



Deliverable 2.1.1

Strategies for Empowering Patients for Web-based Self-management

Project title:	Support of Patient Empowerment by an intelligent self-management pathway for patients
Project acronym:	EMPOWER
Project identifier:	FP7-ICT-2011-288209
Project instrument:	STREP
Web link:	www.empower-fp7.eu
Dissemination level:	PU (public)
Contractual delivery:	2012-06-30
Actual delivery:	2012-06-28
Leading partner:	USI



The research leading to these results has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under grant agreement No 288209, EMPOWER Project.

Document History

Version	Date	Changes	From	Review
V0.1	2012-02-27	Initial Document	USI	SRFG
V0.1	2012-03-06	Study contents – outline	SRFG	All Partners
V0.2	2012-04-05	Study content Appendix: Questioning Route	USI	SRFG, MoH, GO IN
	2012-4-27	Study draft – section 6	SRFG	All Partners
V.0.3	2012-5-25	Study 2 nd draft	SRFG	USI
V0.4	2012-06-03	SRFG inputs added, revised until page 75	USI	SRFG
V0.5	2012-06-06	Recommendations added, chapter “Needs” adapted, start of formatting, chapter “Best Practices” to be further adapted, input GO IN added, input MoH reworked	USI	All Partners
V0.6	2012-06-21	Sections adapted by USI and SRFG. Integration of interviews with Turkish patients and doctors. Harmonization of references, figures and schemes	USI	All Partners
V1.0	2012-06-27	All the latest inputs are integrated, references harmonized and executive summary added	USI	SRFG

EMPOWER Consortium Contacts

Beneficiary	Name	Phone	E-Mail
SRFG	Manuela Plößnig	+43 662 2288 402	manuela.ploessnig@salzburgresearch.at
HMGU	Claudia Hildebrand	+49 89 3187 4182	hildebra@helmholtz-muenchen.de
GOIN	Siegfried Jedamzik	+49 8 41956161	siegfried.jedamzik@googlemail.com
USI	Peter J. Schulz	+41586664724	peter.schulz@usi.ch
SRDC	Asuman Dogac	+90 312 210 13 93	asuman@srcd.com.tr
ICOM	Ilias Lamprinos	+302106677953	labil@intracom.gr
MOH	Ali Kemal Caylan	+903125851907	alikemal.caylan@saglik.gov.tr

Table of Contents

1	Executive Summary.....	7
2	EMPOWER in a Nutshell.....	9
3	Introduction.....	10
3.1	Objective and target groups of the study	10
3.2	Description of the task.....	10
3.3	Methods	11
4	Chronic Care and Diabetes Management.....	12
4.1	Best Practices in Diabetes Care.....	12
4.2	Diabetes interventions by means of technology.....	15
4.2.1	Personalized interventions	18
4.2.2	The doctor-patient relationship	19
4.3	Technological Interventions: Outcome measures and related components	19
4.3.1	Clinical and related outcome measures.....	20
4.3.2	Nonclinical outcome measures.....	22
4.3.3	Usability	23
4.3.4	Limitations of reviewed studies.....	24
4.4	Implications for the EMPOWER Project.....	24
4.5	Situation in Germany.....	26
4.5.1	Examples of chronic care management programmes in general	26
4.5.2	Examples of diabetes management programmes in specific	27
4.6	Situation in Turkey	28
4.6.1	Examples of chronic care management programmes in general	28
4.6.2	Examples of diabetes management programmes in specific	28
5	Comparative analysis of digital competence for web-based patient empowerment methods and tools	33
5.1	Introduction	33
5.2	The concept of digital competence in eHealth	33
5.2.1	Modelling and measuring competence	33
5.2.2	Digital competence in eHealth.....	35
5.3	Evidence of digital competence in Europe.....	38
5.3.1	Access to ICTs.....	38
5.3.2	Frequency of computer and internet usage	42
5.3.3	Comparison of skill levels and internet activities.....	43
5.3.4	ICT uptake of general practitioners in the field of eHealth	46
5.3.5	Typology of internet users per age	49
5.4	Gender differences.....	49
5.4.1	Usage and attitude towards the internet	50
5.4.2	Interest and search behaviour for eHealth topics.....	51

5.4.3	Gender-specific differences in numeracy.....	52
5.5	The issue of digital divide in EMPOWER.....	53
5.5.1	Current state of European digital divide.....	53
5.5.2	Needs and demands by younger senior citizens	55
5.6	Implications for the EMPOWER project.....	56
6	Conceptual framework of web-based patient empowerment.....	57
6.1	Main concepts for Patient Empowerment	57
6.2	User Characteristics: An analysis in view of the proposed framework	60
6.2.1	Psychological Empowerment	61
6.2.2	Literacy Components	66
6.2.3	Sources/Inferences	67
6.2.4	Limitations.....	68
6.3	The EMPOWER Project: Fostering self-management in diabetes patients.....	70
6.3.1	The context of the EMPOWER project	70
6.3.1	Patient-physician-relationship.....	71
6.3.2	Problem solving & decision making	75
6.3.3	Resource utilization	77
6.3.4	Changing behaviour	78
6.3.5	Observation of Daily Living.....	80
6.3.6	E-learning concepts supporting chronic disease self-management competences and skills	82
6.4	Summary of user needs relevant for EMPOWER	86
6.4.1	Patients` needs relevant for EMPOWER.....	86
6.4.2	Doctors` needs relevant for EMPOWER.....	90
7	Identification of user behaviour patterns	91
7.1	Objective	91
7.2	The persona method in eHealth projects	92
7.2.1	Purpose of the method	92
7.2.2	Characteristics of personas and guiding principles	93
7.2.3	Steps in developing personas	96
7.2.4	Elements of a persona description	98
7.2.5	Examples of personas description for eHealth application.....	103
7.3	Persona development for EMPOWER.....	104
7.3.1	Determination of target groups	104
	Hypothesis: Differentiation of potential EMPOWER target groups: Doctors, dietician and self-help group moderators	106
7.3.2	Categorization of the set of EMPOWER personas	109
7.3.3	The description and verification of personas set.....	113
8	Recommendations.....	123
8.1	Recommendations for the EMPOWER approach	123
8.2	Recommendations for EMPOWER services and functionalities	124

8.3	Recommendations for the information sources in EMPOWER	126
8.4	Recommendations as regards gender and digital divide issues	127
8.5	Recommendations for the pilot-implementation of EMPOWER services	128
8.6	Recommendations for the EMPOWER users	129
8.6.1	Patients (all types; IT savvy, young senior citizen)	129
8.6.2	General practitioners	129
9	Annex	130
9.1	Focus groups and interviews – guide	130
9.1.1	Questioning route focus group with doctors: Ingolstadt 28/03/2012.....	130
9.1.2	Questioning route focus groups with patients: Ingolstadt 27-28/03/2012	135
9.1.3	Focus Groups: Patient Questionnaire.....	140
9.1.4	Guideline for the interviews with Turkish doctors 7/6/2012	142
9.1.5	Guideline for the interview with Turkish patients 7/6/2012	144
9.1.6	Questionnaire for the Turkish patients.....	146
10	References.....	148

Abbreviations

DC	Digital Competence
DoW	Description of Work
ED	Emergency Department
EHR	Electronic Health Record
GP	General practitioners
HCP	Health Care Provider
IBCT	Interactive Behaviour Change Technologies
ICT	Information and Communication Technology
IGT	Impaired Glucose Tolerance
IST	Information Society Technology
MBG	Monitoring Blood Glucose
ODLs	Observations of Daily Living
OHA	Oral hypoglycemic agents
PHA	Personal Health Applications
PHR	Personal Health Records
SDM	Shared Decision Making
WHO	World Health Organization

1 Executive Summary

The main objective of the pre-study is to identify focal concepts and strategies that help fostering chronic patients' empowerment. The Pre-Study is based on an extensive literature review, a focus groups study with German doctors and patients to learn more about their experiences and needs, and individual Skype-interviews with Turkish patients and doctors. The results of this study are the starting point for the continuing EMPOWER activities:

- The technical requirement specifications in Task 3.2 "Gathering Technical Requirements of EMPOWER Architecture";
- The educational and information material for self-management to be developed throughout the project (Task 4.2);
- The storyboard development as the essential part for the design of the Pilot Application (Task 8.2)
- The exploitation strategy of the components developed in EMPOWER project.

The literature review investigates the main concepts of the theoretical background of EMPOWER, the best examples of ICT based self-management programs, and gender issues and the adoption rate of ICTs in Europe, with a specific focus on Turkey and Germany.

The main findings of the pre-study are presented in a summary of identified needs (6.4) of both, diabetes patients and doctors, regarding diabetes management. The needs of diabetes patients are based on the results of the literature review and the analysis of the focus groups and interviews, and are presented according to the following headlines, which were identified throughout the study: 1. Sense making in diabetes care; 2. Behaviour Change in diabetes care; 3. Social Interaction in diabetes care; 4. Monitoring in diabetes care. Only where evidence was striking, further attention was paid to demographics. As for doctors more general needs are identified that are not grouped according to topics.

An example of patient's need of the first category is the following:

Need: Timely Information

Patients have to make sense out of the things they are experiencing and seeing. Especially patients, who would like to exercise a great deal of control, easily get frustrated about e.g. MBG levels (Chen, 2010).

Women

Women in particular tend to be more frustrated with regard to their results than men. If results are not as expected they tend to ask more often where these results come from. Only with time they make sense out of it. In order to keep frustration levels and possible negative consequences low it is important to provide patients with timely information and possible explanations.

An example of a doctor's need is written below:

Need: Effectiveness and Efficiency

In order to develop in accordance with the patient a treatment plan that involves mutual understanding based on diagnosis, best practices and understanding of the (development of the) disease, doctors need to have the most important information ready. This means a prepared patient that keeps track of his behaviour and has the ability to communicate behavioural patterns.

Time constraints and growing workload on the doctors' side create the need for streamlined information. Information has to be structured and not be overloaded. Information given to the doctors should be as compact as possible.

Turkish Doctors

One doctor mentioned that he would need a tool that would allow him to communicate faster with his patients. He already gave out his telephone number to those people he seemed to be most in need of it.

A second important result of the pre-study is the definition of persona sketches (7.3). Personas are a method to keep designers and developers focused on the users when determining appropriate functionality, prioritise features, design interaction interfaces etc.

The final result of the pre-study is a list of recommendations (8), which is based on sound results of the literature review and of the inductive analysis of two focus groups with patients (age range 60+; retired) and one focus group with physicians in Germany (3/2012). The recommendations are further adapted to the findings from the interviews conducted with Turkish patients and doctors. The recommendations are formulated in order to support keeping the focus on the most common needs and requirements of the EMPOWER users: different types of diabetes patients and general practitioners, eventually family care givers, self-help groups or trained nurses.

Four main recommendations are related to the general EMPOWER approach:

1. Follow a holistic approach in "Patient Empower" for chronic care and diabetes
2. Foster patient empowerment with "meaningful" interventions
3. Promote face-to-face interaction and technology-supported interaction equally
4. Develop a clear Unique Selling Proposition (USP) for EMPOWER services

Nine recommendations are drawn for EMPOWER services and functionalities:

1. Monitor continuously and provide timely feedback
2. Consider services and strategies supporting newly learned behavior patterns - Be repetitive
3. Cater for the need of social interaction
4. Get the partner involved and develop services that include both
5. Connect with already existing social networks
6. Develop services with "quick" wins for the target groups
7. Increase the awareness of regular monitoring
8. Aim at easy to use, almost seamless collection process of Observation of Daily Livings
9. Didactical concept of multimedia information and resources for younger senior citizens

Five recommendations are formulated with regard to the information sources in EMPOWER:

1. Tell them why
2. Aim for personalized information
3. Help to keep track of the "bigger picture" (of the course of the chronic disease)
4. Cater for current, updated information (e.g. RSS feeds for actualization of information)
5. Provide streamlined and visualized information

Four recommendations address gender and digital divide issues:

1. Be aware of different emotional strategies influencing the use of EMPOWER services
2. Develop support functionalities and strategies out-balancing gender-different numeracy skills
3. Unlock the value of gender-differences in internet based health information behaviour
4. Closely follow all interaction design and usability strategies for senior citizens

Three recommendations refer to the implementation of Pilot Application:

1. Cater for accompanying measures to keep pilot-users in the pilot implementation.

2. Evaluate beforehand users' levels of empowerment.
3. Evaluate (self-evaluation) beforehand users' functional abilities.

And the last four recommendations refer to the EMPOWER users, the first two to the patients and the last two to general practitioners:

1. Unlock the value of the digital world for your safety and better decisions in diabetes self-management
2. Consider to hire your personal assistant
3. Do not follow a “top-down” approach to treating patients
4. Facilitate integrated care

2 EMPOWER in a Nutshell

Patient Empowerment involves patients to a greater extent in their own healthcare process and disease management becomes an integrated part of their daily lives. The capability of self-management opens to them the possibility for patients not only to contribute to their own healthcare but also to be more in control of their disease. EMPOWER develops a modular and standard-based Patient Empowerment Framework which facilitates the self-management of diabetes patients based on PHRs and on context-aware, personalised services. EMPOWER focuses the research and development efforts on a patient-centric perspective that also involves healthcare professionals. EMPOWER provides knowledge-based Self-Management Pathways for diabetes patients. This includes

- (1) Services for the specification and execution of actions to change behaviour according to diabetes-specific health care needs. Patients can develop personalised action plans which include recommendations from the treating physicians and patients' preferences
- (2) Services for monitoring of vital, physical, mental parameters as well as physical and lifestyle activities based on health standards.



Figure 1: EMPOWER Management Pathways

EMPOWER semantically integrates multiple information sources (EHR/PHR, diabetes guidelines, patterns of daily living) for a shared knowledge model. The Self-Management Pathways facilitate the specification of recommendations that allow specifying individual goals for the patient. Based on these goals, relevant information and their preferences patients can specify their individual diabetes-specific actions. The Self-Management Pathways are an iterative process where executed actions and reported patterns of daily life can be evaluated. Recommendations, goals and actions can be updated iteratively according to current needs and preferences. Finally, the services in EMPOWER will embrace semantic interoperability based on health standards such as HL7 (Health Level Seven International, 2012) and IHE (IHE, 2011) profiles.

EMPOWER addresses long-term goals and short-term activities in order to facilitate the self-management of patients with diabetes and thus the treatment of chronic diseases. The pilot

applications in Germany and Turkey will demonstrate that the holistic and patient-centric approach of EMPOWER can improve disease management by personalised self-management services helping diabetes patients to cope better with their condition.

3 Introduction

3.1 Objective and target groups of the study

The main objective of the pre-study is to identify focal concepts and strategies that help fostering chronic patients' empowerment. Since these concepts and strategies are highly dependent on the specific context of a chronic illness this document will be focused on diabetes self-management, and specifically on how this is enhanced by Information Communication Technology. Diabetes self—management education is critical for diabetes care, therefore national standards (Funnel et al. 2009) worldwide are nowadays dealing with it. The starting point of the pre study is the review of scientific literature and best practices from the field with a focus on Europe. These first outcomes are compared and integrated with results from focus groups and interviews with diabetes patients and experts.

The results of the study, and in particular the recommendation part, will be the starting point for the continuing EMPOWER activities, i.e.:

- the technical requirement specifications in Task 3.2 “Gathering Technical Requirements of EMPOWER Architecture”;
- the educational information material for self-management to be developed throughout the project (Task 4.2);
- the storyboard development as the essential part for the design of the Pilot Applications (Task 8.2);
- the exploitation strategy of the components developed in the EMPOWER project.

In order to fulfil the main goal of the project, meaning high acceptance and usage of the EMPOWER services by patients (and their treating physicians) (see DoW p. 51), this task will be targeting different groups. The groups will be targeted either directly or indirectly:

- the software-developer partners / group of the EMPOWER consortium (direct);
- the organising group of the pilot diabetes management programmes, using the to-be developed EMPOWER software (direct);
- the interested public in patient self-management for chronic care and diseases (indirect).

3.2 Description of the task

This deliverable presents the development of the pre-study for the EMPOWER project and how it was conducted. The pre-study serves as input for the technical requirement specifications (Task 3.2), and in the long run will form the basis for the exploitation strategy. It reviews existing literature and models on coping strategies of patients suffering from diabetes, and it analyzes models and concepts of patient self-management.

The deliverable is structured as follows: in the following a section dealing with state of the art diabetes self-management, both drawing from academic literature and national standards, will be presented. After that the identified topics and results will be related to the core conceptual topics of EMPOWER, together with the results of focus groups and interviews which have been conducted with diabetes experts and patients both in Germany and in

Turkey. All the important findings will then be summarized in the recommendations part, which will support and form the basis of the further work of the technological partners. Starting from this last section the EMPOWER consortium will translate everything that was achieved into technical requirements.

