, T. (1960), "Marketing Myopia", *Harvard Business Review*, July - August, 1960.
- Lewis, N. (2010), "Army using telemedicine for healthcare delivery", *InformationWeek Healthcare Newsletter*, UBM TechWeb, <http://www.informationweek.com/news/healthcare/patient/showArticle.jhtml?articleID=225701968> (accessed: 11.10.2010).
- Lewis, D., Chang, B.L. & Friedman, C.P. (2005), "Consumer health informatics", in: Lewis, D., Eysenbach, G., Kukafka, R., Stavri, P.Z. & Jimison, H. (Eds.), *Consumer Health Informatics: Informing Consumers and Improving Health Care*, Springer, New York, pp. 1-7.
- Liang, B.A. & Mackey, T. (2011), "Commentary: direct-to-consumer advertising with interactive internet media: global regulation and public health issues", *The Journal of American Medical Association*, Vol.305(8), pp. 824-825.
- Lieberman Y. & Stashevsky, S. (2002), "Perceived risks as barriers to Internet and e-Commerce usage", *Qualitative Market Research, An International Journal*, Vol. 5(4), pp. 291-300.
- Liu, L.S. & Hayes, G.R. (2010), "Evaluating the usefulness and usability of collaborative personal health record systems", *CSCW 2010; Workshop on Research in Healthcare: Past, Present, and Future*. Savannah, GA.
- Locke, J. (1960), "*The second treatise on civil government*", <http://www.constitution.org/jl/2ndtreat.htm> (accessed: 28.9.2010).
- Looney, H.F., Jacobson, M. & Redding, M.J. (2005), "*Personalized Marketing Architecture*", U.S. Patent Application No. 11/203,444, Publication No. 2006/0074769, U.S.

- Lovett, K.M. & Mackey, T.K. (2013), "Online threats to senior safety: The direct-to-consumer medical marketplace and elder Abuse", *NAELA Journal*, Vol.9(1).
- Maarse, H. (2006), "The privatization of health care in Europe: an eight-country analysis", *Journal of Health Politics, Policy and Law*, Vol. 31(5), pp. 981-1014.
- Mail Online (2007), "Japan's latest invention: The dental training robot that can 'feel pain'", *Mail Online*, 30th November, 2007, <http://www.dailymail.co.uk/news/article-498530/> (accessed 10.3.2011).
- Malandraki, G.A., Markaki, V., Georgopoulos, V.C., Bauer, J.L., Kalogeropoulos, I. & Nanas, S. (2013), "An international pilot study of asynchronous teleconsultation for oropharyngeal dysphagia", *Journal of Telemedicine and Telecare*, Vol. 19(2), pp. 75-79.
- Manring, M.M., Hawk, A., Calhoun, J.H. & Andersen, R.C. (2009), "Treatment of war wounds: a historical review", *Clinical Orthopaedics and Related Research*, Vol. 467(8), pp. 2168-2191.
- Maran, N.J. & Glavin, R.J. (2003), "Low- to high-fidelity simulation – a continuum of medical education?", *Medical Education*, Vol. 37(Suppl. 1), pp. 22-28.
- Marescaux, J., Leroy, J., Gagner, M., Rubino, F., Mutter, D., Vix, M., Butner, S.E. & Smith, M.K. (2001), "Transatlantic robot-assisted telesurgery", *Nature*, Vol. 413, pp. 379-380.
- Markle Foundation (2013), "*Common Framework for Networked Personal Health Information: Overview and Principles*", Markle Foundation.
- Marti, S.J.W. (2005), "*Autonomous interactive intermediaries: social intelligence for mobile communication agents*", doctoral dissertation, Massachusetts Institute of Technology, June 2005.
- Martin, C.A. (2000), "EU-funded project on the elderly", *Nutrition & Food Science*, Vol. 30(6), pp. 279-282.
- McDaid, D. & Park, A. (2011), "Online health: untangling the web", *Bupa Health Pulse 2010*.

McLaughlin, H. (2009), "What's in a name: client, patient, customer, consumer, expert by experience, service user – what's next?", *British Journal of Social Work*, Vol. 39, pp. 1101-1117.

McManus, J., Salinas, J., Morton, M., Lappan, C. & Poropatich, R. (2008), "Teleconsultation program for deployed soldiers and healthcare professionals in remote and austere environments", *Prehospital and Disease Medicine*, Vol. 23(3), pp. 210-216.

Mead, P. (2000), Clinical guidelines: promoting clinical effectiveness or a professional minefield? *Journal of Advanced Nursing*, Vol. 31(1), 110-116.

Mensing, C., Boucher, J., Cypress, M., Weinger, K., Mulchamy, K., Barta, P., Hosey, G., Kopher, W., Lasichak, A., Lamb, B., Mangan, M., Norman, J., Tanja, J., Yauk, L., Wisdom, K. & Adams, C. (2002), "National standards for diabetes self-management education", *Diabetes Care*, Vol. 25(1), pp. 140-147.

Merriam-Webster Dictionary (2012), <http://www.merriam-webster.com/dictionary/case%20study>, (accessed: 22.8.2012).

Meristö, T., Muukkonen, P., Nurminen, M.I. & Tuohimaa, H. (Eds.), *OmaHyvinvointi-hankkeen loppuraportti*, Turku, pp. 19-23 (Finnish).

Middleton, S., Barnett, J. & Reeves, D. (2001), "What is an integrated care pathway", *What is...? Series*, Vol. 3(3), Hayward Group Plc, U.K.

Miettinen, R. (1999), "The riddle of things: Activity theory and actor-network theory as approaches to studying innovations", *Mind, Culture and Activity*, Vol. 6(3), pp. 170-195.

Miles, S.H. (2004), "Abu Ghraib: its legacy for military telemedicine", *Lancet*, Vol. 364, pp. 725-729.

Ministry of Finance (2013), "A Structural Policy Programme to Strengthen Conditions for Economic Growth and Bridge the Sustainability Gap in General Governmental Finances", <http://valtioneuvosto.fi/tiedostot/julkinen/budjetti/290813/Structural-policy-programme.pdf> (accessed: 25.9.2013).

Ministry of Justice, Finland (2007), *"The Constitution of Finland"*.

Ministry of Social Affairs and Health (2012), http://www.stm.fi/stm/toiminta_ja_talous/palvelujen_menot (Finnish, accessed: 7.8.2012).

Moilanen, J., Knape, N., Häkkinen, U., Hujanen, T. & Matveinen, P. (2008), "Terveysthuollon Menot ja Rahoitus", Stakesin Raportteja, Vol. 16. (Finnish).

Moline, J. (1997), "Virtual reality for health care: a survey", in: Riva, G. (Ed.), "Virtual reality in neuro-psycho-physiology: cognitive, clinical and methodological issues in assessment and rehabilitation", pp. 3-34.

Moravec, H. (1988), "Mind children: the future of robot and human intelligence", Harvard University Press, U.S.

Mori, M. (1970), "The Uncanny Valley" (translated by MacDorman, K.F. & Minato, T.), *Energy*, Vol. 7(4), pp. 33-35.

Morris, T.J., Pajak, J., Havlik, F., Kenyon, J. & Calcagni, D. (2006), "Battlefield medical information system – tactical (BMIST): The application of mobile computing technologies to support health surveillance in the Department of Defense", *Telemedicine and e-Health*, Vol. 12(4), pp. 409-416.