The pre-study covers the following topics:

- Literature review on different information seeking behaviors, coping strategies for patients with chronic diseases with a focus on diabetes and the usage of the internet,
- Comparative analysis of media competences and skills for using web-based patient empowerment and self-management activities in relation to age, gender, social level (in countries involved);
- European and international initiatives and projects with focus on self-management of chronic diseases and in particular on diabetes (Best Practice Collection);
- Solutions for self-control (technological and non-technological);
- Barriers and enablers for patient empowerment and self-management
- Challenges for concepts and solutions for web-based motivation and self-efficacy strategies.

The focus of the pre-study is to survey internet information behavior, media and device preferences and media competences and skills of diabetes patients in relation to e.g. age, gender, social criteria. Furthermore, the pre-study aims to analyze how the acceptance of the collection of daily living patterns and routines can be organized and structures for different groups of diabetes patients. The objective is to understand different approaches how patients want to be and can be supported in their self-management and to provide on this basis different approaches and levels of services for EMPOWER. Hence, the results of the study will allow specifying different levels of services based on criteria such as social criteria, age, technological skills and access to Internet services. The requirements for the Pilot Applications defined in Task 8.1, and a workshop including medical and health experts such as patient representatives will basically support the requirement specification for EMPOWER and in particular provide additional input for the pre-study.

3.3 Methods

The pre-study was based on three main methodologies: desktop research, focus groups, and individual semi-directive interviews.

The desktop research aimed at covering the state of the art on diabetes interventions by means of ICTs, and also to present the theoretical framework of the project. The literature review was conducted in different scientific databases, starting from PubMed, to the more specific databases the publishing houses (Wiley, Sage etc.). Results from the desktop research are presented in sections 4 and 5 of this deliverable. Main findings from the research on chronic illness self-management through the use of ICT with a focus on diabetes are presented in part 4. Section 5 presents a comparative analysis on digital competence for web-based patient empowerment.

The following chapter (6) presents the results of the focus group study and interviews with diabetes patients and doctors in Turkey and Germany. Results are analysed in view of the proposed theoretical background (framework) which is also presented in this chapter.

Since the purpose of the pre-study was the identification of focal concepts and strategies which help fostering chronic patients' empowerment one objective was to collect data from this particular population. As the pilot applications will be validated in Turkey and in Germany we collected information and needs from patients and doctors in the two countries.

Focus groups were used to collect information in Germany, where three group discussions took place from March 27th-28th, 2012. The focus groups were organized by GOIN, and USI

provided invitation letters for the purpose of recruitment. A first focus group with patients was conducted by a facilitator from USI and supported by a co-facilitator. Nine patients suffering from diabetes mellitus type 2 took part in the focus group discussion. Another focus group brought together other nine patients, while a third one involved seven doctors. A grid of the questions for both patients and doctors is in the Annex 9.1.

The focus groups lasted one hour and a half, and they were recorded and transcribed. After each focus group's session the researchers met for debriefing. A thematic analysis with a continuous comparison among researchers was conducted and the results are displayed in section 6.2.

Based on the analysis of the focus groups and literature review a needs analysis was conducted (6.4).

A different methodology has been used to collect data from Turkey. Because of organizational reasons the questions prepared for the focus groups were asked to Turkish patients and doctors in individual interviews mediated by Skype. The interviews lasted for about 40 minutes, and they were conducted on June 7th 2012. Two doctors and three patients were interviewed. The last interview was conducted with the daughter of a diabetes patient. During the interviews an interpreter from MoH was present who simultaneously translated the questions asked by USI researchers. For matter of time the interviews were registered but not transcribed. On the basis the recordings and their notes USI researchers integrated the results from the analysis of the data into the final draft of the deliverable D211.

The last two sections deal with the identification of user behaviour patterns (7). Using the persona method, different persona sets were developed for EMPOWER (7.3).

The last section (8) presents a number of recommendations based on the previous findings and should lay the basis for further progress of this project.

4 Chronic Care and Diabetes Management

4.1 Best Practices in Diabetes Care

In this section four main example of best practices are presented. The first one refers to Stanford diabetes self-management program, which have been largely presented in the literature and will be discussed in the literature review about technological interventions for diabetes.

A second example is a study on best practices in the field of diabetes care, which sum up the main characteristics that works for both patients and doctors. A third one is an example of a large scale study which make some important issues arising on the needs of patients suffering from diabetes. A last example is the collection of best practices from Canadian Diabetes Associations, which collected 45 practices on the basis of some standard criteria. The notes refer to the original documents.

1. The Stanford Diabetes Self-Management Program¹

The Diabetes Self-Management workshop is part of the broader Stanford Self-management program for chronic disease. The workshop is given *"2½ hours once a week for six weeks, in community settings such as churches, community centers, libraries and hospitals."*

It involves people with type 2 diabetes mellitus, who attend the program in groups of 12-16, two leaders facilitate the workshop through the use of a detailed manual. Both of them are patients suffering from diabetes.

¹ <http://patienteducation.stanford.edu/programs/diabeteseng.html>

The topics include:

- 1) techniques to deal with the symptoms of diabetes, fatigue, pain, hyper/hypoglycemia, stress, and emotional problems such as depression, anger, fear and frustration;
- 2) appropriate exercise for maintaining and improving strength and endurance;
- 3) healthy eating
- 4) appropriate use of medication;
- 5) working more effectively with health care providers. Participants will make weekly action plans, share experiences, and help each other solve problems they encounter in creating and carrying out their self-management program.

Course material have been reviewed by health professionals. Each of the participant is given a copy of the companion book (Living a Healthy Life with Chronic Conditions), and an audio relaxation tape, and an audio exercise tape.

The program has been successfully evaluated and the results have been largely published (Lorig et al. 2003). One of the key factors of the effectiveness of this program is the way it is taught. The participation to the groups is fostered such as the mutuality, and this makes the participants more confident in their ability to manage their condition and to live their life actively.

2. Diabetes Care Interventions: A Best Practices Study

A study from Mayo Clinic "Diabetes Care Interventions: A Best Practices Study,"² revealed three best practices for both physicians and patients to utilize in on-going diabetic treatment. All together these practices greatly enhance the treatment of diabetes:

Use of a diabetes patient registry. The number of patients is constantly increasing thus worsening the ratio between patients and health professionals. Therefore there should be a solution to maintain accurate records and information. The availability of a patient registry would also facilitate the situations of a change of the doctor, or even unexpected occurrences. In this way both doctors and health providers can have a better view of patients' medical history. This can serve also for alerting doctors about compliance issues or other problems such as: scheduling blood tests to measure haemoglobin A1c (HbA1c)/lipid/micro albumin levels and making certain patients are complying with treatment regimens.

Patient performance reporting and feedback tools. There are many treatment measures for diabetes patients, and their conditions are in constant change therefore they need the adjustments of treatments by doctors. A system for comprehensive reporting and feedback would help to mitigate errors and therefore foster patients' and doctors' quality of life. Moreover this system would allow physicians to identify priorities, and most effective interventions. This kind of monitoring can be both paper pencil or technological, but of course the use of EHR would facilitate the process.

² <http://www.mayo.edu/mayo-edu-docs/center-for-translational-science-activities-documents/christianson>
<http://www.medpagetoday.com/Columns/And-Now-a-Word/30842>

Use of a dietician. Patients suffering from diabetes have to face nutrition and physical activity problems. It would be therefore useful for them to address their needs through the help of a dietician beyond their conventional doctor. The dietician encourages the patient to become more active in monitoring diabetes, therefore can foster empowerment.

3. The DAWN study

An important example from which we can collect best practices in diabetes care, and above all the description of some needs of diabetes patients, is the DAWN study³, a cross-sectional international survey started in 2001. As summarized by the publications resulting from project and from Funnel (Funnel 2006) review, five are the key findings of this project which point to the main needs of diabetes patients.

- **Promote active self-management** – self reported rates of self-management (compared with the recommendations received) were particularly low both in type 1 and type 2. Also providers rated that their patients have a low adherence, especially type 2.
- **Enable better psychological care for patients with diabetes** – as resulted from the survey diabetes distress was quite common among all patients, and providers described the patients as being concerned about this. They also assessed that distress is interfering with self-management. Distress was not just connected with diagnosis and the first stages of the illness, but also with the long run.
- **Quality of relationships between providers and patients** – the majority of patients rated the quality of their relationship with health care providers as good. On their side the providers assess the need to understand more of the psychosocial consequences of diabetes and of the cultural differences. In line with the literature a better relationship was related to better health outcomes.
- **Team-based care** – team care was not so present in diabetes patients' lives, even though it scored higher in diabetes type 1. Patients who collaborated with nurses reported better self-management behaviours. Patients also felt that their providers were not talking to each other about them. Providers seem to be not satisfied by the payment for chronic care.
- **Overcome barriers to the effective use of medication therapy** – both patients and physicians identified barriers to the use of medications. Patients reported that it was too complicated to use medications. They also blame themselves for their low adherence, even though this was less the case for the ones who reported to have a better diet and to be able to self-manage the disease and also have less diabetes-distress.

The results from this study are in line with what health care professionals and patients suffering from diabetes were already aware of. Diabetes generates further problems that become barriers to the adequate control and self-management. On the other hand the health care system is not prepared to react to that and to support chronic illness adequately. These are the issues that should be taken into account by individuals and society, and with all the means possible, also through the use of technology, to deal with diabetes. The strategies enacted to counter attack problems have to take into account these needs.

³ <http://www.dawnstudy.com/>

4. Canadian Diabetes Association: Best practices in Diabetes Education⁴

Canadian Diabetes Association published a catalogue of 45 “best” or “promising” practices in diabetes education on the basis of the six Process Standards from the Standards for Diabetes Education in Canada developed by the Association’s Diabetes Educator Section (DES). Each practice should meet the following standards in order to be inserted in the catalogue:

1. Diabetes education is based on ongoing, client centered needs assessment of individuals and or communities.
2. Plans for diabetes education are client-centered and ongoing.
3. Implementation of diabetes education is client-centered and facilitates learning.
4. Diabetes education services partner with other resources and services required by individuals, support persons and/or communities affected by diabetes.
5. Diabetes education is provided according to the practice standards of the healthcare professionals involved.
6. The effectiveness and quality of diabetes education services are regularly evaluation and revised, as needed.

The document which can be downloaded from the link in the footnotes lists all the practices in details, but the six standards give already an overview of what a best practice in diabetes education should achieve.

4.2 Diabetes interventions by means of technology

The prevalence of diabetes is increasing and the projection for the next decades draws a global epidemic that is constantly expanding. For this reason research from different fields is focusing on fostering diabetes self-management, and since the costs for healthcare are becoming unsustainable the creation of interventions based on ICT seem to be the only viable solution. Traditional approaches are now inadequate because they cannot reach people, they have not been able to support long term behaviour change, and mostly because resources are lacking for establishing proper self-management education and follow up support (Glasgow et al. 2012). As described by Piette (2007) “Interactive Behavior Change Technology (IBCT) is one potential resource for improving the effectiveness of diabetes management programs given the very real limits on funding and staffing time”. Moreover with the words of Verhoeven the “use of technology that supports electronic information and communication exchange has a significant positive effect on both clinical and behavioural outcomes” (Verhoeven et al. 2010).

So far many studies in the literature have shown to be more or less effective and to produce good outcomes on different levels, such as clinical or psychological. However some authors pointed out that without an integration of these systems with personal health records, and without embedding them in the broader healthcare system (Glasgow et al. 2012; Piette 2007; Krishna and Boren 2008) this effectiveness is drastically reduced. The assumption of the necessity to integrate new systems into the broader healthcare service is therefore the basis for new technological intervention to be effective under many respects in the field of diabetes. But this is not the only open question. There are still some gaps in science concerning the right type of self-management, or whom we should target more. Although a clear taxonomy is missing, which could help revising properly diabetes interventions and respective outcomes, there is already some evidence that can serve designing new technologies for diabetes self-management (Boren et al. 2008). In the following we will divide

⁴ <http://www.diabetes.ca/documents/for-professionals/Bestpractice-eng.pdf>

these insights into types of technologies, types of contents and aims, and outcomes. The latter will be further exploited in paragraph 3.3.3.

In 2005, Jackson reviewed interventions with type 1 diabetes patients. The interventions observed were: internet-based, telephone-based and computer-assisted integration of clinical information. Those technologies were reviewed with regard to outcomes, and internet interventions showed a positive impact on patient-centered outcomes⁵. Telephone interventions had a positive impact on primary care visits, whilst computer-assisted integration of clinical management had a positive effect on the health care outcomes (Jackson et al 2006). Internet based interventions were also effective in terms of support, since they were able to affect support both from pre-existing relationships as well as from new relationships formed during the intervention (Barrera et al. 2002).

Verhoeven and colleagues revised technology-based interventions and divided technologies into: a communication, and synchronous communication. The first typology includes monitoring and delivering feedback via email, internet, cell phone, automated messaging systems, or other tools of this kind. On the other hand synchronous communication involves real-time, face-to-face contact through videoconferencing and connecting two or more persons simultaneously. The last type appeared to be less suitable to foster self-management, while asynchronous communication was mostly used. In his evaluation asynchronous interaction reported *“more improvements in clinical values and self-care”*, synchronous application *“reported more improvements in usability of technology and cost reduction”*, and combined applications *“scored best according to quality of life”* (Verhoeven et al., 2010, p. 679). He also underscored one common problem related to ICTs, namely that satisfaction with technology depended mostly on education and training (Verhoeven et al., 2010).

In many cases elsewhere specific kind of technologies, such as the use of telephones, have shown to be suitable also for minorities (Krishna & Boren, 2008). Cell phones have been shown to be reliable tools for monitoring and exchanging information between patient and HCP, and the new possibilities given by smartphones and applications would enhance this effectiveness. *“ICT, especially asynchronous applications such as mobile phones, is being used increasingly for improving diabetes care, resulting in an increased and even more reliable transmission of clinical values and intensified patient-caregiver information exchange.”* (Verhoeven et al., 2010)

Areas of interventions, aims and contents are often mixed in the literature, and they are all strongly connected with health outcomes. However we will try to distinguish here some of the most important. Technological tools in the field of diabetes interventions can serve to:

1. *“Assist patients and their clinicians in monitoring changes in health and self-care needs;*
2. *Support patients’ efforts to make behaviour changes by promoting health and effective self-care;*
3. *Enhance communication between patients and potential support for their disease management”* (Piette, 2007).

In the categorization of Piette (2007) the areas of intervention are: medication adherence; physical activity; patient to patient support; informal caregivers, which are four critical parts in diabetes patients’ lives.

5

http://patienteducation.stanford.edu/research/Review_Findings_CDSMP_Outcomes1%208%2008.pdf

<http://diabetes.niddk.nih.gov/resources/HealthTools/index.aspx>

<http://patienteducation.stanford.edu/research/>

Wagner Chronic Care Model:

http://www.improvingchroniccare.org/index.php?p=The_Chronic_Care_Model&s=2

As one of the conclusions in his review Verhoeven and colleagues (2010) assessed that *“Technology-based interventions should not only address clinical or disease aspects but also consider behavioural control and the care delivery process in order to realize sustainable changes in diabetes care. This implies for health care applications that they should combine information with at least one additional ICT functionality for behaviour change, education, decision supports, or social support with peers or families to have optimal results.”* (Verhoeven et al., 2010, p. 668).

Apart from information, Lorig’s successful interventions included individualized exercise programs, cognitive symptoms’ management, methods for managing negative emotions, *“aspects of physician-patient communication, healthy eating; fatigue management; action planning; feedback; and methods for solving problems that result from living with a chronic disease”*. (Lorig et al., 2006, p. 965) Aim of her course was to enhance self-efficacy, and therefore was taking care of all motivational aspects a part from pure information.

Nevertheless, various interventions anyway already include these behavioural components through education, monitoring, and communication.

Depending on the focus of the researchers involved, on the theoretical background, and on the areas of intervention of the technology, there are different outcome measures that have been taken into account. A unique taxonomy is still lacking, but we could divide them in: behavioural outcomes, biological outcomes, and psychosocial variable following the recent classification of Glasgow (Glasgow et al., 2012). The table below is extracted by a systematic literature review of Boren, and divided the outcomes into classes (Boren et al., 2008).