Mueller, H. & Kaufmann, E.L. (2001), "Wellness tourism: Market analysis of a special health tourism segment and implications for the hotel industry", *Journal of Vacation Marketing*, Vol. 7(1), pp. 5-17.

Murdoch, J. (1998), "The spaces of actor-network theory", *Geoforum*, Vol. 29(4), pp- 357-374

Müller, H., Hanbury, A. & Shorbaji, Al. N. (2013), "Health Information Search to Deal with the Exploding Amount of Health Information Produced", *Journal of Information in Medicine*, Vol. 51(6), pp. 516-518.

Mäkelä, M., Sainio, S., Åström, M. & Bergström, M. (1998), "Local population responsibility in Finnish health centres in 1989-1993", *European Journal of Public Health*, Vol. 8(4), pp. 313-318.

Männikkö-Barbutiu, S. (2002), "Networking for accessibility: elderly people and new technology", in: Miesenberger, K., Klaus, J., & Zagler, W. (Eds.) *Computers helping people with special needs*, LNCS 2398, Springer, Berlin Heidelberg, New York, U.S.

Nass, C., Steuer, J. & Tauber, E.R. (1996), "Computers are social actors", *Proceedings of CHI'94, "Celebrating Independence"*, Boston, U.S., pp. 72-78.

Nass, C. & Moon, Y. (2000), "Machines and mindlessness: social responses to computers", *Journal of Social Issues*, Vol. 56(1), 81-103.

Nehring, W.M. & Faaidd, F. (2008), "U.S. boards of patient nursing and the use of high-fidelity patient simulators in nursing education", *Journal of Professional Nursing*, Vol. 24(2), pp. 109-117.

Neter, E. & Brainin, E. (2012), "eHealth Literacy: Extending the Digital Divide to the Realm of Health Information", *Journal of Medical Internet Research*, Vol.14(1).

Neufeld, J. D., Yellowlees, P.M., Hilty, D.M., Cobb, H. & Bourgeois, J. (2007), "The e-Mental health consultation service: providing enhanced primary-care mental health services through telemedicine", *Psychosomatics*, Vol. 48(2), pp. 135-141.

Nicosia, F. (1966), "*Consumer Decision Processes*", Prentice Hall, Englewood Cliffs.

Nijholt, A. (2003), "Disappearing computers, social actors and embodied agents", *Proceedings of the 2003 International Conference on Cyberworlds (CW'03)*, pp. 128-134.

Norris, P. (2001), "*Digital divide: civic engagement, information poverty, and the Internet worldwide*", Cambridge University Press, UK.

Nurminen, M.I. (2006), "Work Informatics - An Operationalisation of Social Informatics", In: Berleur, J., Nurminen, M. I. & Impagliazzo, J. (Eds.), *Social Informatics: An Information Society for All? In Remembrance of Rob Kling*, IFIP International Federation for Information Processing Vol. 223, Springer, New York, pp. 407-416.

O'Connor, A.M., Bennet, C.L., Stacey, D., Barry, M., Col, N.F., Eden, K.B., Entwistle, V.A., Fiset, V., Holmes-Rovner, M., Khangura, S., Llewellyn-Thomas, H. & Rover, D. (2009), "Decision aids for people facing health treatment or screening decisions (review)", *The Cochrane Library 2009*, Issue 3, Wiley & Sons, U.S.

O'Connor, A., Wennberg, J.E., Legare, F., Llewellyn-Thomas, H.A., Moulton, B.W., Sepucha, K.R., Sodano, A.G. & King, J.S. (2007), "Toward the 'tipping point': decision aids and informed patient choice", *Health Affairs (Millwood)*, Vol. 26(3), pp. 716-725.

OECD (2009), "*OECD Factbook 2009: Economic, Environmental and Social Statistics*", OECD.

OECD (2011a), *Households with broadband access, 2000-2010*, <http://www.oecd.org/> (accessed: 19.3.2012).

OECD (2011b), *Households with Access to Computer at Home (Including PC, Portable, Handheld)*, <http://www.oecd.org> (accessed: 19.3.2012).

OECD (2013), *Fixed (wired) broadband subscriptions per 100 inhabitants*, <http://stats.oecd.org/> (accessed 27.8.2013).

Oemig, F. & Blobel, B. (2011), "Establishing semantic interoperability between HL7 v2.x and V3: a Communication Standards Ontology (CSO)", *Journal of Health Informatics*, Vol. 3(4), pp. 153-157.

Ojanperä, V. (2011), "IBM:n suoritin matkii aivoja" *Tietokone*, 18th August, 2011, http://www.tietokone.fi/uutiset/ibm_opetti_suorittimen_ajattelemaan_aivojen_la_illa (accessed: 19.8.2011).

Okamura, K., Fujimoto, M., Orlikowski W., & Yates, J. (1994), "Helping CSCW applications succeed: the role of mediators in the context of use", *Proceedings of Computer Supported Collaborative Work Conference*, ACM Press, U.S.

Olla, P., & Tan, J. (2009), "Personal health records systems go mobile: defining evaluation components", in: Olla, P. & Tan, J. (Eds.), *Mobile Health Solutions for Biomedical Applications*, IGI Global, U.S., pp. 45-70.

Ollman, G. (2007), "*The vishing guide*", IBM Global Technology Services, http://www.infosec.co.uk/ExhibitorLibrary/140/IBM_ISS_vishing_guide_20.pdf (accessed: 26.2.2010).

Oxford Dictionaries (2012), <http://oxforddictionaries.com/definition/english/paradigm> (accessed: 15.8.2012).

Paasivaara, L. & Suhonen, M. (2005), "Focal aspects of co-operation between the private, public and third sectors in a sparsely populated area in northern Finland", *International Journal of Circumpolar Health*, Vol. 64(4), pp. 346-353.

Page, W.F., Young, H.A. & Harriet, M. (2007), "*Long-Term Effects on Participation in Project SHAD (Shipboard Hazard and Defence)*", The National Academies Press, Washington D.C., U.S.

- Palm, E. (2011), "Who Cares? Moral Obligations in Formal and Informal Care Provision in the Light of ICT-Based Home Care", *Health Care Analysis*, Vol.21, pp. 171-188.
- Palmer, S., Tubbs, I. & Whybrow, A. (2003), "Health coaching to facilitate the promotion of healthy behavior and achievement of health-related goals", *International Journal of Health Promotion & Education*, Vol. 41(3), pp. 91-93.
- Park, Y. & Chang, K. (2009), "Individual and group behavior-based customer profile model for personalized product recommendation", *Expert Systems with Applications*, Vol. 36, pp. 1932-1939.
- Parker, M. (2005), "False dichotomies: EBM, clinical freedom, and the art of medicine", *Journal of Medical Ethics; Medical Humanities*, Vol. 31, pp. 23-30.
- Parson T. (1951), "*The Social System*". The Free Press, Glencoe.
- Pavlou, P.A. (2003), "Consumer acceptance of electronic commerce: integrating trust and risk with the technology acceptance model", *International Journal of Electronic Commerce*, Vol. 7(3), pp. 69-103.
- Pettitt, M.B., Norfleet, J. & Descheneaux, C.R. (2009), "Task specific simulation for medical training: fidelity requirements compared with levels of care", *Interservice/Industry Training, Simulation, and Education Conference (IITSEC)*, 2009.
- Perner, J. (1999), "Theory of mind", in: Bennet, M. (Ed.), "*Developmental Psychology: Achievements and Prospects*", Psychology Press, Taylor & Francis Group, U.S., pp. 205-230.
- Pew Internet (2013), "Who's Online", [http://www.pewinternet.org/Static-Pages/Trend-Data-\(Adults\)/Whos-Online.aspx](http://www.pewinternet.org/Static-Pages/Trend-Data-(Adults)/Whos-Online.aspx) (accessed: 6.9.2013).
- Pilloud, C., Sandoz, Y., Swinarski, C., Zimmerman, B. (1987), "*Commentary on the Additional Protocols of 8 June 1977 to the Geneva Conventions of 12 August 1949*", International Committee of the Red Cross, Martinus Nijhoff Publishers.
- Pratt, W., Unruh, K., Civan, A. & Skeels, M.M. (2006), "Personal health information management", *Communications of the ACM*, Vol. 49(1), pp. 51-55.
- Premack, D. & Woodruff, G. (1978), "Does the chimpanzee have a theory of mind", *The Behavioral and Brain Sciences*, Vol. 4, pp. 515-526.

Prensky, M. (2001), "Digital natives, digital immigrants, part 1", *On The Horizon*, Vol. 9(5), pp. 2-6.

Price, D., Pollock, A.M., & Shaoul J. (1999), "How the world trade organisation is shaping domestic policies in health care", *Lancet*, Vol. 354, pp. 1889-1892.

Pursley, D. (2010), "MicroTCA evolves to serve rugged military designs", *The Journal of Military Electronics & Computing*, Vol. 12(9), pp. 28-34.

Quadrello, T., Hurme, H., Menzinger, J., Smith, P.K., Veisson, M., Vidal, S. & Westerback, S. (2005), "Grandparents use of new communication technologies in a European perspective", *European Journal of Ageing*, Vol. 2(3), pp. 200-207.

Ralston, J.D., Revere, D., Robins, L.S. & Goldberg, H.I. (2004), "Patients' experience with a diabetes support programme based on an interactive electronic medical record: qualitative study", *British Medical Journal*, Vol. 328(7449), pp. 1159-1162.

Ramzan, Z., & Wüest, C. (2007), "Phishing attacks: analyzing trends in 2006", *Proceedings of CEAS 2007, 4th Conference on Email and Anti-Spam*, August 2-3, 2007, Mountain View, California, U.S.

Rappaport, J. (1987), "Term of empowerment/exemplars of prevention: toward a theory of community psychology", *American Journal of Community Psychology*, Vol. 15(2), pp. 121-148.

Rasmussen, N. (2008), "*On speed: the many lives of amphetamine*", New York University Press, New York, U.S.

Ray, S.M., Wylie, D.R., Rowe, A.S., Heidel, E. & Franks, A.S. (2012), "Pharmacy student knowledge retention after completing either a simulated or written patient case", *American Journal of Pharmaceutical Education*, Vol. 76(5), Article 86.

Rechel, B., Doyle, Y., Grundy, E. & McKee, M. (2009), "How can health systems respond to population ageing?", *Health Systems and Policy Analysis*, Policy Brief 10, World Health Organization.

Reddy, R. (2006), "Robotics and intelligent systems in support of society", *IEEE Intelligent Systems*, Vol. 21(3), pp. 24-31.

Reeves, B. & Nass, C. (1996), "*The Media Equation: How People Treat Computers, Television, and the New Media Like Real People and Places*", Cambridge University Press, New York, U.S.

- Robins, L.N., Davis, D.E. & Goodwin, D.W. (1974), "Drug use by U.S. army enlisted men in Vietnam: a follow-up on their return home", *American Journal of Epidemiology*, Vol. 99(4), pp. 235-249.
- Robinson, J.C. (2005), "Managed consumerism in health care". *Health Affairs (Millwood)*, Vol. 24(6), pp. 1478-1489.
- Roomans, H., Berger, G., Marcos, M., ten Teije, A., Seyfang, A. & van Harmelen, F. (2002), "Asbru protocol for the management of hyperbilirubinemia in the healthy term newborn", *Technical Report IR-495*, Vrije Universiteit Amsterdam. www.protocure.org/old/Protocols/jaundice-protocolAug28.pdf (accessed: 25.3.2011).
- Rose, K.L. (2010), "Case Management", in: Harris, M.D. (Ed.), *Handbook of Home Health Care Administration, 5th Edition*, Jones and Bartlett Publishers, Ontario, Canada, pp. 297-300.
- Rosen, K.R. (2008), "The history of medical simulation", *Journal of Critical Care*, Vol. 23, pp. 157-166.
- Rosenberg, W. & Donald, A. (1995), "Evidence based medicine: an approach to clinical problem-solving". *British Medical Journal*, Vol. 310, pp. 1122–1126.
- Rosner, F. (2010), "Ethical dilemmas for physicians in time of war", *Israel Medical Association Journal*, Vol. 12, pp. 133-135.
- Rosser, W.W. (2002), "The decline of family medicine as a career choice", *Canadian Medical Association Journal*, Vol. 166(11), pp. 1419-1420.
- Sackett, D.L., Rosenberg, W.M., Gray, J.A., Haynes, R.B. & Richardson, W.S. (1996), "Evidence based medicine: what it is and what it isn't", *British Medical Journal*, Vol. 312, pp. 71-72.
- Salem, M., Eyssel, F., Rohlfing, K., Kopp, S. & Joublin, F. (2013), "To Err is Human(-like): Effects of Robot Gesture on Perceived Anthropomorphism and Likability", *International Journal of Social Robotics*, Vol. 5(3), pp. 313-323.
- Samosseiko, D. (2009), "The Partnerka – what is it and why should you care", *Virus Bulletin Conference 2009, VB2009*, pp. 115-120.
- Sanromá, M. & Adserá, J.M. (2010), "From electronic medical records to the personal health space: how ICTs will transform healthcare in the next decade", In: Arias-Oliva, M., Bynum, T.W., Rogerson, S. & Torres-Coronas, T. (Eds.),

Ethicomp 2010, The Backwards, Forwards and Sideways Changes of ICT, pp. 473-482.

Santana, S., Lausen, B., Bujnowska-Fedak, M., Chronaki, C.E., Prokosch, H. & Wynn, R. (2011), "Informed citizen and empowered citizen in health: results from an European survey", *BMC Family Practice*, Vol. 12(20).

Saritas, O., & Keenan, M. (2004), "Broken promises and/or techno dreams? The future of health and social services in Europe", *The Journal of Future Studies, Strategic Thinking and Policy*, Vol. 6(5), pp. 281-291.

Scalvini, S., Baratti, D., Assoni, G., Zanardini, M., Comini, L. & Bernocchi, P. (2013), "Information and communication technology in chronic diseases: a patient's opportunity", *Journal of Medicine and the Person*.

Scanail, C.N., Carew, S., Barralon, P., Noury, N., Lyons, D. & Lyons, G.M. (2006), "A review of approaches to mobility telemonitoring of the elderly in their living environment", *Annals of Biomedical Engineering*, Vol. 34(4), pp. 547-563.

Schindler, D. & Toman, J. (1988), "*The Laws of Armed Conflicts*", Martinus Nijhoff Publisher, The Netherlands.