Knowledge and prevention
1. Understanding diabetes ^{18,27,37,38}
2. Self-care and monitoring ^{25,38}
3. Prevention and management of complications ^{15,18,27,37,38}
4. Emergencies ³⁰
5. Foot and skin hygiene ^{18,26,37,38}
6. Oral hygiene ¹⁸
7. Regular eye examination ^{18,26}
8. Smoking cessation ^{21,22}
Glucose level
9. Blood glucose monitoring and recording ^{16,18,25–27,29,33,37,38}
10. Urine testing ^{27,37}
11. Insulin adjustment and administration ^{16,18,27,33,37,38}
12. Medication ^{18,26,37,38}
Diet and activity
13. Diet and nutrition ^{15–24,26,27,31,34–38}
14. Food purchasing and meal planning ^{27,34–36}
15. Exercise and physical activity ^{17,18,21,22,26–28,31,33,34,38}
Management and coping
16. Alcohol ²⁷
17. Goal setting ^{17,19–26,28,35,36,38}
18. Problem solving ^{19,20,28}
19. Self-motivation ²⁸
20. Social support ^{25,32}
21. Stress management ¹⁸
22. Social activities ¹⁵
23. Coping ²⁵
24. Traveling ^{27,33}

Table 1: Diabetes Education Content (from: Boren et al., 2008, p.142)

Before an extensive section on outcomes, the following will focus on recommendations for effective diabetes interventions that we inherited from the literature, and that will be further explained later: (1.) the necessity to involve patients in the design of the interventions, and (2.) the importance of embedding the technological intervention into the primary care system.

4.2.1 Personalized interventions

An extensive part of the literature reviewed stressed the importance to design personalized interventions. Most successful technological environments allowed individual access, individual setting of goals, provided motivational support etc.

Krishna (Krishna & Boren, 2008) described the website intervention as a “basis of personalized advice and support from the diabetes care team”. This has two main implications: on the one hand the health care team can provide personalized advices on the basis of patient history, and on the other hand patients can set individual goals and receive motivational messages related to them. Diabetes patients have to overcome barriers to conduct a healthy lifestyle, and if the systems collect their personal history, their goals, and monitor clinical information they could be programmed with algorithms to motivate patients through messages.

The role of the patient as the one who is setting his/her own goals is also underscored by Glasgow (Glasgow et al., 2012), whose perspective on effective diabetes self-management interventions is fully patient-centered. He suggests to create websites with “individual logins and individual action plans for: medication taking, healthy eating and physical activity”. The patient should be the protagonist and individuate himself the personal barriers to self-management, and the problem solving strategies to overcome them through his/her action plan. Even though these conditions are successful for the creation of an effective intervention, Glasgow underlines the importance of integrating those systems in PHRs, thus to have stronger results. Together with Barrera, Glasgow also stresses the importance of social support interventions that are able to target individuals (Barrera et al., 2002).

The personalized approach has already shown to be successful in Lorig’s works. All the programs for chronic conditions she developed with her team were “built on needs assessments that identified patient-perceived disease-related problems” (Lorig et al., 2006, p. 965). Those interventions included “individualized exercise programs; use of cognitive symptom management such as relaxation, visualization, distraction, and self-talk; methods for managing negative emotions such as anger, fear, depression and frustration; an overview of medications; aspects of physician-patient communication; healthy eating; fatigue management; action planning; feedback; and methods for solving problems that result from living with a chronic disease. The course is taught in an interactive manner designed to enhance self-efficacy.”

As an implication it is therefore important to design patient-centered technologies, and to involve patients from the very beginning of the design. *“The advantage of IBCT (Interactive Behaviour Change Technologies) communication is that diabetes services can enter the real world in which patients live. IBCT services must be based on a holistic patient-centered model that takes patients’ full range of comorbid conditions and their own goals into account”* (Piette, 2007).

The necessity to focus on patients and involve them since the intervention’s design is also crucial for Verhoeven, who assessed that there is a need of “better tailored” applications’ to patients’ needs. Targeting their needs does not only mean to make them part of the process, but also to account for differences in the population. For example in Boren’s study (Boren, 2009) persons with low level of health literacy have shown to be interested in telephone support but worse communication with HCP and less willingness to engage in medical decision making were reported.

Again Krishna (Krishna & Boren, 2008) assessed that telephone-based interventions had positive results even with ethnic minorities and persons with lower socioeconomic status. These are just some of the differences that can arise, but effective interventions should be able to address differences in age, socio economic status, media literacy, ethnic minorities etc.

4.2.2 The doctor-patient relationship

For a patient to be able to self-manage his/her disease means to have enough knowledge, and also motivation in order to participate in shared decision making and to “*work together with their HCPs*” (Lorig et al., 2006). Moreover, as assessed by Krishna (Krishna & Boren, 2008), “*quality health care requires effective collaboration between clinicians and patients*”.

If on the one hand the aim of a self-management intervention is to give to patients information and the possibility to increase their motivation, it is on the other hand important to remember that the ultimate goal is their participation in the process of care. In this view the relationship with doctors, and in general with HCPs, should be fostered by technologies for self-management.

Primary care is often lacking the resources to give patients the education they need in the first place, and then to continue the relation with them with follow-up support. Therefore diabetes self-management interventions by means of technology, which aim at facilitating patients everyday life should account for an integration of these technologies in the primary care activities. Patients would need to have follow-up and constant monitoring in order to become properly empowered (Glasgow et al., 2012). Internet-based support interventions for example “affect support from pre-existing relationships as well as the new relationships that are formed as part of the intervention. Internet-based interventions might facilitate support seeking from new and pre-existing sources of support” (Barrera et al., 2002).

In the literature asynchronous applications as mobile phones have shown to be effective in diabetes care, because they ensure a reliable transmission of clinical data and allow an “intensified patient-caregiver information exchange (Vehoeven et al., 2010). Moreover the interventions based on the use of telephone⁶ had positive results even with persons of “*low socioeconomic status and ethnic minorities*”(Krishna and Boren 2008). Unfortunately for now few diabetes care interventions have been used to support collaboration between caregivers and patients, in order to “balance self-care and professional care” (Verhoeven et al., 2010). This clearly indicates a need to better exploit technologies for their communication potential to profit from the potential of mobile phones and new smartphones (Krishna & Boren, 2008).

Interactive technologies are a potential resource to improve the effectiveness of diabetes management programs. These tools can primarily: “1. Assist patients and their clinicians in monitoring changes in health and self-care needs; 2. Support patients’ efforts to make behaviour changes by promoting health and effective self-care; 3. Enhance communication between patients and potential supports for their disease management.” (Piette, 2007).

4.3 Technological Interventions: Outcome measures and related components

Different outcome measures are useful in determining the impact of technological intervention systems on diabetes care (Adaji et al., 2008).

⁶ We are referring here to the use of mobile phone for asynchronous interventions, such as games, applications, messaging etc.

The aim of the following section is to identify outcome measures of technology-based interventions and their related intervention components, with a main focus on web-based interventions.

Only few web-based interventions in the field of chronic diseases have tried to measure empowerment as an outcome measure as such. Samoocha and colleagues (2010) identified in their review on web-based interventions with a focus on patient's empowerment (not diabetes specific) only two studies that measured explicitly empowerment; including one study using the Diabetes Empowerment Scale (DES) (Anderson et al., 2000).

According to Anderson and Funnell (2010) empowerment consists of two components, a process and an outcome component. The former refers to increasing a patient's capacity to think critically and make informed decisions, whereas the second component refers to measurable increases in these abilities. Within this framework health care providers are responsible to ensure that

"(...) patients are equipped to make decisions informed by an adequate understanding of diabetes self-management and an awareness of the aspects of their personal lives that influence their self-management decisions."
(Anderson & Funnell, 2010, p.4).

As specific empowerment related outcome measures are still rarely used in studies, we will refer in the following section to outcomes that relate to what has been described by Anderson and Funnell (2010) as the outcome component. In order to better understand if patient's were able to make more informed and more critical decisions, we can use the outcome measures that have been used so far in studies as a proxy of empowerment and related behavioural changes.

The most prominent outcome measures are changes in the HbA1c level. We divided outcome measures into clinical and their related outcomes, *medication* or *weight management*; and nonclinical outcomes, such as *self-efficacy* or *diabetes knowledge*. Finally we will briefly talk about *usability* as an outcome measure.

4.3.1 Clinical and related outcome measures

HbA1c

In general HbA1c changes are considered to be indicators of behavioral change, (Minet et al., 2010), such as medication adherence, physical activity, improved monitoring, etc. Thus, most of the interventions that include the usage of technologies focus on the change in HbA1c levels as a measure of success.

McMahon and colleagues (2005) found in their web-based intervention with diabetes patients a greater decline in HbA1c over time than in patients receiving only usual care. Further, they showed that patients who had a greater adherence with the program also had greater improvements in HbA1c levels than patients who showed less program adherence.

Participants received a notebook together with a glucose meter and a blood pressure monitor. The notebook would connect the patients automatically to a diabetes education and management website⁷ which allowed uploads from blood pressure and glucose monitoring devices and displayed these data in graphs and tables. Further an internal messaging system was installed allowing participants and care managers to interact. The care manager would answer within 1 day during office hours. The website also provided web-enabled diabetes educational modules and was linked to other web-based diabetes resources. An advanced practice nurse and certified diabetes educators would review participant data from the website and based on treatment algorithms for glucose and hypertension management, make suggestions to the primary care provider and participants (McMahon et al., 2005).

⁷ <http://www.mycareteam.com/about/Background.aspx>

Costa and colleagues (2009) found in their review on IT-based management interventions that interventions which were implemented when the mean baseline of HbA1c was 9.0 – 11.0% were related with significant improvement in HbA1c (7.5% - 7.68).

Balas and colleagues (2004) found in their literature review on studies that used computerized knowledge management systems in diabetes care that most of these systems were somehow related to improvements of HbA1c. In particular were improvements related to the usage of computerized analysis of home glucose records. Additionally, studies using distant diabetes control showed to help insulin dependent diabetes patients to reduce their doses of insulin, blood glucose levels and even to decrease their glycated hemoglobin levels without an increase in clinician contact. Further, they found that in systems where blood glucose levels were transmitted automatically via computer led to improved HbA1c and blood glucose levels and that automatic insulin dose adjustment resulted in lower dose among intervention patients (Balas et al., 2004).

Russell-Minda and colleagues (2009) found similar results in their systematic review on studies that included self-monitoring devices, such as blood pressure devices, heart rate monitors, pedometers or accelerometers or web-enabled technologies, moderately strong evidence that self-monitoring of blood glucose devices (SMBG) may be an effective tool to maintain metabolic control. However, they pointed out that evidence in particular suggests that SMBG testing may be more effective in noninsulin-treated type 2 diabetes patients to improve glycemic control.

In general, cell phones and other wireless devices have shown to have an impact on lowering HbA1c levels. Studies that showed good results included the usage of cell phones with SMS and internet. Patients initially set up their data on a website, including such information as blood glucose values, kinds and dosages of insulin, etc. Afterwards the patient would receive recommendations and reminders via SMS on a weekly basis (Russell-Minda et al. 2009).

Verhoeven and colleagues (2010) showed that most of interventions that included teleconsultations (via email, cell phone, automated messaging systems as well as synchronous communication such as videoconferencing) had an impact on HbA1c levels. Balas and colleagues (2004) also reviewed the physician's perspective and found that interventions which were targeted towards physicians and which generated automatically summaries for diabetes patients did not lead to a significant decrease of HbA1c levels between the intervention and the control group. Nevertheless, the interventions enhanced the overall compliance of physicians with recommended diabetes care procedures and guidelines.

Ali and colleagues (2011) conducted a qualitative literature review specifically on studies that integrated electronic medical records and computer decision-support systems (EMR-CDSS tools) for clinical diabetes care and found that most of the studies demonstrated a HbA1c reduction in diabetes patients over the duration of a year.

Medication

With regard to maintaining a high degree of glycemic control it is of major importance that a patient with diabetes type 2 adheres to his prescribed medication.

Medication adherence can serve as an indicator of a patient's self-management behavior (Verhoeven et al., 2010). Nevertheless changing medication patterns or medication adherence are still rarely evaluated in interventions involving IT. Without evaluating the change or reduction in medication (OHA or insulin), one cannot solely attribute changes due to the interventions (Costa et al., 2009).

Depression

Steed and colleagues (2003) suggested in their review on psychological outcomes of different types of interventions that psychological interventions with the *"aim to reduce the negative mood states through mainly cognitive approaches"* (Steed et al., 2003, p.5) seem to be more often associated with improvements in depression than educational or self-management interventions. Nevertheless, it has to be kept in mind that psychological

interventions showed to include samples with comparably higher baseline levels of depression.

Hospitalization Rates

Dorr and colleagues (2008) developed a care management program that used a team-based approach in order to address the needs of chronically ill patients. Care managers in primary care clinics were trained and equipped with information technology to record and track and react to patients' data. The tools included structured protocols and guidelines for various conditions and diseases, such as diabetes mellitus. Further a patient worksheet and a care management tracking database. Based on current evidence, experts revised and updated guidelines and protocols. Further, a locally developed EHR system was available, which included reminders, notes and functions, such as a detailed patient summary sheet. Based on protocols from the care management tracking database and the patients' worksheets the care managers developed in accordance with the patient a care plan. Every decision taken by a care manager was revised within 24 hours by a team physician. The application could generate reports on the population the care manager saw with information such as medication adherence or tasks from care plans that were not yet completed.

Even though patients with diabetes mellitus showed to have a higher number of comorbidities than other patients with chronic conditions, these patients showed a reduced likelihood of death at year 1 and 2 of the intervention. Further, hospitalization rates showed to be less in the first and second year of the interventions than for patients with diabetes mellitus in the control group.

Chiou and colleagues (2009) extracted visits from a disease management evaluation database in the US emergency department and outpatient clinic, made by 6412 type 2 diabetes patients. They found that patients who adhered to suggested clinic visit schedules by the DMP were less likely to come to the emergency department for less urgent care.

Weight Management

Russell-Minda and colleagues (2009) did not find any significant improvements with regard to weight management when reviewing studies that dealt with the usage of SMBG devices. With regards to pedometers and accelerometers they concluded that evidence about effectiveness of these devices for improving diabetes self-management is still limited. The studies also yielded no strong evidence for weight management, such as reduction of BMI or body fat.

4.3.2 Nonclinical outcome measures

Self-efficacy

23 out of 42 studies showed that technological interventions improved patients' disease management. In particular web-based disease management programs which asynchronous communication enhanced patients' self-management. Out of these 23 interventions only one included synchronous communication. Thus, it may show that synchronous communication is less suitable to enhance patients' self-management. Indicators of better self-management were better management of blood sugar transfer and medication adherence (Verhoeven, 2010).

Costa and colleagues (2009) found that studies which used HbA1c levels as the main outcome measure rarely evaluated psychological factors that may have influenced the patients. Even though psychological factors can eventually influence glycemic control. Studies have shown that high diabetes self-efficacy is directly related with a lower HbA1c levels.

Quality of Life

It has been identified that in studies that used teleconsultations (e.g. communication via SMS or videoconferencing) the level of quality of life in diabetes patients improved slightly less than compared to HbA1c levels. Comparability between studies was however limited as

different measurement tools were used to evaluate quality of life. A big range of assessment tools was used, such as the Diabetes Quality of Life (DQOL) measure (Verhoeven et al., 2010).

Unexpectedly a small number of studies showed that the level of depression and/or worries increased, which could be explained due to knowledge overload leading to the fact that patients became more aware of their situation leading eventually to depression.

A raise of the level of quality of life was often associated with synchronous communication with video. Nevertheless overall *combined applications* (including synchronous and asynchronous communication) showed to be most successful with regard to quality of life (Verhoeven et al., 2010).

Interaction Effects

Verhoeven and colleagues (2010) reported that 28 out of 29 evaluated interventions, which involved teleconsultation, eventually improved patient-caregiver interaction. Interventions included asynchronous and synchronous communication but did not yield different interactional benefits. Both intervention types increased the intensity of contact between the caregiver and the patient. Caregivers were perceived as being more supportive according to the patients. Further, both intervention types showed to increase effectiveness of communication, increased metabolic data transmission, improved the availability and completeness of data among caregivers and improved communication between caregivers. Nevertheless, the authors could not identify any particular type of medium that would contribute the most to quality of interaction.

Knowledge

Verhoeven and colleagues (2010) suggested that due to their findings it is arguable that synchronous communication is more suitable to enhance knowledge, while asynchronous communication is more appropriate to enhance disease management.

Besides it was proposed that patients which were already diagnosed prior to participating in an intervention may have already gained the knowledge to develop strategies to handle their disease. In particular those patients that are successful in maintaining their glucose level close to 7% may have already acquired sufficient knowledge and adapted sufficient management strategies (Costa et al., 2009).