Schneiderman, B. (1989), "A nonanthropomorphic style guide: overcoming the humpty-dumpty syndrome", *The Computing Teacher*, Vol. 16(7).

Scott, G.C. & Lenert, L.A. (2000), "What is the next step in patient decision support", *Proceedings of the AMIA Symposium 2000*, pp. 784-788.

Scott, J.P. & Roberto, K.A. (1985), "Use of informal and formal support networks by rural elderly poor", *The Gerontologist*, Vol.25(6), pp. 624-630.

Segal, I. & Shahar, Y. (2008), "A distributed system for support and explanation of shared decision-making in the prenatal testing domain", *Journal of Biomedical Informatics*, Vol. 42(2), pp. 272-286.

Seniorwatch 2 (2008), *Final report of the Seniorwatch 2 - assesment of the senior market for ICT progress and developments*, http://ec.europa.eu/information_society/newsroom/cf/itemdetail.cfm?item_id=4286 (accessed: 26.2.2010).

Seropian, M.A., Brown, K., Gavilanes, J.S., Driggers, B. (2004), "Simulation: not just a manikin", *Journal of Nursing Education*, Vol.43(4).

Sharpe, D.B. (1996), "Out with the old, in: with the new", *The Journal of Design & Technology*, Vol.1(1), pp. 24-36.

Shelley, W.B. & Shelley, E.D., (2006), "*Consultations in dermatology: studies of orphan and unique patients*", Cambridge University Press, U.S.

Shore, J.H. (2013), "Videoconferencing in the Delivery of Psychiatric Care", *The American Journal of Psychiatry*, Vol.170(3), pp. 256-262.

Shuster, E. (1997), "Fifty years later: the significance of the Nuremberg Code", *The New England Journal of Medicine*, Vol. 337, pp. 1436-1440.

Sila, I. (2013), "Factors affecting the adoption of B2B e-commerce technologies", *Electronic Commerce Research*, Vol. 13(2), pp. 199-236.

Sillanpää, V. & Lönnqvist, A. (2010), "The role of intellectual capital in non-profit elderly care organizations", *Journal of Intellectual Capital*, Vol. 11(2), pp. 107-122.

Sillence, E., Briggs, P., Harris, P. & Fishwick, L. (2007), "Going online for health advice: changes in usage and trust practices over the last five years", *Interacting with Computers*, Vol. 19, pp. 397-406.

Slater, D. (1995), "*Consumer culture & modernity*", Blackwell Publishing, U.S.

Smith, D. (2010), "Q+A: how does healthcare overhaul affect Medicare?", *Reuters*, 22.3.2010, <http://www.reuters.com/article/idUSTRE62J1FS20100322> (accessed: 26.8.2010).

Snyder, L. & Leffler, C. (2005), "Ethics manual, fifth edition", *Annals of Internal Medicine*, Vol. 142, pp. 560-582.

Sobkin, V.S. & Leontiev, D.A. (1992), "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.

Somerville, M.M., Lampert, L.D., Dabbour, K.S., Harlan, S. & Schader, B. (2007), "Toward large scale assessment of information and communication technology literacy: implementation considerations for the ETS ICT literacy instrument", *Reference Services Review*, Vol. 35(1), pp. 8-20.

Spitzer, K.L., Eisenberg, M.B., & Lowe, C.A. (1998), "*Information literacy: essential skills for the information age*", ERIC Publications, U.S.

Stahl, B.C., Heersmink, R., Goujon, P., Flick, C., Hoven van den, J. Wakamuma, K.J., Ikonen, V. & Rader, M. (2010), *International Journal of Technoethics*, Vol. 1(4), pp. 20-38.

Stake, R.E. (2008), "Qualitative Case Studies", In: Denzin, N.K. & Lincoln, Y.S. (Eds.), *Strategies of Qualitative Inquiry, 3rd Edition*, Cambridge University Press, Cambridge, UK.

Stewart, J. (2000), "Cafematics: the cybercafé and the community", In: Gurnstein, M. (Ed.), *Community Informatics*, Idea Group, Toronto, Canada, pp. 320-338.

Stewart, J. (2007), "Local experts in domestication of information and communication technologies", *Information, Communication & Society*, Vol. 10(4), pp. 547-569.

Stewart, J. & Hyysalo, S. (2008), "Intermediaries, users and social learning in technological innovation", *International Journal of Innovation Management*, Vol.12(3), pp. 295-325.

Strauss, M.P. (2005), "A new approach to an old foe: Implementation of an early goal-directed sepsis treatment protocol", *Journal of Emergency Nursing*, Vol. 31(1), pp. 34-38.

Sullivan, J.S. (2010), "*Wearable body armor*", U.S. Patent Application No. 12/714,121, Publication No. 2010/0212056 A1, U.S.

Sullivan, P. (2000), "Enter the hospitalist: new type of patient creating a new type of specialist", *Canadian Medical Association Journal*, Vol. 162(9), pp. 1345-1346.

Svenaesus F. (2001), "*The Hermeneutics of Medicine and Phenomenology of Health: Steps Towards Philosophy of Medical Practice*". Dordrecht: Kluwer Academic Publishers.

Swan, M. (2009), "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.

Szasz, T. & Hollender, M.A. (1956), "A contribution to the philosophy of medicine: the basic model of the physician-patient relationship", *Archives of Internal Medicine*, Vol. 97(5), pp. 585-592.

Tahan, H.A. (2007), "The Case Management Process", in: Powell, S.K., Tahan, H.A. (Eds.). *CMSA Core Curriculum for Case Management*, Lippincott, Williams & Wilkins, Philadelphia, U.S, pp. 177-189.

Tang, P.C., Ash, J.S., Bates, D.W., Overhage, J.M., & Sands, D.Z. (2006), "Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption", *Journal of the American Medical Informatics Association*, Vol. 13 (2), pp. 121-126.

Tang, P.C., Overhage, J.M., Chan, A.S., Brown, N.L., Aghighi, B., Entwistle, M.P., Hui, S.L., Hyde, S.M., Klieman, L.H., Mitchell, C.J., Perkins, A.J., Qureshi, L.S., Waltmyer, T.A., Winters, L.J. & Young, C.Y. (2013), "Online disease management of diabetes: Engaging and Motivating Patients Online With Enhanced Resources-Diabetes (EMPOWER-D), a randomized controlled trial", *Journal of the American Medical Informatics Association*, Vol. 20, pp. 526-534.

Taylor, C.R. (2004), "Consumer privacy and the market for customer information", *The RAND Journal of Economics*, Vol. 35(4), pp. 631-650.

Teevan, J., Jones, W. & Bederson, B.B. (2006), "Personal information management", *Communications of the ACM*, Vol. 49 (1), pp. 40-43.

The Telegraph (2014), "NHS legally barred from selling patient data for commercial use", <http://www.telegraph.co.uk/health/10669295/NHS-legally-barred-from-selling-patient-data-for-commercial-use.html> (accessed: 7.3.2014).

Teperi, J., Porter, M.E., Vuorenkoski, L. & Baron, J.F. (2009), "*The Finnish Health Care System: a Value-Based Perspective*", Sitra, Helsinki, FI.

The Ministry of Social Affairs and Health: Sosiaali- ja terveystalvelujen kilpailuttamisen toimivuus (Finnish), *Reports and Memorandums 2012*, Vol.1(8).

The Register (2011), "Insulin pump maker ignores diabetic's hack warnings", 25th August, 2011, http://www.theregister.co.uk/2011/08/25/medtronic_insulin_pump_hacking/ (accessed: 1.9.2011).

Thirumalai, S. & Sinha, K.K. (2010), "Customization of the online purchase process in electronic retailing and customer satisfaction: An online field study", *Journal of Operations Management*, Vol. 29(5), pp. 477-487.

Thorpe, N., Deslich, S., Sikula, A. & Coustasse, A. (2012), "Combating medicare fraud: a struggling work in progress", *ranklin Business & Law Journal* Vol. 2012(4), pp. 95-107.

Timonen, V., Convery, J. & Cahill, S. (2006), "Care revolutions in the making? A Comparison of cash-for-care programmes in four European countries", *Ageing & Society*, Vol. 26, pp. 455-474.

Timpka, T., Eriksson, H., Ludvigsson, J., Ekberg, J., Nordfeldt, S. & Hanberger, L. (2008), "Web 2.0 systems supporting childhood chronic disease management: a pattern language representation of a general architecture", *BMC Medical Informatics and Decision Making*, Vol. 8(54), pp. 1-11.

Toiviainen, H. (2007), "Konsumerismi, Potilaiden ja Kuluttajien Aktiivinen Toiminta sekä Erityisesti Lääkäreiden Lokemukset ja Näkemykset Potilaista Kuluttajina" (Finnish), Tutkimuksia 160, Stakes, Helsinki.

Trebble, T.M., Hansi, N., Hydes, T., Smith, M.A. & Baker, M. (2010), "Process mapping the patient journey through health care: an introduction", *British Medical Journal*, Vol. 341, pp. 341-401.

Trigg, R.H. & Bødger, S. (1994), "From implementation to design: tailoring and the emergence of systemization in CSCW. *Proceedings of Computer Supported Collaborative Work Conference*, ACM press, U.S., pp. 45-54.

Tritter, J.Q. & McCallum, A. (2006), "The snakes and ladders of user involvement: moving beyond Arnstein", *Health Policy*, Vol. 76, pp. 156-168.

Trivedi, S. (2007), "The next wave of innovation nanotech with defence", *Proceedings of the IEEE International Conference on Electro/Information Technology*", Chigago, IL, pp. 594-599.

Tuohy, C.H., Flood, C.M. & Stabile, M. (2004), How does private finance affect public health care systems? Marshaling the evidence from OECD nations", *Journal of Health Politics, Policy and Law*, Vol. 29(3), pp. 359-396.

Tuomainen, M., Mykkänen, J., Luukkonen, I., Itälä, T., Kotinurmi, P., Han, Y., Sommer, N., Nykänen, P. & Toivanen, M. (2010), "Omahyvinvointi-hanke, PHR-katsaus".

Turun Sanomat (2010), "Tietojärjestelmien viat vaarantavat potilasturvallisuutta", 6.12.2010 (Finnish).

Ubel, P.A. (2006), "Patient decision making", In: Chang, A.E. , Ganz, P.A., Hayes, D.F., Kinsella, T.J., Pass, H.I., Schiller, J.H., Stone, R.M. & Strecher, V. (Eds.) *Oncology: an Evidence-Based Approach*, Section One, pp. 177-183. Springer, U.S.

Ubel, P.A., Loewenstein, G. & Jepson, C. (2003), "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.

United Kingdom Parliament (1977), "*Unfair Contract Terms Act 1977*", <http://www.statutelaw.gov.uk/content.aspx?activeTextDocId=224526> (accessed: 3.10.2010).

Vance, K., Howe, W. & Dellavalle, R.P. (2009), "Social internet sites as a source of public health information", *Dermatologic Clinics*, Vol. 27(2), pp. 133-136.

Vandebosch, H., Beullens, K. & Bulck, J. V. D. (2005), "Elderly and ICT: Scenarios for the future", *Digital Utopia in the Media: From Discourses to Facts*, Barcelona, pp. 951-962.

Varshney, U. (2009), "*Pervasive healthcare computing: EMR/EHR, wireless and health monitoring*", Springer, U.S.

Veerger, M., Hermans, L. & Cunha, C. (2012), "Web campaigning in the 2009 European Parliament elections: A cross-national comparative analysis", *New Media & Society*, Vol. 15(1), pp. 128-148.

Villanueva, T. (2009), "Family Medicine, the specialty of the future: the Portuguese situation within the European context", *International Archive of Medicine*, Vol. 2(36), pp. 1-3.

Virtanen, P., Suoheimo, M., Lamminmäki, S., Ahonen, P. & Suokas, M. (2011), "*Matkaopas asiakaslähtöisten sosiaali- ja terveystalvelujen kehittämiseen*", Tekesin katsaus 281/2011 (Finnish).

Vollmar, L.C. (2003), "Military medicine in war: the Geneva Conventions today". In Beam, T.E., Sparacino, L.R. & Beam, T.E. (Eds.), *Military Medical Ethics, Volume 2*, Bethesda, Maryland, U.S., pp. 739-772.

de Vries, A. (1980), "Health care responsibility", *Metamedicine*, Vol. 1, pp. 95-106.

- Väätänen, A., Laarni, J., Heinilä J. & Välikkynen, P. (2009), “*WPI&WP2: Puettavat käyttöliittymät sotilas- ja pelastustoiminnoissa, State-of-the-Art -kirjallisuuskatsaus*”, SAWUI-konsortio (Finnish), Tammikuu 2009.
- Vygotsky, L.S. (1978), "*Mind in the society: the development of higher psychological processes*", Harvard University Press, U.S.
- Waitzkin, H. (1985), “Information giving in medical care”, *Journal of Health and Social Behavior*, Vol. 26(2), pp. 81-101.
- Wallach, H.S., Safir, M.P., Samana, R., Almog, I. & Horef, R. (2011), “How Can Presence in Psychotherapy Employing VR Be Increased? Chapter for Inclusion in: Systems in Health Care Using Agents and Virtual Reality”, *Studies in Computational Intelligence*, Vol. 337, pp. 129-147.
- Walsh, C.J., Paluska, D., Pasch, K., Grand, W., Valiente, A. & Herr, H. (2006), “Development of a lightweight, underactuated exoskeleton for load-carrying augmentation”, *Proceedings of the 2006 IEEE International Conference on Robotics and Automation*, Orlando, Florida, U.S., pp. 3485-3491.
- Walsham, G. (1997), “Actor-Network theory and IS research: current status and future prospects”, in: Lee, A.S., Liebenau, J. and DeGross, J. I. (Eds.), *Information systems and qualitative research*, Chapman & Hall, London, UK, pp. 466-480.
- Wang, M., Lau, C., Matsen, F.A., III & Y. Kim. (2004), “Personal health information management system and its application in referral management”, *IEEE Transactions on Information Technology in Biomedicine*, Vol. 8 (3), pp. 287-297.
- Warschauer, M. (2003), “*Technology and social inclusion: rethinking the digital divide*”, MIT Press, U.S.
- Weaver, A. (2011), “High-fidelity patient simulation in nursing education: an integrative review”, *Nursing Education Perspectives*, Vol. 32(1), pp. 37-40.
- Weaver, J.B.III, Thompson, N.J., Weaver, S.S. & Hopkins, G.L. (2009), “Healthcare non-adherence decisions and internet health information”, *Computers in Human Behavior*, Vol. 25, pp. 1373-1380.
- Weizenbaum, J. (1966), “ELIZA – a computer program for the study of natural language communication between man and machine”, *Communications of the ACM*, Vol.9(1), pp.36-45.