4.3.3 Usability

Osborn and colleagues (2010) reviewed a number of studies that evaluated the usability of the employed intervention tools. Patients indicated that they valued the most secure electronic communication and tracking tools. Barriers to patients were:

- lost or unknown usernames and passwords and
- missing knowledge about features that were provided by the programs (such as glucose tracking).

Further, it was identified that patients did not think of information that was simply placed in the web-based environment as being stimulating. Meaning that provided information has to be provided in an interactive manner by actively engaging the patient in processing the information.

Verhoeven and colleagues (2010) found out that 45 out of 56 studies, which evaluated usability of technology, the usability was assessed positively among participants.

In particular asynchronous interaction was considered to be helpful, while synchronous communication was assessed as being user-friendly by the users. Nevertheless, it has to be pointed out that no systematic comparison could be made, as the participants in the control groups did not use any kind of technology.

Especially interventions which included the usage of cell phones and other mobile devices and videoconferences were considered to be highly satisfactory for participants.

Out of 11 studies, which were evaluated negatively by its users, five studies involved web-based disease management programs which included blood-glucose monitoring and messaging with care providers. Main critique concerned reliability, such as inaccuracy of provided information or installation problems of computer/internet connections or patients' inability to handle the unit due to problems in hand-eye coordination.

In general, reviewers pointed out that usability of technological based interventions has to be assessed with regard to (1.) the level of the familiarity with IT and (2.) with regard to disease progression, (3.) comorbidities and (4.) natural ageing which may reduce the cognitive capacity of participants to handle IT-based interventions appropriately.

4.3.4 Limitations of reviewed studies

The comparability of the studies is limited due to the fact that interventions have been conducted in different environments, such as community health care settings or clinical/GP settings. Further, different studies included different groups of stakeholders.

In addition, sample characteristics greatly varied from one intervention to another. Diabetes type, familiarity with IT, basic diabetes knowledge and other skills may have been important cofounders. Costa and colleagues (2009) suggested that especially with regard to the different types of diabetes, different medication and differences in lifestyle changes may have caused differences in individual's self-management strategies and may have influenced outcome measures.

Further, the taxonomy of different intervention types still greatly varies from one study to another. Which points to the need of developing a coherent vocabulary on technology based interventions across different disciplines and research fields.

Another limitation is that up until 2010 only few studies have involved more than one treatment group. Consequently they have been limited in determining which specific aspects of web-based/technological aspects caused changed and which were the ones that were most beneficial to the patients and providers (Osborn et al., 2010).

4.4 Implications for the EMPOWER Project

In the following section the results of the previous literature research results will be evaluated along the 4 objectives of the EMPOWER Project.

- Objective 1 – fostering self-management with adaptive and secure patient pathways
- Objective 2 – supporting behavior changes with personalized action plans
- Objective 3 – collecting patterns of daily living
- Objective 4 – semantic interoperability with existing Personal Health Application

In general web-based interventions or technology enhanced interventions have shown to be useful in reducing:

- HbA1c levels, by integrating self-monitoring devices, such as glucose meters and blood pressure devices and computerized transmission of these data, as well as by integrating medical health records.
- hospitalization rates.

And useful in increasing:

- self-efficacy.
- diabetes knowledge, in particular when asynchronous communication is used.
- communication between patients and health care providers.

Reduction or change of medication as an outcome measure has been rarely evaluated. Reduction of depressions seemed to be rather related to interventions that included psychological components than solely focusing on the enhancement of self-management of diabetes patients.

Weight management as an outcome variable of diabetes self-management programs still seems to not to reach expectancies. Most studies with the aim of weight management focus on preventing diabetes rather than on self-management strategies for those that already developed diabetes. Nevertheless, it has to be kept in mind that studies that only evaluated e.g. HbA1c can be considered to be an outcome of eventual weight loss.

Quality of life seemed to improve throughout most of the studies, even though slightly less than HbA1c levels. Nevertheless, comparability between studies was distorted due to the fact that most studies use different measures to assess quality of life.

With regard to patient web portals which integrate electronic medical records and patient health records targeting diabetes patients Osborn and colleagues (2010) found that these portals: “...*enhance patient-provider communication, increase overall satisfaction with care, expand access to health information, and improve disease management and patient outcomes in diabetes*” (Discussion, par 2).

From the review of the literature some practical implications, and suggestions for the development of future technologies for diabetes self-management emerged. In the following they are summarized into six main categories, which are linked to each other.

- (1.) First of all it is important to start from an accurate *observation* of the studies in the literature, which means identifying the barriers and the enablers of self-management in order to design proper interventions and to identify “potential solutions” (Piette, 2007).
- (2.) A second important implication is to *tailor technologies to different populations*. This implies to use technologies in a way that they can target the different types of patients distinguished by *age, media literacy, technology availability, level of health literacy, needs* etc. (Boren 2009; Piette, 2007).
- (3.) A third implication is to *avoid the use of technology for the sake of technology* but to use it on the basis of a solid behavioural theory. This has two main consequences: the first one that appropriate technology should be used depending on the aims, the target etc; a second one is that every intervention should be theory driven (Glasgow et al., 2012; Verhoeven et al., 2010; Piette, 2007).
- (4.) A fourth recommendation is that *ICTs should support human contact and exchange*, more specifically monitoring and follow up. This dimension highlights the importance of fostering doctor-patient communication, and in general that ICTs should be able to facilitate contact between patient and health care provider. The stress on communication and exchange is fundamental for the motivation of the patients, who should not just use technology to be informed and to insert data but also to use it to enhance communication between themselves and their health care providers. (Glasgow et al., 2012; Boren, 2009; Piette, 2007).
- (5.) The fifth aspect is the necessity to *translate* the needs of persons involved in diabetes care into a new technology. Everybody should be involved in designing the intervention, thus allowing the development of *personalized medicine*. Key stakeholders should participate in the requirement analysis of a new technology in order to have a better definition of *the context, the channels and the content* (Glasgow et al. 2012; Boren 2009; Verhoeven et al., 2010; Piette, 2007). Many authors stress the importance of *integrating the technologies with primary care activities*. This is the logical step for the usefulness of a diabetes intervention.
- (6.) As a last implication it is important to *pay attention to content, and not just try to develop self-management strategies but to have an holistic approach*. A technology for diabetes patients should account for other needs such as *education, information, support or communication* (Boren, 2009; Piette, 2007).

4.5 Situation in Germany

4.5.1 Examples of chronic care management programmes in general

Unfavorable health behavior styles are widespread and nowadays different populations have a high prevalence for developing type II diabetes. There are both signs of improvement in lifestyle in terms of health, as well as signs of deterioration. Unfavorable changes are especially prevalent in younger people and families in lower social classes. Since the influence of lifestyle is a complex task, it can be assumed from that that the health system can only exert a limited influence.

Health-related lifestyle changes require a number of different measures to provide information about behavioral training to motivate possible long-term changes. The elements have to be individually adapted to different social and age groups. Support from assigned professionals or "coaches" can also be a component.

Communication between treating physician and patient is a necessary element. Recently, it has become clear that disease management programs (DMP) rely more and more on elements of case management.

Offered by health insurers and providers of their own or third parties - DMPs themselves - such as the DMP under § 137f SGB V. It is the responsibility of the DMP offering health insurance to ensure that an appropriate offer is available. Participation is also preceded by a positive vote and a medical statement of participation of the patient/insured.

Patients take part in a program that includes a regular exchange of information between the treating doctor and the above-described highly qualified personnel. The extension of eligibility to the program is particularly linked to the fact that the participation of the patient is positive. Basis for the assessment is not as with DMPs in accordance with § 137f SGB V. The central role is the compliance of the patient, whether the behavioral changes necessary to be fulfilled. In this sense a lack of co-participation in the program is terminated by the insurance company.

Prerequisite for the consideration of the risk adjustment process is that the structured treatment program approved by the Federal Insurance Office is accredited. To obtain authorization, a list of requirements must be met, as laid out in detail in the risk structure compensation regulation (RSAV).

The requirement "catalog" refers to six areas, which are specified in the "with the law on the reform of the risk structure compensation in the statutory health insurance" imported § 137f SGB V are as follows:

1. Treatment according to evidence-based guidance, taking into account the particular supply sector, and, if available, taking into account the criteria in accordance with § 137e Section 3 No. 1 SGB V,
2. carried out quality assurance measures,
3. Requirements and procedures for the enrollment of the insured person to a program, including the period of participation,
4. Training of service providers and insured,
5. Documentation and
6. Evaluation of the effectiveness and costs (evaluation) and at intervals between the evaluations of a program and the duration of its authorization under § 137g SGB V.⁸

The coordinating committee as suggested for structured treatment programs suitable diseases:

8

http://www.bundesversicherungsamt.de/cln_115/nn_1046154/DE/DMP/dmp_inhalt.html#doc1046158bodyText1

- diabetes mellitus
- Breast Cancer
- Coronary heart disease
- Asthma / COPD.

Indikation	Laufende Programme	Teilnahme am DMP	Versicherte, die in einem (oder mehreren) DMP eingeschrieben sind
Asthma bronchiale	1.817	765.828	
Brustkrebs	1.705	128.927	
Chronisch obstruktive Lungenerkrankung	1.823	604.051	
Diabetes mellitus Typ 1	1.657	146.919	
Diabetes mellitus Typ 2	1.832	3.600.092	
Koronare Herzkrankheit	1.784	1.670.448	
Insgesamt	10.618	6.916.265	5.998.886

Stand: Januar 2012

Table 2: DMP in Germany⁹

4.5.2 Examples of diabetes management programmes in specific

Patients who participate in a DMP for type 2 diabetes enjoy advantages such as diabetes training, cooking classes or regular check-ups at the doctor. Meanwhile, nearly half of all diabetics in Germany is enrolled in a DMP. Such programs, known as "chronically ill-programs", exist since 2003 for various medical conditions: for example for asthma, coronary heart disease, breast cancer and for diabetes mellitus type 1 and 2. DMPs were established on the initiative of health insurances.

The aim is to provide each participant a tailored, structured treatment and to promote cooperation between primary care physicians, diabetologists and clinics. Aim is to prevent further diabetes-related long-term complications, such as the heart and kidney failure.

Patients who participate in DMPs are more likely to have check-ups and better blood sugar and blood pressure values. Secondary diseases are rare among them. Thus, preventing further costs in the patients' treatment. Although the expenses have increased for outpatient treatment, the hospital costs have fallen.

The health insurance receives additional money on a monthly basis for each DMP-diabetic from the health fund from which the contributions of the insured on the individual health insurance are distributed. The doctors get the diabetes-specific services separately reimbursed. The money is to offset the additional costs of the physician for his treatment.

DMP participants are entitled eye and feet examinations at least once a year. Also patients who do not participate in a DMP are entitled to these services but in the DMP the physician documents all services and events.

DMP has a clear advantage when it comes to the training of the participants. The funds pay for DMP participants the training.

Participation in the DMP is voluntary. Anyone who wants can to get off at any time or in case of a move to log and enroll at a new doctor again. However, if the patient do not perceive two quarters of his follow-up appointments the the health insurances excludes this person from the program register.¹⁰

⁹ http://www.bundesversicherungsamt.de/cln_115/nn_1046154/DE/DMP/dmp_inhalt.html

¹⁰ http://www.aok-bv.de/lexikon/d/index_00296.html

Examples for Services of Diabetes DMP

Type 2 diabetes

- agreement on individual outcomes (eg, HbA1C, blood pressure values) and appropriate therapy planning
- participation in training, including nutritional advice and guidance on blood sugar, high blood pressure and blood pressure self-monitoring
- testing for protein in the urine (as needed, for example, once a year)
- annual monitoring of renal function (serum creatinine value)
- at least once a year examination of the retina
- at least once a year and quarterly inspection of the feet with an increased risk

Type 1 diabetes

- agreement on individual outcomes (eg, A1C, blood pressure values) and appropriate therapy planning
- participation in training (depending on training level), high blood pressure with instructions for self-control
- at least once a year to test protein in the urine, with multiple positive evidence of renal function (serum creatinine value)
- from the fifth year after diagnosis annual examination of the retina
- at least once a year and quarterly inspection of the feet with an increased risk

4.6 Situation in Turkey

The following information provided in this subchapter is solely written for the purpose of this material, basing on the figures and information contained in several resources such as Turkish Annual Book of Statistics, Common Diabetes Practices, and interviews with doctors and nurses.

4.6.1 Examples of chronic care management programmes in general

Social movement and awareness for chronic diseases

Various “Prevention and Control Programs” were initiated in Turkey within the framework of relevant studies aimed at improving the cooperation between primary and secondary level healthcare institutions, settling the system on disease prevention, early diagnosis, adequate treatment and regular follow-up of the patients, as well as improving their quality of life by reducing mortality and morbidity.

The World Health Organization (WHO) warns that chronic diseases are increasing rapidly and that they will constitute the highest workload in the healthcare systems in the future. Moving from this point, The Turkish Ministry of Health (MoH) revised the structure for chronic diseases and established two new departments to specialize in chronic diseases and health promotion. Examples include successful initiatives such as the “National Tobacco Control Program”, which was developed in line with the WHO framework on tobacco control or the implementation of an action plan with regard to chronic respiratory diseases. Further initiatives cover fields such as obesity and cardiovascular diseases.

4.6.2 Examples of diabetes management programmes in specific

The WHO estimates that unless urgent action is taken, deaths from diabetes will increase by more than 50% in ten years worldwide¹¹. According to the Turkish Diabetes Epidemiology

¹¹ <http://www.who.int/features/factfiles/diabetes/facts/en/index1.html>

study (TURDEP), the diabetes prevalence in our country is 7.2% (8.0% among women and 6.2% among men). Among the leading causes of death in Turkey, Ischemic Heart Diseases by 21.7% and Cerebrovascular Diseases by 15.0% are the most common causes of death, followed by diabetes ranking the eighth by 2.2%¹².

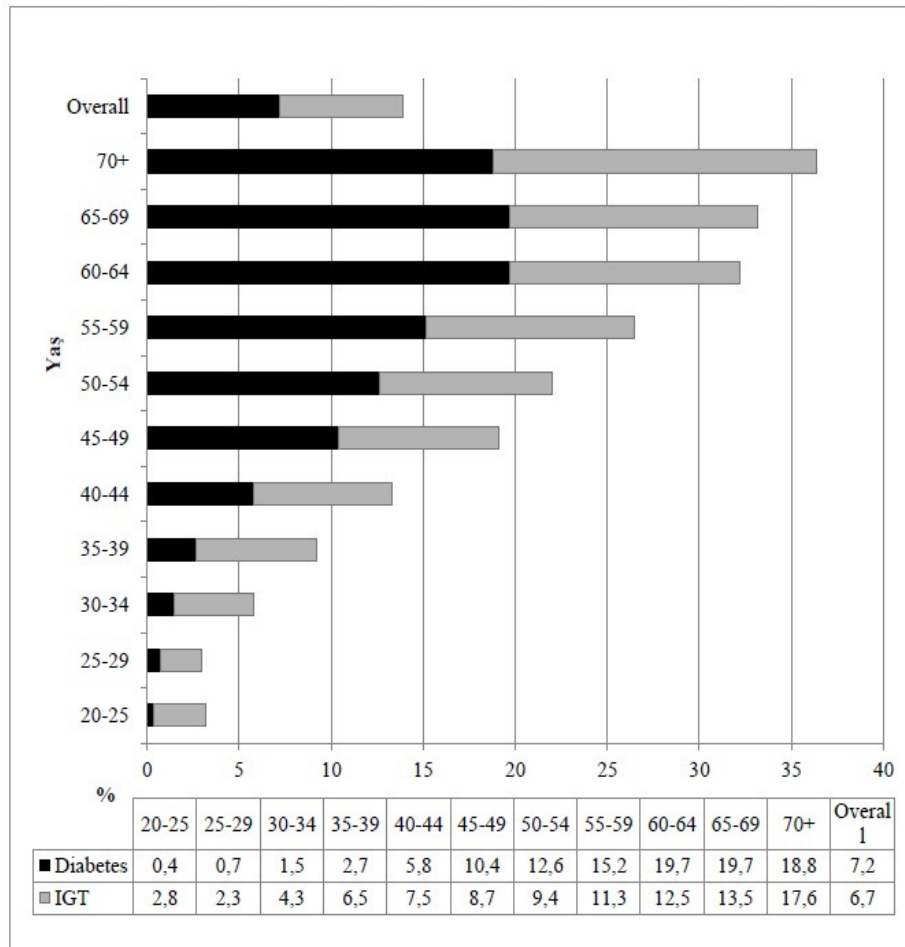
The Turkish Diabetes Epidemiology Study (TURDEP-I), which was conducted between 1997 and 1998 in 270 villages and 270 urban sub-districts in 24788 randomly selected persons older than 20 years of age, found national prevalence of Type 2 diabetes to be 7.2%, and prevalence of impaired glucose tolerance (IGT) 6.7% (13). TURDEP-I findings on the prevalence of diabetes and IGT are shown in Graph 1 in 5-year intervals, beginning at 20 years of age. Based on these percentages and the 2007 census data from Turkish Statistics Institution (TRSI), there are more than 2.85 million people with Type 2 diabetes, and around 2.6 million people with IGT in Turkey. The study notes that diabetes is more common among women and in urban regions, and the risk for developing diabetes is associated with aging, obesity, hypertension, family history of diabetes, poor education, low income and habits like smoking, drinking alcohol, fast food consumption, passive life style, lack of exercises etc. When considered with WHO and IDF estimations, TURDEP-I findings suggest an upward trend of diabetes prevalence.