- van Wel, L. & Royakkers, L. (2004), "Ethical issues in web data mining", *Ethics and Information Technology*, Vol. 6, pp. 129-140.
- Weide, U. (2005), "Law and the German universal healthcare system: a brief contemporary overview", *German Law Journal*, Vol. 6(8), pp. 1143-1172.
- Wesensten, N.J., Belenky, G. & Balkin, T.J. (2005), "Cognitive readiness in network-centric operations", *Parameters*, Spring 2005, pp. 94-105.
- Whitmore, J., Hickey, P., Doan, B., Harrison, R., Kisner, J., Beltran, T., McQuade, J., Fischer, J. & Marks, F. (2006), "*A Double-Blind Placebo-Controlled Investigation of the Efficacy of Modafinil for Maintaining Alertness and Performance in Sustained Military Ground Operations*", Air Force Research Lab Brooks AFB TX, Human Effectiveness Dir/Biodynamics and Protection Div.
- Wielhouwer, P.W. (2005), "Toward information superiority: the contribution of operational net assessment", *Air & Space Power Journal*, Fall 2005, pp. 85-96.
- Wikipedia Commons (2011), "L'Inconnue de la Seine", *Wikipedia Commons*, http://en.wikipedia.org/wiki/L%27Inconnue_de_la_Seine (accessed: 24.2.2011).
- Williams, E., Abarbanel, H., Brenner, M., Despain, A., Drell, S., Dyson, F., Joyce, G., Lewis, N., Press, W., Vesceky, J., & Woodin, H. (2008), "*Human Performance*", The Mitre Corporation, Virginia, U.S.
- Williams, J. (2010), "Social networking applications in health care: threats to the privacy and security of health information", *SEHC '10 Proceedings of the 2010 ICSE Workshop on Software Engineering in Health Care*, pp. 39-49.
- Wolf Olins & Flamingo (2013), "*The New Mainstream: Creating a New Relationship Between People and Brands*", <http://gamechangers.wolffolins.com/> (accessed: 17.9.2013).
- Wolfe, S., Bagley, R.F., Kasius, R.V., Bury, J.D., Garson, J.Z., Reynold, J., Gold, M., Spasoff, A. & Teed, G. (1972), "The family doctor", *The Millbank Memorial Fund Quarterly*, Vol. 50(2), Pt. 2, pp. v-198.
- WONCA (2002), "*The European Definition of General Practice / Family Medicine*", WONCA Europe, 2002.
- World Health Organization (2008), *The Tallinn Charter*, WHO European Ministerial Conference on Health Systems, Tallinn, Estonia, 25-27 June, 2008.

- Wright, P., Jansen, C. & Wyatt, J.C. (1998), "How to limit clinical errors in interpretation of data", *The Lancet*, Vol. 352(9139), pp. 1539-1543.
- Yang, C., Tsai, C., Cheng, K. & Chen, S. (2012), "Low-invasive implantable devices of low-power consumption using high-efficiency antennas for cloud health care", *IEEE Journal on Emerging and Selected Topics in Circuits and Systems*, Vol. 2(1), pp. 14-23.
- Yiannoudes, S.S. (2007), "Identifying criteria for the design of affective socially engaging kinetic architectural structures", *3rd IET International Conference on Intelligent Environments*, pp. 73-80.
- Yin, S. (2011), "Japanese Scientists Invent Robot That Learns, Thinks, and Acts", *PC Magazine*, <http://www.pcmag.com/article2/0,2817,2390277,00.asp> (accessed: 8.8.2011).
- Zickuhr, K. & Madden, M. (2012), *Older Adults and Internet Use*, http://www.pewinternet.org/~media/Files/Reports/2012/PIP_Older_adults_and_internet_use.pdf (accessed: 27.8.2013).
- Zisberg, A., Gur-Yaish, N. & Shochat, T. (2010), "Contribution of Routine to Sleep Quality in Community Elderly", *Sleep*, Vol. 33(4), pp. 509-514.
- Östlund B. (1995) "*Gammal är äldst – om teknik i äldre människors liv*", Linköping Studies in Arts and Science No 129, Tema, Linköping University.



"The Radio Teledactyl". An image from a cover page from a popular science magazine of the mid-1920⁵²s.

⁵² Gernsback, H. (1925), "The radio teledactyl", *Science and Invention*, February 1925, cover.

Turku Centre for Computer Science

TUCS Dissertations

1. **Marjo Lipponen**, On Primitive Solutions of the Post Correspondence Problem
2. **Timo Käkölä**, Dual Information Systems in Hyperknowledge Organizations
3. **Ville Leppänen**, Studies on the Realization of PRAM
4. **Cunsheng Ding**, Cryptographic Counter Generators
5. **Sami Viitanen**, Some New Global Optimization Algorithms
6. **Tapio Salakoski**, Representative Classification of Protein Structures
7. **Thomas Långbacka**, An Interactive Environment Supporting the Development of Formally Correct Programs
8. **Thomas Finne**, A Decision Support System for Improving Information Security
9. **Valeria Mihalache**, Cooperation, Communication, Control. Investigations on Grammar Systems.
10. **Marina Waldén**, Formal Reasoning About Distributed Algorithms
11. **Tero Laihonen**, Estimates on the Covering Radius When the Dual Distance is Known
12. **Lucian Ilie**, Decision Problems on Orders of Words
13. **Jukkapekka Hekanaho**, An Evolutionary Approach to Concept Learning
14. **Jouni Järvinen**, Knowledge Representation and Rough Sets
15. **Tomi Pasanen**, In-Place Algorithms for Sorting Problems
16. **Mika Johnsson**, Operational and Tactical Level Optimization in Printed Circuit Board Assembly
17. **Mats Aspñäs**, Multiprocessor Architecture and Programming: The Hathi-2 System
18. **Anna Mikhajlova**, Ensuring Correctness of Object and Component Systems
19. **Vesa Torvinen**, Construction and Evaluation of the Labour Game Method
20. **Jorma Boberg**, Cluster Analysis. A Mathematical Approach with Applications to Protein Structures
21. **Leonid Mikhajlov**, Software Reuse Mechanisms and Techniques: Safety Versus Flexibility
22. **Timo Kaukoranta**, Iterative and Hierarchical Methods for Codebook Generation in Vector Quantization
23. **Gábor Magyar**, On Solution Approaches for Some Industrially Motivated Combinatorial Optimization Problems
24. **Linas Laibinis**, Mechanised Formal Reasoning About Modular Programs
25. **Shuhua Liu**, Improving Executive Support in Strategic Scanning with Software Agent Systems
26. **Jaakko Järvi**, New Techniques in Generic Programming – C++ is more Intentional than Intended
27. **Jan-Christian Lehtinen**, Reproducing Kernel Splines in the Analysis of Medical Data
28. **Martin Büchi**, Safe Language Mechanisms for Modularization and Concurrency
29. **Elena Troubitsyna**, Stepwise Development of Dependable Systems
30. **Janne Näppi**, Computer-Assisted Diagnosis of Breast Calcifications
31. **Jianming Liang**, Dynamic Chest Images Analysis
32. **Tiberiu Seceleanu**, Systematic Design of Synchronous Digital Circuits
33. **Tero Aittokallio**, Characterization and Modelling of the Cardiorespiratory System in Sleep-Disordered Breathing
34. **Ivan Porres**, Modeling and Analyzing Software Behavior in UML
35. **Mauno Rönkkö**, Stepwise Development of Hybrid Systems
36. **Jouni Smed**, Production Planning in Printed Circuit Board Assembly
37. **Vesa Halava**, The Post Correspondence Problem for Market Morphisms
38. **Ion Petre**, Commutation Problems on Sets of Words and Formal Power Series
39. **Vladimir Kvassov**, Information Technology and the Productivity of Managerial Work
40. **Frank Tétard**, Managers, Fragmentation of Working Time, and Information Systems