“Diabetes Prevention and Control Program Action Plan (2011/2014)” was can be reached online and downloaded at the following link:

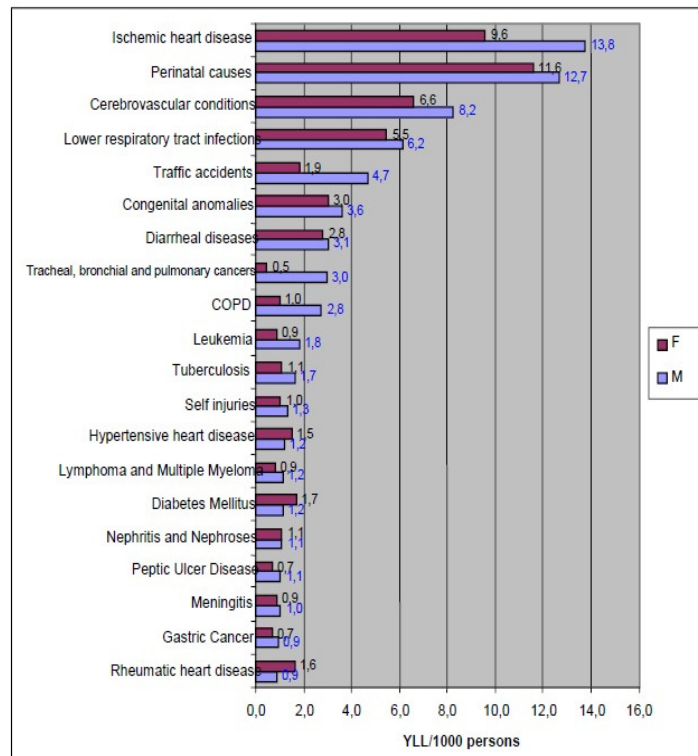
<http://diabturk.org/content/en/>

Below are some figures for easy illustrations of some statistical diabetes facts in Turkey.

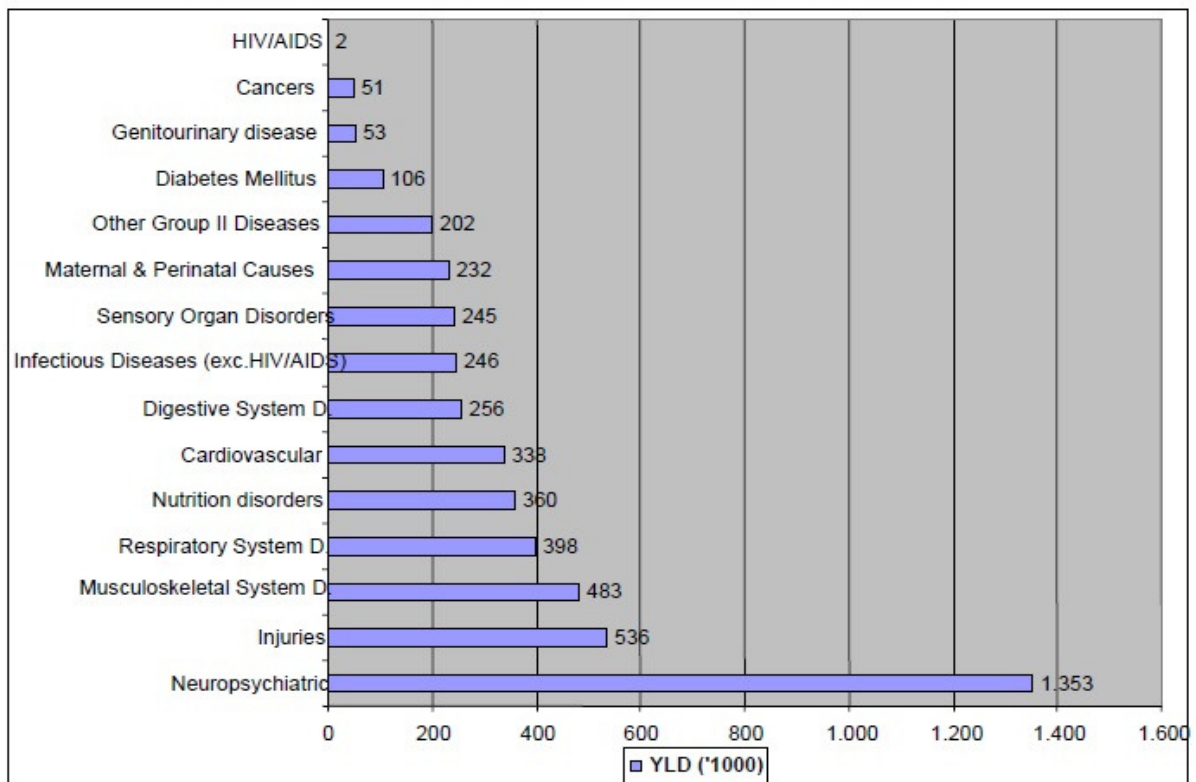
¹² TURDEP: http://www.turkendokrin.org/files/file/TURDEP_II_2011.pdf



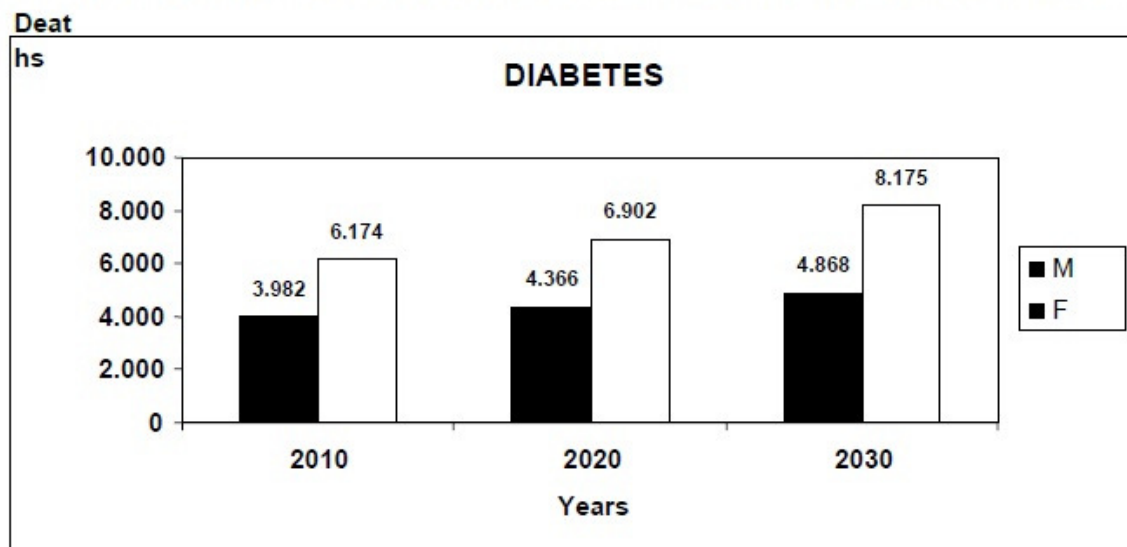
Graph 1: Prevalences of Diabetes and Impaired Glucos Tolerance in Turkey
 (From: Satman İ, Yılmaz MT, Şengül A, et al. Population-based study of diabetes and risk characteristics in Turkey: Results of the Turkish Diabetes Epidemiology Study (TURDEP). Diabetes Care 2002; 25:1551-6.)



Graph 2: Distribution of Top 20 Diseases Comprising Years of Life Lost (YLL/1000 persons) by Gender



Graph 3: Burden of non-fatal disease by main disease groups (YLD)



Graph 4: Diabetes-Related Deaths Predicted for Years 2010, 2020 and 2030 in Men and Women

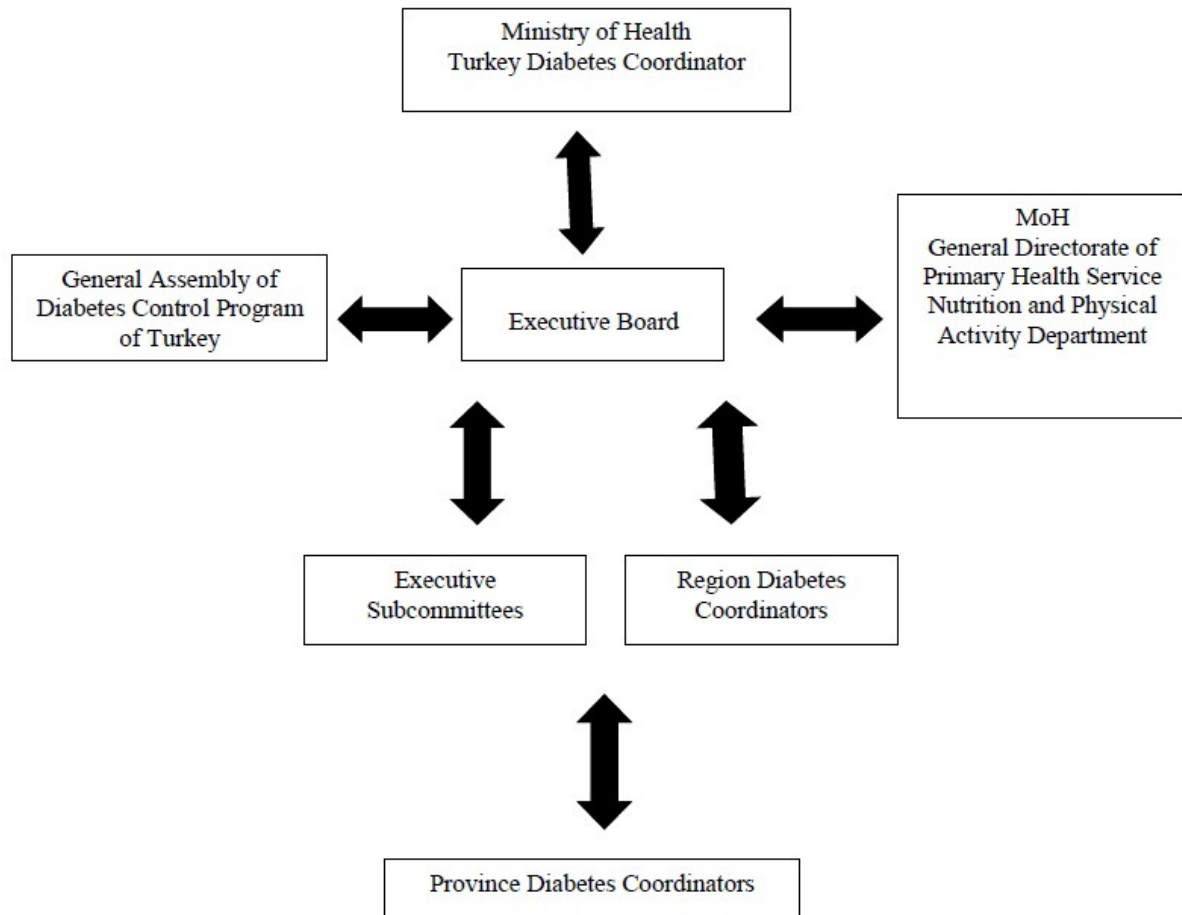


Figure 2: Organogram of the Diabetes Control Program of Turkey

Diabetes Control Program of Turkey is administered by the Executive Board, who report to the Ministry of Health. The Executive Board has 4 sub-divisions and it works together with these four bodies. Under all bodies there provincial level diabetes coordinates, who are responsible for diabetes management of a limited area only, in most cases a city.

5 Comparative analysis of digital competence for web-based patient empowerment methods and tools

5.1 Introduction

Purpose of this section is to provide a *“Comparative analysis of media competences and skills for using web-based patient empowerment and self-management activities in relation to age, gender, social level, (in countries involved) etc.”* (see description of task T.2.1 in the EMPOWER proposal). It will give a differentiated view on the current status of digital competence in Europe and especially in the countries in which the EMPOWER pilots will be implemented (Germany and Turkey). It serves as input for the coming tasks in the EMPOWER project, such as the design of EMPOWER content and materials displayed online to EMPOWER users, or, the strategies for the pilot-implementation and evaluation. The section

- Gives a brief insight into the concept of digital competence,
- Provides statistical evidence on access to ICTs, use of ICTs and diffusion of digital competence of potential EMPOWER users (patients and general practitioners),
- Highlights gender differences (esp. type of eHealth activity; numeracy skills) and,
- Discusses the relevance of the digital divide among ICT savvy patients and senior citizens¹³.

5.2 The concept of digital competence in eHealth

5.2.1 Modelling and measuring competence

The origin of the word “competence” dates back to the 16th century (Latin (noun): *competentia*; Verb: *competere*) and it is a very important and widely used concept in psychological, pedagogical and/or sociological field of science. In the literature the term is mainly applied with two different meanings: Firstly, in the sense of authority (i.e. having the concrete responsibility and right to do and decide something), and, secondly, in the sense of ability (i.e. to have the knowledge, the skills and the experience to do something) (Mulder 2006). In order to be able to use the EMPOWER tool and service patients and doctors need *to be competent* and to have *the competence* to use the tool, e.g. no medical exclusion reason.

Moreover, Schneckenberg and Wild (2006) claim that the meaning of “competence” depends always on the specific cultural, linguistic and application context. They point out:

“A first approach may be inferred from the work of Franz Weinert, who is based in the psychological field of competence research. Weinert tries to bridge the gap between the psychological and pedagogical concept of competence on the one side and sociological concepts on the other side. He defines competence in human and social sciences as “...a roughly specialised system of abilities, proficiencies, or skills that are necessary to reach a specific goal. This can be applied to individual dispositions or to the distribution of such dispositions within a social group or an institution” (Weinert, 2001). A substantial element of the competence definition is the relation of competence to performance, which links competence to action in social situations (Chomsky, 1980). Competence is not limited to the acquisition of skills. Competence is dealing with the ability to handle challenges that occur in

a specific situation in an appropriate way. Competences are expressed and demonstrated in an act of performance and they are always related to a specific social context. Van der Blij defines competence with a focus on performance as "... the ability to act within a given context in a responsible and adequate way, while integrating complex knowledge, skills and attitudes" (Van der Blij, 2002)." (cited in Schneckenberg and Wild, 2006)

It will not be enough in EMPOWER to speak of "skilled users", but patients and doctors need to demonstrate their competences to use the EMPOWER services, which should lead to certain outcomes (see e.g. section on outcome). The well-known researcher on competences, Erpenbeck and Heyse (1999), have constructed an assessment model for competences that defines and integrates *personal, social and communicative, methodical and subject-specific competences* into an overarching *action competence* (Erpenbeck and Heyse 2004 cited in Schneckenberg and Wild 2006).

The measuring of competence in education, and specifically in medical education and training is an important and very complex issue. In the field of medical training, the concept by Miller (1990), which is illustrated below, has found attraction in measuring the competences of clinical staff. If EMPOWER is used in a clinical setting, this model could be applied.

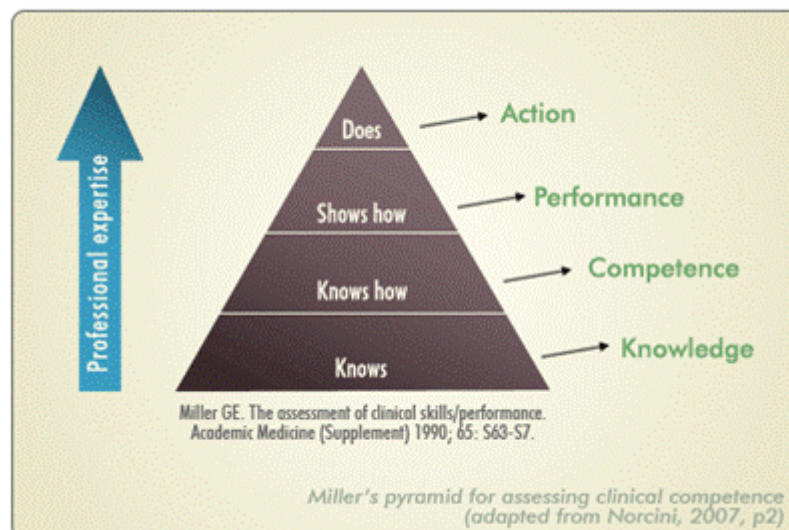


Figure 3: Miller Pyramid

5.2.2 Digital competence in eHealth

Terms such as “media competence”, “media literacy”, “computer-literacy”, “ICT literacy”, “internet / e-literacy” or “digital competence” are not really new terms, they root in developments which can be traced back to the emergence of (old) mass media (e.g. television, radio) and the advent of (new) media, e.g. computers and internet in the 1970s. Due to the rapid change of these technologies, the competences related to use them have changed throughout the time. Therefore, sometimes the “digital world context is made explicit with a compound term, such as “internet literacy”, but sometimes the context of the concept is to be understood implicitly (Information literacy, media literacy) (Ala-Mutka, 2011, p.19).

The research project “Digital Competence: Identification and European-wide validation of its key components for all levels of learners (DIGCOMP)”, financed by the European Union (2010-2012¹⁴), researches on the key components of Digital Competence (DC) in terms of the knowledge, skills and attitudes needed for European citizens to be digitally competent nowadays. It aims at identifying competences especially for all levels of learners and contexts.

In the European Commission dialogue on “Digital Agenda” *digital competence* is regarded as one of the eight key competences for lifelong learning¹⁵ (besides communication in a mother tongue, communication in a foreign language, mathematical competence and basic competences in science and technology, learning to learn, social and civic competences, sense of initiative and entrepreneurship, cultural awareness and expression). It is regarded as necessary to fully participate in an Information Society, which proposes to use IT enhanced services, such as eHealth applications, and is defined as follows:

"Digital competence involves the confident and critical use of information Society technology (IST) for work, leisure, learning and communication. It is underpinned by basic skills in ICT: the use of computers to retrieve, access, store, produce, present and exchange information, and to communicate and participate in collaborative networks via the Internet." (see Digital Agenda Scoreboard, 2011).

The DIGCOMP project follows a broad approach of how to conceptualize digital competence and summarizes (Ala-Mutka, 2011):

"Digital competence requires a sound understanding and knowledge of the nature, role and opportunities of IST in everyday contexts: in personal and social life as well as at work. This includes main computer applications such as word processing, spreadsheets, databases, information storage and management, and an understanding of the opportunities and potential risks of the Internet and communication via electronic media (e-mail, network tools) for work, leisure, information sharing and collaborative networking, learning and research. Individuals should also understand how IST can support creativity and innovation, and be aware of issues around the validity and reliability of information available and of the legal and ethical principles involved in the interactive use of IST.

Skills needed include the ability to search, collect and process information and use it in a critical and systematic way, assessing relevance and distinguishing the real from the virtual while recognizing the links. Individuals should have skills to use tools to produce, present and understand complex information and the ability to access, search and use internet-based

¹⁴ For study results see project homepage at the European Joint Research Centre: <http://is.jrc.ec.europa.eu/pages/EAP/DIGCOMP.html>

¹⁵ See European A European reference framework for European Union (EU) countries and the Commission available at: http://europa.eu/legislation_summaries/education_training_youth/lifelong_learning/c11090_en.htm

services. Individuals should also be able use IST to support critical thinking, creativity, and innovation.

Use of IST requires a critical and reflective attitude towards available information and a responsible use of the interactive media. An interest in engaging in communities and networks for cultural, social and/or professional purposes also supports this competence." (cited in Digital Agenda Scoreboard, 2011; based on Ala-Mutka, 2011).

This official approach of the European Commission, as outlined is considered to be a "very broad concept" of digital competences. As the figure below depicts, it includes much more than basic skills in the actual functional use of ICT as a tool. It incorporates also similar-partly overlapping- concepts such as digital literacy, eSkills and media literacy.

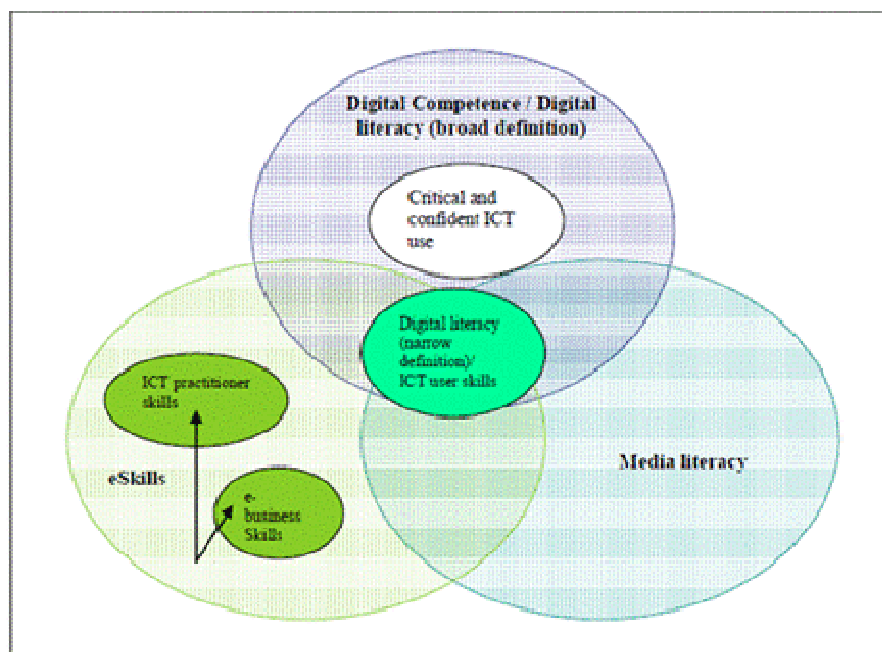


Figure 4: Relation of the different concepts of digital competence, digital literacy, eSkills and media literacy. (from: European Commission - Digital Agenda Scoreboard (2011; n.no.)

In the following, the most vital elements to digital competence are shortly described:

1) Digital Literacy:

The terms digital literacy, as originally suggested by Paul Glistner (1997) meant the "ability to understand and use information in multiple forms from a wide variety of sources when it is presented via computers" (cited in Ala-Mutka, 2011, p. 28).

Martin and Grudziecki (2006) worked out a very comprehensive definition for the concept of digital literacy:

"Digital Literacy is the awareness, attitude and ability of individuals to appropriately use digital tools and facilities to identify, access, manage, integrate, evaluate, analyze and synthesize digital resources, construct new knowledge, create media expressions, and communicate with others, in the context of specific life situations, in order to enable constructive social action; and to reflect upon this process." (Martin & Grudziecki, 2006:255).

This is the most comprehensive short definition of digital literacy found in the literature.

Martin (2008) also further elaborated its meaning, concluding that:

- “Digital literacy involves being able to carry out successful digital actions embedded within life situations, which may include work, learning, leisure, and other aspects of everyday life;
- Digital literacy, for the individual, will therefore vary according to his/her particular life situation, and also be an on-going lifelong process developing as the individual's life situation evolves;
- Digital literacy is broader than ICT literacy and will include elements drawn from several related “literacies”.
- Digital literacy involves acquiring and using knowledge, techniques, attitudes and personal qualities, and will include the ability to plan, execute and evaluate digital actions in the solution of life tasks.
- Digital literacy also includes the ability to be aware of oneself as a digitally literate person and to reflect on one's own digital literacy development.” Martin, A. cited in Ala-Mutka (2011: 29).

2) eSkills:

The term e-Skills has been used by the European Commission especially in the context of ICT use in the professional field of work and it refers to three sets of skills:

1. ICT practitioner skills: the capabilities required for researching, developing, designing, strategic planning, managing, producing, consulting, marketing, selling, integrating, installing, administering, maintaining, supporting and servicing ICT systems.
2. e-business skills: the capabilities needed to exploit opportunities provided by ICT, notably the Internet; to ensure more efficient and effective performance of different types of organisations; to explore possibilities for new ways of conducting business/ administrative and organisational processes; and/ or to establish new businesses.
3. ICT user skills: the capabilities required for the effective application of ICT systems and devices by the individual. ICT users apply systems as tools in support of their own work. User skills cover the use of common software tools and of specialised tools supporting business functions within industry (see European e-Skills Forum). ICT practitioner skills and e-business skills can be considered as more specialised ICT skills, ICT user skills are closer to the more general concept of digital literacy (for description see Annex, European Commission, Digital Agenda Scoreboard, 2011).

3) Media Literacy

The term media literacy was already heavily discussed before the advent of the computer. A very important distinction to the other concepts is, that the representatives of media literacy and media competence focus also on the aspect of knowledge about the structures and ways of functioning of media tools and content. The idea is that any user should understand and be able to interpret the “coding and semiotic systems used by the media” (see early media pedagogue Dieter Baacke, 1997; media psychologists in Batinic & Appel, 2008; Aufenanger 2009). The European Commission defines media literacy as follows and has identified its importance by creating “The European Charter of media literacy” (<http://www.euromedialiteracy.eu/>) and supporting European networks on media literacy policies, such as EuroMeduc (2009; <http://www.euromeduc.eu>).

"Media literacy relates to the ability to access the media, to understand and critically evaluate different aspects of the media and media context and to create communications in a variety of contexts."

"Media literacy relates to all media, including television and film, radio and recorded music, print media, the internet and all other new digital communication technologies." (for description see Annex, European Commission, Digital Agenda Scoreboard, 2011).

5.3 Evidence of digital competence in Europe

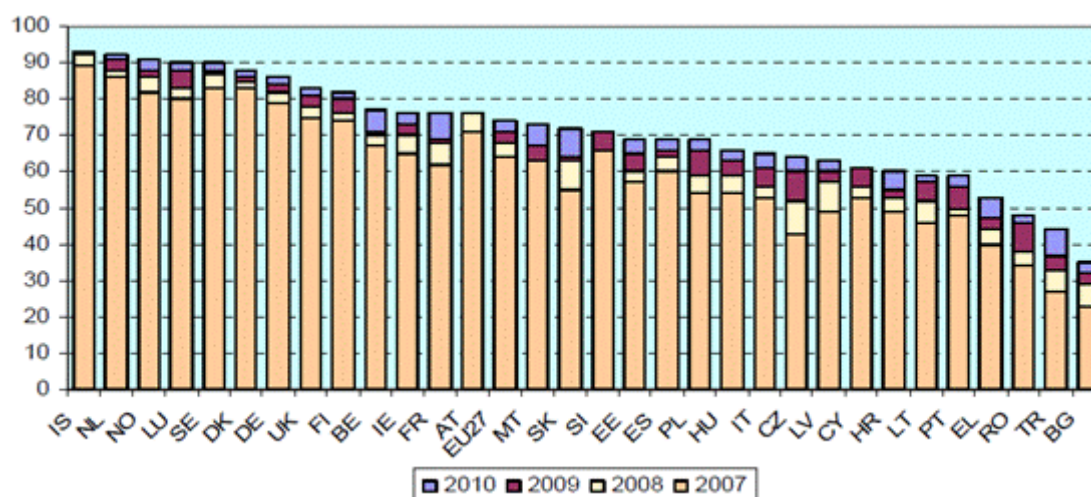
This section provides statistical evidence of access and use of ICTs and of the diffusion and different levels of digital competence in Europe. Wherever possibly, focus lies on the provision of an overview for Germany and Turkey as most important countries for the EMPOWER pilot-project implementation. The data was derived from a current survey of the European Commission, prepared for the strategic actions "Digital Agenda for Europe" and its newly published Digital Scoreboard (2011)¹⁶.

5.3.1 Access to ICTs

5.3.1.1 General access to computer and internet

One prime precondition for EMPOWER users to become digital competent is, firstly, to have access to the diverse types of ICTs needed for diabetes self-management (e.g. data transmission, data input/output device, communication platform). Therefore, the two tables below shows the supply of European households with ICTs (access to computer and internet).

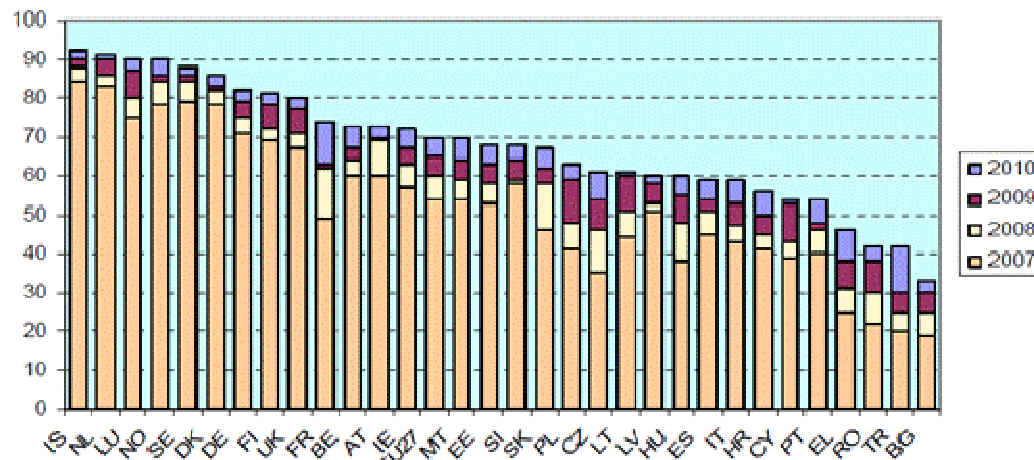
In 2010, in Europe 27, the access rate of a computer and internet at home, has risen almost to 70% on average. In 2010, almost 90% of households in Germany are reported to have access to a computer at home, 45% homes are equipped in Turkey.



Graph 5: % households having access, via one of its members, to a computer
(from: Digital Agenda Scoreboard, 2011)

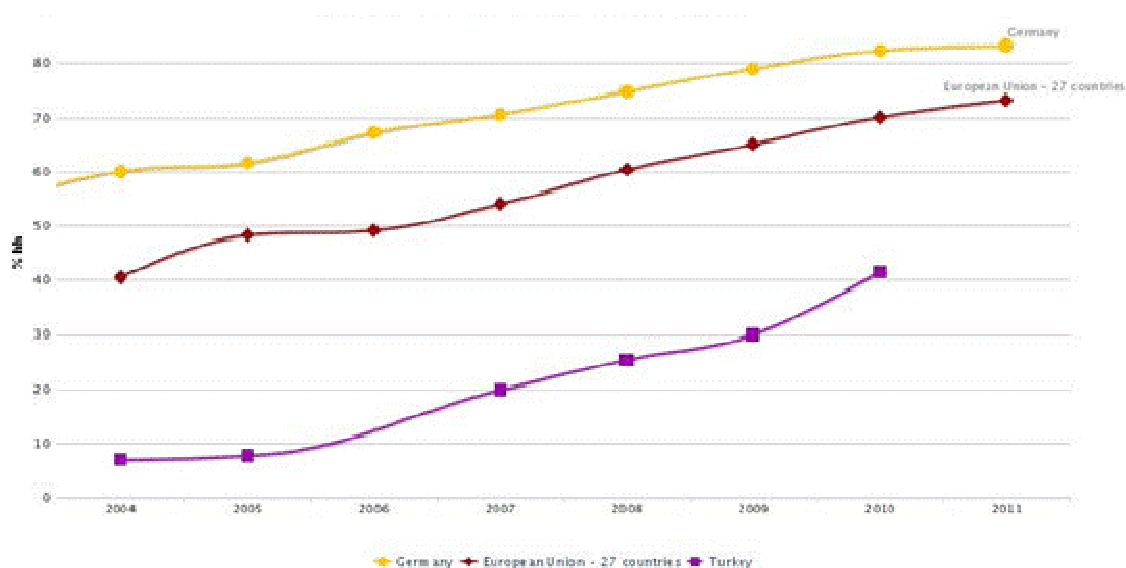
¹⁶ For more information on the Digital Agenda : http://ec.europa.eu/information_society/digital-agenda/index_en.htm and its Scoreboard http://ec.europa.eu/information_society/digital-agenda/scoreboard/index_en.htm.

During the last five years, access to internet/internet connections per household has substantially risen in all countries, but especially in Turkey, France, Spain and the Czech Republic (Digital Agenda Scoreboard, 2011).