41. **Jan Manuch**, Defect Theorems and Infinite Words
42. **Kalle Ranto**, Z_4 -Goethals Codes, Decoding and Designs
43. **Arto Lepistö**, On Relations Between Local and Global Periodicity
44. **Mika Hirvensalo**, Studies on Boolean Functions Related to Quantum Computing
45. **Pentti Virtanen**, Measuring and Improving Component-Based Software Development
46. **Adekunle Okunoye**, Knowledge Management and Global Diversity – A Framework to Support Organisations in Developing Countries
47. **Antonina Kloptchenko**, Text Mining Based on the Prototype Matching Method
48. **Juha Kivijärvi**, Optimization Methods for Clustering
49. **Rimvydas Rukšėnas**, Formal Development of Concurrent Components
50. **Dirk Nowotka**, Periodicity and Unbordered Factors of Words
51. **Attila Gyenesei**, Discovering Frequent Fuzzy Patterns in Relations of Quantitative Attributes
52. **Petteri Kaitovaara**, Packaging of IT Services – Conceptual and Empirical Studies
53. **Petri Rosendahl**, Niho Type Cross-Correlation Functions and Related Equations
54. **Péter Majlender**, A Normative Approach to Possibility Theory and Soft Decision Support
55. **Seppo Virtanen**, A Framework for Rapid Design and Evaluation of Protocol Processors
56. **Tomas Eklund**, The Self-Organizing Map in Financial Benchmarking
57. **Mikael Collan**, Giga-Investments: Modelling the Valuation of Very Large Industrial Real Investments
58. **Dag Björklund**, A Kernel Language for Unified Code Synthesis
59. **Shengnan Han**, Understanding User Adoption of Mobile Technology: Focusing on Physicians in Finland
60. **Irina Georgescu**, Rational Choice and Revealed Preference: A Fuzzy Approach
61. **Ping Yan**, Limit Cycles for Generalized Liénard-Type and Lotka-Volterra Systems
62. **Joonas Lehtinen**, Coding of Wavelet-Transformed Images
63. **Tommi Meskanen**, On the NTRU Cryptosystem
64. **Saeed Salehi**, Varieties of Tree Languages
65. **Jukka Arvo**, Efficient Algorithms for Hardware-Accelerated Shadow Computation
66. **Mika Hirvikorpi**, On the Tactical Level Production Planning in Flexible Manufacturing Systems
67. **Adrian Costea**, Computational Intelligence Methods for Quantitative Data Mining
68. **Cristina Seceleanu**, A Methodology for Constructing Correct Reactive Systems
69. **Luigia Petre**, Modeling with Action Systems
70. **Lu Yan**, Systematic Design of Ubiquitous Systems
71. **Mehran Gomari**, On the Generalization Ability of Bayesian Neural Networks
72. **Ville Harkke**, Knowledge Freedom for Medical Professionals – An Evaluation Study of a Mobile Information System for Physicians in Finland
73. **Marius Cosmin Codrea**, Pattern Analysis of Chlorophyll Fluorescence Signals
74. **Aiying Rong**, Cogeneration Planning Under the Deregulated Power Market and Emissions Trading Scheme
75. **Chihab BenMoussa**, Supporting the Sales Force through Mobile Information and Communication Technologies: Focusing on the Pharmaceutical Sales Force
76. **Jussi Salmi**, Improving Data Analysis in Proteomics
77. **Orieta Celiku**, Mechanized Reasoning for Dually-Nondeterministic and Probabilistic Programs
78. **Kaj-Mikael Björk**, Supply Chain Efficiency with Some Forest Industry Improvements
79. **Viorel Preoteasa**, Program Variables – The Core of Mechanical Reasoning about Imperative Programs
80. **Jonne Poikonen**, Absolute Value Extraction and Order Statistic Filtering for a Mixed-Mode Array Image Processor
81. **Luka Milovanov**, Agile Software Development in an Academic Environment
82. **Francisco Augusto Alcaraz Garcia**, Real Options, Default Risk and Soft Applications
83. **Kai K. Kimppa**, Problems with the Justification of Intellectual Property Rights in Relation to Software and Other Digitally Distributable Media
84. **Dragoş Truşcan**, Model Driven Development of Programmable Architectures
85. **Eugen Czeizler**, The Inverse Neighborhood Problem and Applications of Welch Sets in Automata Theory

86. **Sanna Ranto**, Identifying and Locating-Dominating Codes in Binary Hamming Spaces
87. **Tuomas Hakkarainen**, On the Computation of the Class Numbers of Real Abelian Fields
88. **Elena Czeizler**, Intricacies of Word Equations
89. **Marcus Alanen**, A Metamodeling Framework for Software Engineering
90. **Filip Ginter**, Towards Information Extraction in the Biomedical Domain: Methods and Resources
91. **Jarkko Paavola**, Signature Ensembles and Receiver Structures for Oversaturated Synchronous DS-CDMA Systems
92. **Arho Virkki**, The Human Respiratory System: Modelling, Analysis and Control
93. **Olli Luoma**, Efficient Methods for Storing and Querying XML Data with Relational Databases
94. **Dubravka Ilić**, Formal Reasoning about Dependability in Model-Driven Development
95. **Kim Solin**, Abstract Algebra of Program Refinement
96. **Tomi Westerlund**, Time Aware Modelling and Analysis of Systems-on-Chip
97. **Kalle Saari**, On the Frequency and Periodicity of Infinite Words
98. **Tomi Kärki**, Similarity Relations on Words: Relational Codes and Periods
99. **Markus M. Mäkelä**, Essays on Software Product Development: A Strategic Management Viewpoint
100. **Roope Vehkalahti**, Class Field Theoretic Methods in the Design of Lattice Signal Constellations
101. **Anne-Maria Ernvall-Hytönen**, On Short Exponential Sums Involving Fourier Coefficients of Holomorphic Cusp Forms
102. **Chang Li**, Parallelism and Complexity in Gene Assembly
103. **Tapio Pahikkala**, New Kernel Functions and Learning Methods for Text and Data Mining
104. **Denis Shestakov**, Search Interfaces on the Web: Querying and Characterizing
105. **Sampo Pyysalo**, A Dependency Parsing Approach to Biomedical Text Mining
106. **Anna Sell**, Mobile Digital Calendars in Knowledge Work
107. **Dorina Marghescu**, Evaluating Multidimensional Visualization Techniques in Data Mining Tasks
108. **Tero Sääntti**, A Co-Processor Approach for Efficient Java Execution in Embedded Systems
109. **Kari Salonen**, Setup Optimization in High-Mix Surface Mount PCB Assembly
110. **Pontus Boström**, Formal Design and Verification of Systems Using Domain-Specific Languages
111. **Camilla J. Hollanti**, Order-Theoretic Methods for Space-Time Coding: Symmetric and Asymmetric Designs
112. **Heidi Himmanen**, On Transmission System Design for Wireless Broadcasting
113. **Sébastien Lafond**, Simulation of Embedded Systems for Energy Consumption Estimation
114. **Evgeni Tsivtsivadze**, Learning Preferences with Kernel-Based Methods
115. **Petri Salmela**, On Commutation and Conjugacy of Rational Languages and the Fixed Point Method
116. **Siamak Taati**, Conservation Laws in Cellular Automata
117. **Vladimir Rogojin**, Gene Assembly in Stichotrichous Ciliates: Elementary Operations, Parallelism and Computation
118. **Alexey Dudkov**, Chip and Signature Interleaving in DS CDMA Systems
119. **Janne Savela**, Role of Selected Spectral Attributes in the Perception of Synthetic Vowels
120. **Kristian Nybom**, Low-Density Parity-Check Codes for Wireless Datacast Networks
121. **Johanna Tuominen**, Formal Power Analysis of Systems-on-Chip
122. **Teijo Lehtonen**, On Fault Tolerance Methods for Networks-on-Chip
123. **Eeva Suvitie**, On Inner Products Involving Holomorphic Cusp Forms and Maass Forms
124. **Linda Mannila**, Teaching Mathematics and Programming – New Approaches with Empirical Evaluation
125. **Hanna Suominen**, Machine Learning and Clinical Text: Supporting Health Information Flow
126. **Tuomo Saarni**, Segmental Durations of Speech
127. **Johannes Eriksson**, Tool-Supported Invariant-Based Programming

128. **Tero Jokela**, Design and Analysis of Forward Error Control Coding and Signaling for Guaranteeing QoS in Wireless Broadcast Systems
129. **Ville Lukkarila**, On Undecidable Dynamical Properties of Reversible One-Dimensional Cellular Automata
130. **Qaisar Ahmad Malik**, Combining Model-Based Testing and Stepwise Formal Development
131. **Mikko-Jussi Laakso**, Promoting Programming Learning: Engagement, Automatic Assessment with Immediate Feedback in Visualizations
132. **Riikka Vuokko**, A Practice Perspective on Organizational Implementation of Information Technology
133. **Jeanette Heidenberg**, Towards Increased Productivity and Quality in Software Development Using Agile, Lean and Collaborative Approaches
134. **Yong Liu**, Solving the Puzzle of Mobile Learning Adoption
135. **Stina Ojala**, Towards an Integrative Information Society: Studies on Individuality in Speech and Sign
136. **Matteo Brunelli**, Some Advances in Mathematical Models for Preference Relations
137. **Ville Junnila**, On Identifying and Locating-Dominating Codes
138. **Andrzej Mizera**, Methods for Construction and Analysis of Computational Models in Systems Biology. Applications to the Modelling of the Heat Shock Response and the Self-Assembly of Intermediate Filaments.
139. **Csaba Ráduly-Baka**, Algorithmic Solutions for Combinatorial Problems in Resource Management of Manufacturing Environments
140. **Jari Kyngäs**, Solving Challenging Real-World Scheduling Problems
141. **Arho Suominen**, Notes on Emerging Technologies
142. **József Mezei**, A Quantitative View on Fuzzy Numbers
143. **Marta Olszewska**, On the Impact of Rigorous Approaches on the Quality of Development
144. **Antti Airola**, Kernel-Based Ranking: Methods for Learning and Performance Estimation
145. **Aleksi Saarela**, Word Equations and Related Topics: Independence, Decidability and Characterizations
146. **Lasse Bergroth**, Kahden merkkijonon pisimmän yhteisen alijonon ongelma ja sen ratkaiseminen
147. **Thomas Canhao Xu**, Hardware/Software Co-Design for Multicore Architectures
148. **Tuomas Mäkilä**, Software Development Process Modeling – Developers Perspective to Contemporary Modeling Techniques
149. **Shahrokh Nikou**, Opening the Black-Box of IT Artifacts: Looking into Mobile Service Characteristics and Individual Perception
150. **Alessandro Buoni**, Fraud Detection in the Banking Sector: A Multi-Agent Approach
151. **Mats Neovius**, Trustworthy Context Dependency in Ubiquitous Systems
152. **Fredrik Degerlund**, Scheduling of Guarded Command Based Models
153. **Amir-Mohammad Rahmani-Sane**, Exploration and Design of Power-Efficient Networked Many-Core Systems
154. **Ville Rantala**, On Dynamic Monitoring Methods for Networks-on-Chip
155. **Mikko Pelto**, On Identifying and Locating-Dominating Codes in the Infinite King Grid
156. **Anton Tarasyuk**, Formal Development and Quantitative Verification of Dependable Systems
157. **Muhammad Mohsin Saleemi**, Towards Combining Interactive Mobile TV and Smart Spaces: Architectures, Tools and Application Development
158. **Tommi J. M. Lehtinen**, Numbers and Languages
159. **Peter Sarlin**, Mapping Financial Stability
160. **Alexander Wei Yin**, On Energy Efficient Computing Platforms
161. **Mikołaj Olszewski**, Scaling Up Stepwise Feature Introduction to Construction of Large Software Systems
162. **Maryam Kamali**, Reusable Formal Architectures for Networked Systems
163. **Zhiyuan Yao**, Visual Customer Segmentation and Behavior Analysis – A SOM-Based Approach
164. **Timo Jolivet**, Combinatorics of Pisot Substitutions
165. **Rajeev Kumar Kanth**, Analysis and Life Cycle Assessment of Printed Antennas for Sustainable Wireless Systems
166. **Khalid Latif**, Design Space Exploration for MPSoC Architectures

167. **Bo Yang**, Towards Optimal Application Mapping for Energy-Efficient Many-Core Platforms
168. **Ali Hanzala Khan**, Consistency of UML Based Designs Using Ontology Reasoners
169. **Sonja Leskinen**, m-Equine: IS Support for the Horse Industry
170. **Fareed Ahmed Jokhio**, Video Transcoding in a Distributed Cloud Computing Environment
171. **Moazzam Fareed Niazi**, A Model-Based Development and Verification Framework for Distributed System-on-Chip Architecture
172. **Mari Huova**, Combinatorics on Words: New Aspects on Avoidability, Defect Effect, Equations and Palindromes
173. **Ville Timonen**, Scalable Algorithms for Height Field Illumination
174. **Henri Korvela**, Virtual Communities – A Virtual Treasure Trove for End-User Developers
175. **Kameswar Rao Vaddina**, Thermal-Aware Networked Many-Core Systems
176. **Janne Lahtiranta**, New and Emerging Challenges of the ICT-Mediated Health and Well-Being Services

TURKU
CENTRE *for*
COMPUTER
SCIENCE

Joukahaisenkatu 3-5 B, 20520 Turku, Finland | www.tucs.fi



University of Turku

Faculty of Mathematics and Natural Sciences

- Department of Information Technology
- Department of Mathematics and Statistics

Turku School of Economics

- Institute of Information Systems Science



Åbo Akademi University

Division for Natural Sciences and Technology

- Department of Information Technologies

ISBN 978-952-12-3068-4
ISSN 1239-1883

Janne Lahtiranta

New and Emerging Challenges of the ICT-Mediated Health and Well-Being Services