Graph 6: % households with internet access
(from: Digital Agenda Scoreboard, 2011)

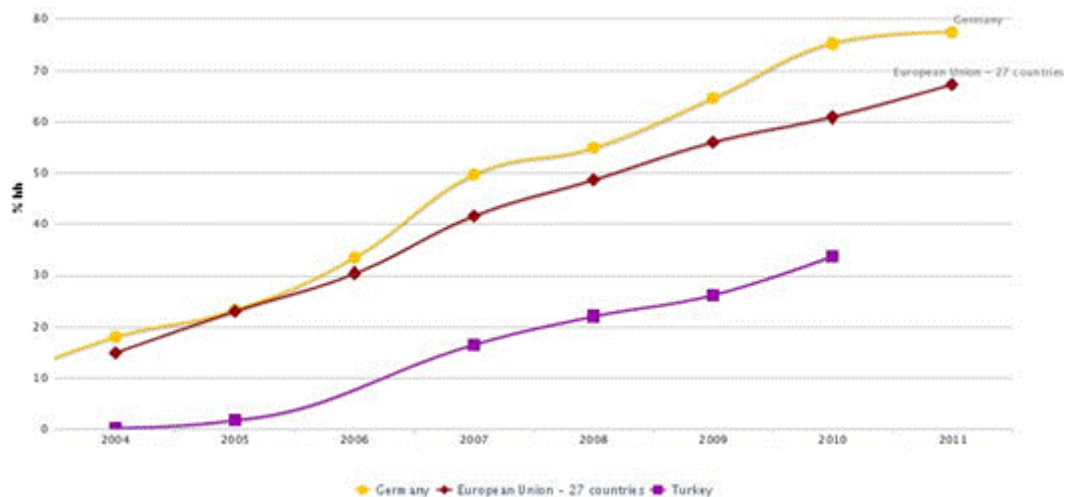
Looking specifically at Germany and Turkey, one can conclude that access to internet is already high in Germany and is expected to grow further in the future in Turkey (10% increase from 2009 to 2010).



Graph 7: % of households with access to the internet at home
(from: Eurostat data - Digital Agenda Scoreboard, 2011)

At the moment it may be anticipated that EMPOWER will base its services on broadband connections. s having a broadband connection

Graph 8 shows a high diffusion rate in Germany and a continuing increase in Turkey, though on a lower level (approx. 35% broadband connection per household).



Graph 8: % of households having a broadband connection

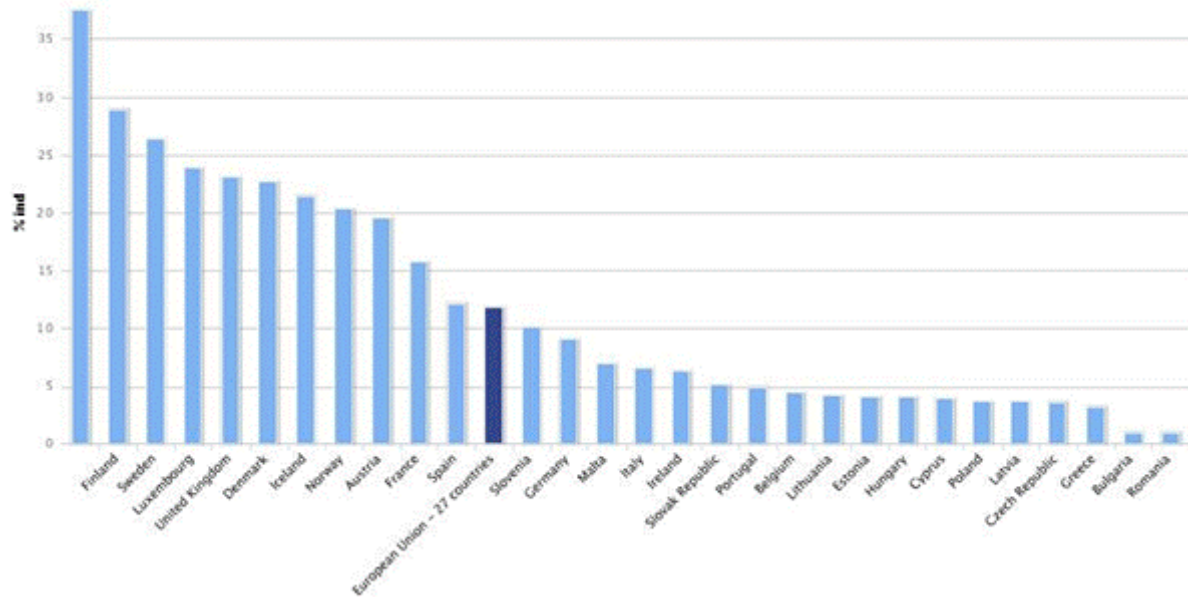
Definition and scope: Households with at least one member aged 16-74. Broadband connection includes: DSL, wired fixed (cable, fiber, Ethernet, PLC), fixed wireless (satellite, WiFi, WiMax) and mobile wireless (3G/UMTS).
 (from: Eurostat - Community survey on ICT usage in Households and by Individuals)

5.3.1.2 Access per type of ICTs

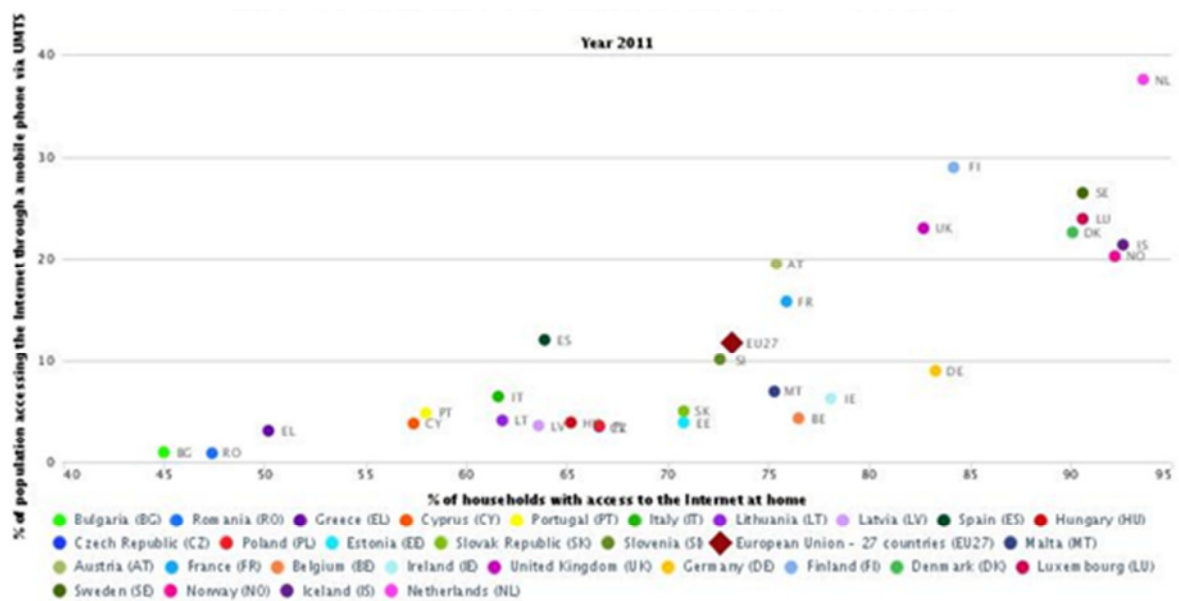
Although the most widely spread device for internet access is still the desktop or laptop computer (68% of households and access from home), a shift in equipment of digital devices can be noticed from computer and television to internet platforms and mobile phones. According to the Digital Scoreboard (2011), on “average 15% of EU households now access the internet via mobile phone, an increase of 4pp. over 2009. In some countries, rates have reached more than 30% (DK, NL, SL, SK and SE) and in Norway the rate has reached 45%. Furthermore, *access via game consoles (7% in EU) and TV (4% in EU) is also on the rise*. They are of particular importance in some of the most advanced ICT countries, showing that these countries not only have higher rates of access to internet but also use a larger variety of devices for doing so.”

The graphs below show (Graph 9, Graph 10) firstly, the diffusion rates of mobile phones in Europe in general, and, secondly, the comparison of using internet from home and from a mobile phone. Whereas the EU average for access via internet from home lies at 73%, the rate for mobile broadband is around 12%, (11,8). Although considerably lower, some countries outperform already that figure.

Unfortunately, for Turkey no data was available on mobile phone access to internet.



Graph 9: % of population accessing the internet through a mobile phone via UMTS (3G) Year 2011
(from: Eurostat – Digital Scoreboard, 2011)

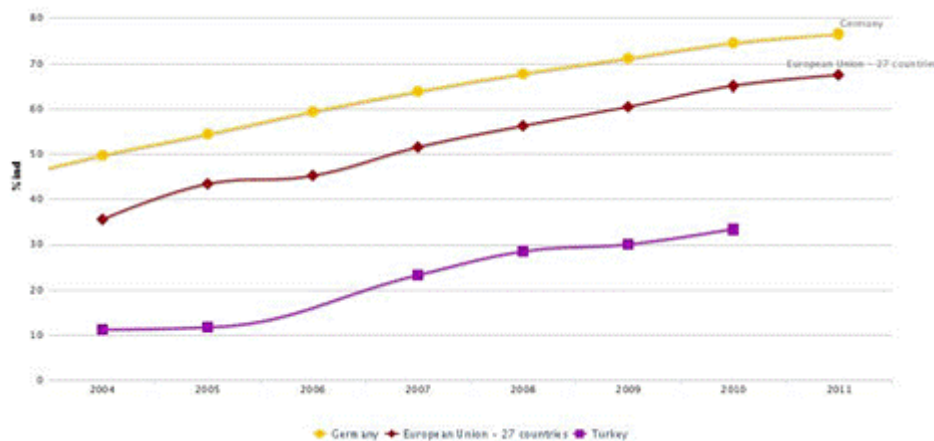


Graph 10: % of households with access to the internet at home and % of population accessing the internet through a mobile phone via UMTS (3G) Year 2011
(from: Eurostat - Community survey on ICT usage in Households and by Individuals)

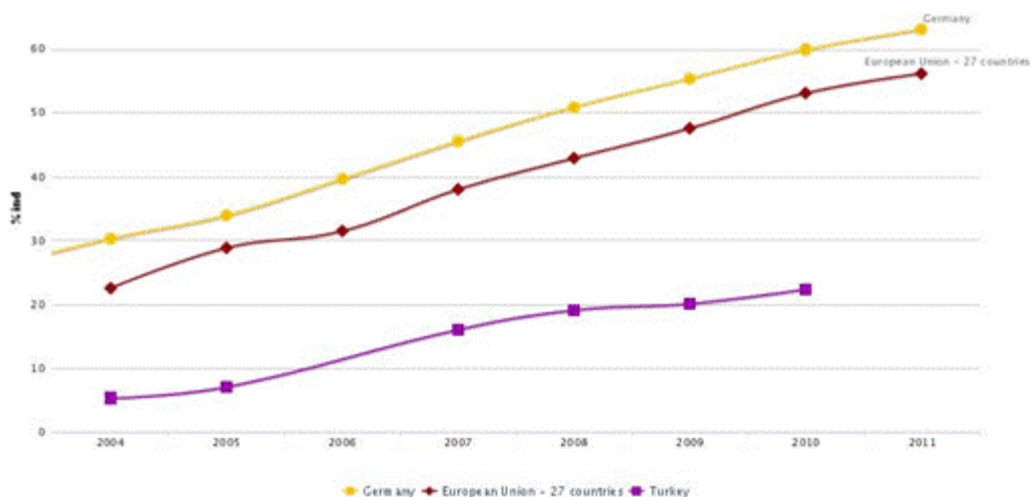
5.3.2 Frequency of computer and internet usage

5.3.2.1 Regular and frequent internet use

Secondly, after having access to internet, it is important to be able to use the computer and internet as to achieve specific goals. The first graph (Graph 11) below indicates that, 70% of German internet user, approx. 34% of Turkish internet users connect at least once a week. The second graph (Graph 12) shows, that from the regular internet users, more than 50% use it almost every day on average in Europe.



Graph 11: % of population who are regular internet users (at least once a week)
 Definitions and scopes: % of population who are regular internet users (at least once a week);
 Individuals aged 16-74, using the internet at least once a week in the last 3 months
 (from: Eurostat - Community survey on ICT usage in Households and by Individuals)



Graph 12: % of population who are frequent internet users (every day or almost every day)
 (from: Eurostat - Community survey on ICT usage in Households and by Individuals)

The frequency of internet may be of relevance when designing the feedback intervals for EMPOWER services (e.g. action plan changes that may be needed once per week).

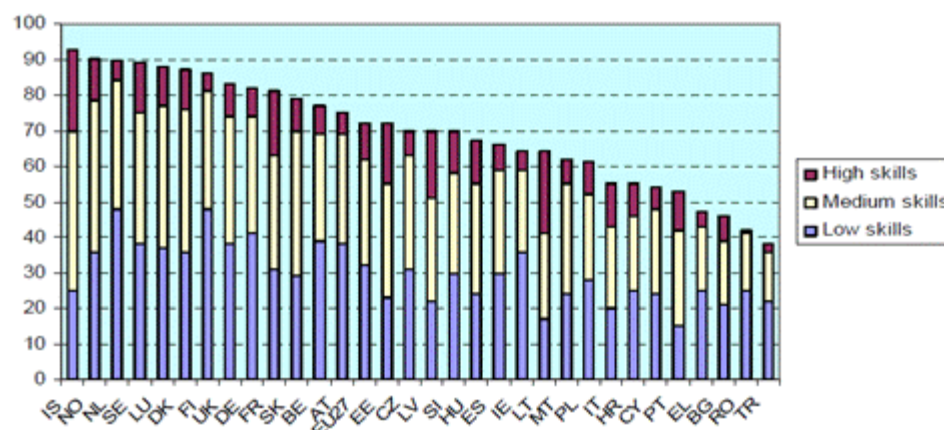
5.3.3 Comparison of skill levels and internet activities

5.3.3.1 Variations in skill levels

There exists no comparable data on European computer skills, let alone for skills needed for eHealth applications. However, the Digital Scoreboard estimates that 32% individual persons in the European Union (EU27) have low level internet skills, 30% have medium level internet skills and 10% have high level internet skills.¹⁷

The percentages of individuals with only low level skills range from 15% in Portugal to 48% in the Netherlands and Finland (33 pp. range). Those with medium level skills range from 14% in Turkey to 45% in Island (31pp. range). And those with high level skills range from 1% in Romania to 23% in Lithuania (22pp.range). While rates of low and medium level skills reflect to a large extent the cross-country patterns of regular internet use (with correlations of 0.79 and 0.91), this is not the case for high level skills (correlation 0.37); countries with high access and basic use do not necessarily have the highest rates of high level skills. These are the countries: Lithuania, Latvia, Norway, Estonia, Sweden and France.” (European Commission, Digital Scoreboard, 2011).

The diffusion of internet skills (Graph 13) is illustrated by the table below.

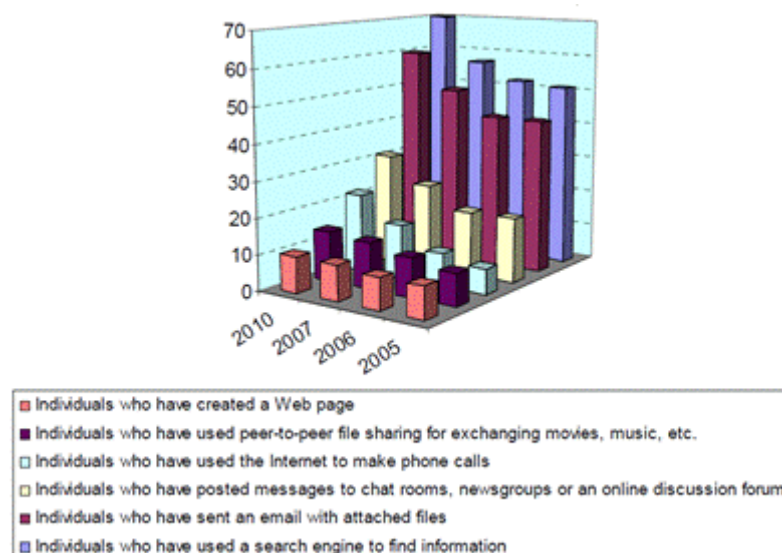


Graph 13: % individuals with internet skills (High, Medium and Low), 2010
(from: Digital Scoreboard, 2011)

Skill levels were sampled according to the type of activities users are able and actually doing while using the computer and internet: Using a search engine and sending an email with attached files can be considered as requiring relatively low levels of skill, posting a message to a chat site or social platform etc. was considered as medium skill level, whereas producing content and or even creating a home-page (CMS system) was considers as high skilled level.

If for the use of EMPOWER services only low to medium-level computer and internet skills are necessary (connect to internet, use of mail, print, write something into a chat, forum or social network platform) then there is a good chance of adoption of these services by more than 30-60% of European individuals.

¹⁷ A good source for computer and internet skills in education is the statistics and key data at the European e EURYDICE, http://eacea.ec.europa.eu/education/eurydice/key_data_en.php

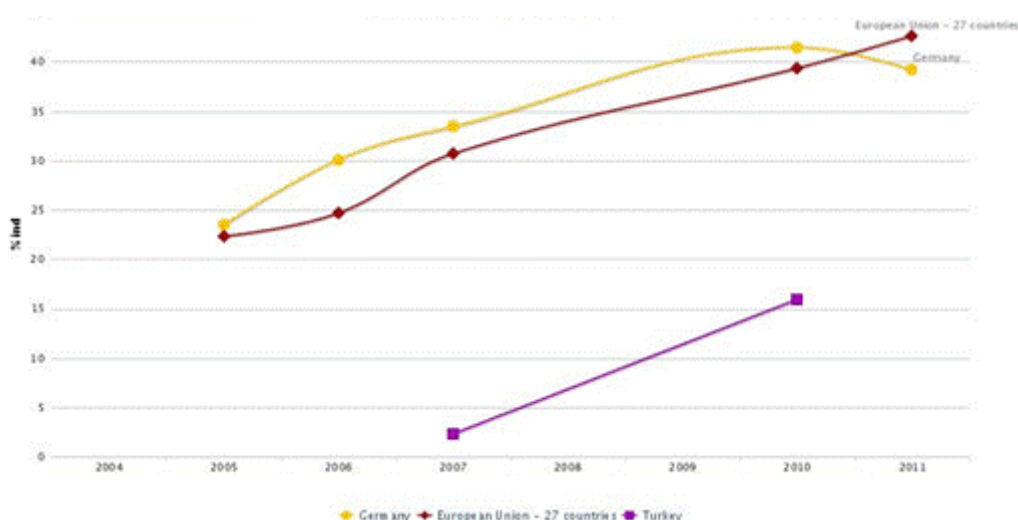


Graph 14: % individuals with various internet skills, EU27
(from: Digital Agenda Scoreboard, 2011; section 4.2)

The report states that the “*varying complexity is also reflected in the rates of use of these various activities*”. While 70% have used a search engine, 60% have sent an email with attached files, 31% have posted messages, 22% have used the internet to make phone calls, 14% have used peer-to-peer file sharing and only 10% have created a web page”

5.3.3.2 Diffusion of internet skills in EMPOWER countries: Germany & Turkey

The graph below (Graph 15) shows that in both countries (Germany and Turkey), the level of skills among the internet users has constantly risen from low to medium average skills during the last decennium. This seems to be a positive outlook for EMPOWER adoption not only among ICT lead users. No data existed for 2011 for Turkey.

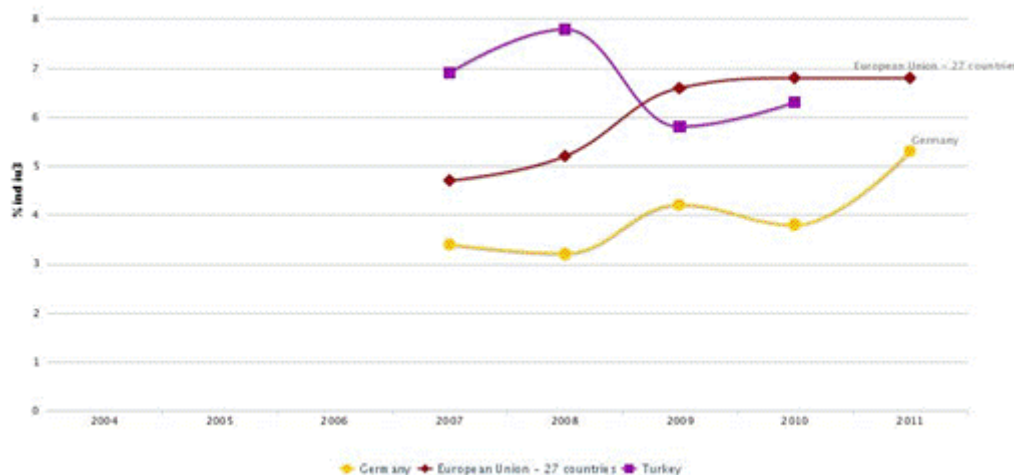


Graph 15: % of individuals with medium or high internet skills (3 or more of 6 internet activities)
Germany and Turkey, 2004-2011
(from: Eurostat - Community survey on ICT usage in Households and by Individuals)

5.3.3.3 Participation in online courses

The graphs below (Graph 16, **Fehler! Verweisquelle konnte nicht gefunden werden.**) indicate the interest of European users to take part in online courses for educational purposes and to participate in social networks, both for informal learning and leisure.

Whereas Graph 16 shows that both Turkey and Germany range now below the EU average (in 2010), the **Fehler! Verweisquelle konnte nicht gefunden werden.** provides evidence that approx. 42% of German users would know how to take part in a social network and maybe share their experience with their disease there (EU average 40%).



Graph 16: % of internet users doing an online course (in any subject)
 Definition and scope: Individuals using internet in the last 3 months, aged 16-74.
 (from: Eurostat - Community survey on ICT usage in Households and by Individuals)

5.3.3.4 Health information search online

The search for health issues is a very important topic among internet users. According to a survey by Pew Internet & American Life Project for health issues), the search for food safety, drug safety, and pregnancy information is among the most often searched fields (Rank 8).

In the study by Fox (2011), the author states that,

*“ 29% of internet users look online for information about food safety or recalls.
 24% of internet users look online for information about drug safety or recalls.
 19% of internet users look online for information about pregnancy and childbirth.
 17% of internet users look online for information about memory loss, dementia, or Alzheimer's.
 16% of internet users look online for information about medical test results.
 14% of internet users look online for information about how to manage chronic pain.
 12% of internet users look online for information about long-term care for an elderly or disabled person.
 7% of internet users look online for information about end-of-life decisions.”(2010¹⁸).*

¹⁸ <http://pewinternet.org/Reports/2011/HealthTopics/Summary-of-Findings/Food-safety.aspx>

Interesting for the acceptance of EMPOWER might be the result, that 14% of individuals are looking especially for information on how to manage chronic care, also those persons, who are typically regarded as “digitally disadvantaged” (Fox, 2011:3).

The most likely groups to look online for health information include:

- Adults who, in the past 12 months, have provided unpaid care to a parent, child, friend, or other loved one
- Women
- Whites
- Adults between the ages of 18-49
- Adults with at least some college education
- Adults living in higher-income households (ibid).

The table below (Graph 17) shows the results for the European Union (average, Germany and Turkey).



Graph 17: % of internet users seeking online information about health
 Definition and scope: Individuals using internet in the last 3 months, aged 16-74. Information about health includes: injury, disease, nutrition, improving health, etc.
 (from: Eurostat - Community survey on ICT usage in Households and by Individuals)

The problem of the digital gap (e.g. especially as regards age and income) will be a topic that will be dealt with in the section “Digital Divide”.

5.3.4 ICT uptake of general practitioners in the field of eHealth

The EMPOWER services are not only to be used by patients, also general practitioners and their employees should be competent to use EMPOWER. Therefore this section takes a look at facts and figures of access to ICTs and digital competence of general practitioners (GP) in this field (with data from Germany).

5.3.4.1 ICT use in practice (pc use; patient data storage)

The benchmarking study on “ICT use among General Practitioners in Europe” (by EMPIRICA, 2008) showed that by 2008, almost “all General Practitioner (GP) practices (87%) in the European Union use a computer. There is a tendency towards larger practices being better equipped — 93% using computers — than smaller ones — 84%. There remain 13% of practices that are currently without any computers and are therefore cut off from the benefits eHealth has to offer.” ... “69% of the EU27 GP practices have an Internet connection. Its use varies according to the size of the practice, with use rates ranging from 61% among single GP practices to 81% among practices of four or more GPs. While there are Member States where Internet use has reached saturation level — such as in Estonia, Finland,

Denmark, Sweden and Iceland — there are also several Member States where less than 50% use the Internet (Bulgaria, Hungary, Romania and Slovakia)“ (Dobrev, 2008:6).

However, access to ICTs is no indicator for using ICTs or internet based applications. The study shows that e.g. data is stored, however, more mainly to ease the administrative process and no clinical data. The table below indicates the type of stored data:

	EU27	EU27+2	BE	BG	CZ	DK	DE	EE	EL	ES	FR	IE	IT	CY	LV	LT	LU	HU	MT	NL	AT	PL	PT	RO	SI	SK	FI	SE	UK	IS	NO
Diagnoses	90	91	93	97	89	93	99	94	74	89	89	79	85	93	58	65	88	99	80	96	88	73	77	69	89	94	81	97	94	100	100
Medications	90	90	93	93	88	99	93	86	71	94	91	95	95	90	50	8	95	99	80	97	84	55	85	36	43	85	96	95	98	100	99
Basic medical parameters	83	83	91	80	82	96	80	58	65	88	93	85	85	86	42	14	90	96	73	94	80	35	63	49	31	71	90	82	98	90	84
Lab results	79	80	96	83	58	99	78	58	64	81	77	82	75	76	42	17	52	91	66	95	79	53	59	63	20	26	98	97	96	93	98
Symptoms/reasons for encounters	77	77	89	94	70	97	67	59	68	82	92	80	64	86	42	28	88	96	70	96	82	46	73	32	33	60	96	95	92	98	95
Medical history	75	75	89	93	74	97	52	55	73	86	89	84	70	83	50	13	90	93	75	95	69	46	63	34	18	48	98	90	95	100	97
Examinations and results	75	75	87	86	62	95	56	51	64	81	81	68	82	67	42	20	60	93	66	95	76	55	67	58	15	35	98	76	88	92	98
Vital signs measurements	74	74	88	93	67	92	59	51	62	80	88	73	69	88	42	12	76	93	64	92	63	34	70	52	15	51	93	73	92	79	85
Treatment outcomes	65	66	81	78	68	96	52	46	62	76	66	53	58	71	50	26	62	92	58	94	77	49	52	25	14	47	88	78	77	76	91
Radiological images	34	35	53	50	20	98	15	47	42	55	65	23	5	29	42	2	43	70	34	43	49	40	29	12	8	10	95	34	30	87	54

Base: GPs storing electronic medical data. Indicator: A2 (cf. annex for more information), % values. Source: empirica, Pilot on eHealth Indicators, 2007.

Table 3: Electronic Patient Data Storage in Germany: Storage of Different Types of Individual Patient Data by GPs storing electronic medical patient data
(from: Dobrev et al., 2008)

“Administrative patient data are stored electronically in 80% of the EU27 GP practices. In some countries, usage rates are at and below the 50% level, going down as far as 26%. Practice size plays a certain role in this regard, with an average difference of 11 percentage points between the smallest and the largest size class. The highest use rates can be found in Denmark (97%), Estonia (98%), Hungary (100%), the Netherlands (97%), Finland (100%), Sweden (96%), the United Kingdom (95%), Iceland (99%) and Norway (98%). Storage of administrative patient data in the practice is least frequently in Greece (49%), Latvia (26%), Lithuania (39%) and Romania (47%). When it comes to different types of patient data stored for medical purposes, data on diagnoses and medications are stored by the highest share of GP practices (92% of practices storing also administrative patient data), followed by basic medical parameters such as allergies etc. (85%), laboratory results (81%), a patient's symptoms or the reasons for his/her visit (79%), the medical history of a patient, ordered examinations and their results (77% each), results of vital sign measurement (76%) and — with some margin — storage of radiological images (35%). 76% of all practices store individual patient data in a structured manner, which facilitates the automatic processing of the data in other electronic systems” (Dobrev et al., 2008: 7).

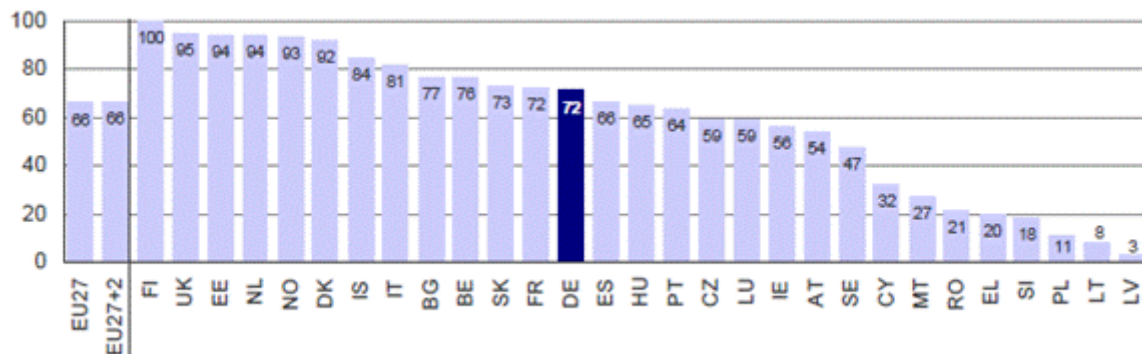
5.3.4.2 Use of PC in the doctor-patient relationship (consultation)

Another similar picture occurs when looking at how and who uses the PC in the consultation process:

“Apart from the storage and exchange of patient data, a computer can also be used in direct interaction with the patient, i.e. during the consultation in the practice. It can be used to display a patient's file to the practitioner, to provide supporting information when making treatment or medication decisions, but also for the explanation of medical issues to the patient, e.g. by means of a graph, photo or animation. 85% of the German GP practices have

a computer available in the consultation room. This computer is actually used for consultation purposes when the patient is present in 72% of the GP practices.

The results for the EU27 show a significant gap between frontrunners with more than 90% of GP practices using a computer (Finland, UK, Estonia, Netherlands and Denmark) and the countries following or lagging behind (less than 30%). With 72% Germany is part of a group of average performers where use rates vary between 60% and 90%.” (Dobrev et al., 2008).



Graph 18: Computer Use in Consultation with the Patient in Germany
(from: Dobrev et al., 2008)

5.3.4.3 Situation of ICT uptake in Turkey (Family Medicine Information System)

The FMIS (Family Medicine Information System) software is a key player in the ICT use of a general practitioner. FMIS is a system via which General Practitioners register their patients, observe their status and can refer them to hospitals. FMIS is a national infrastructure providing a combination of EHR, patient tracking, referral and clinical decision support systems. It is based on the principle that each individual has a family physician (general practitioner - GP) to take care of his/her health; that is, the primary care services. The client applications that are used by the GPs can work both in online and offline modes. They can either record patient observations locally and synchronize with the MoH FMIS Web Services immediately, or synchronize the local data later. The second approach is especially useful when the GPs visit their patients in the rural areas together with their laptops.

The FMIS Performance Evaluation System is also used to evaluate the performance of the General Practitioners with particular regard to immunizations, infant and pregnancy observations, referrals to hospitals and the care of immobile patients. GPs have a baseline salary and based on the calculation of their performance scores automatically by the FMIS, their salaries change each month. When they complete all the expected observations, their salaries are increased. In the opposite case, they can even go below their baseline salaries. Each GP is responsible for 3400-3500 citizens and through the FMIS Decision Support System (DSS) GPs are able to dynamically monitor their own performances. For each month, they are expected to synchronize all patient data till the 7th day of the following month, when the salaries of all GPs are automatically calculated by the FMIS according to their performance scores.

Another use of FMIS is that it is possible to collect very detailed statistics through the FMIS Decision Support System. As of June 2010, out of 81 provinces of Turkey, family medicine is being applied in 43 of them. By the end of 2010, it will be in practice in all provinces; the deployment and the education of healthcare staff is proceeding in parallel in multiple provinces. As of June 2010, the FMIS usage statistics are as follows:

- The number of registered patients: 26,941,729
- The number of registered general practitioners: 9,168
- The number of stored healthcare records: 137,202,811

The Ministry of Health distributes a FMIS client application to GPs for free. On the other hand, some GPs opt for using FMIS client applications by 3rd party vendors, for example, in Manisa and Samsun provinces.¹⁹

5.3.5 Typology of internet users per age

Given the fact that chronic diseases are affecting different age groups, it is well worth to differentiate the access issue to age and socioeconomic background (see section digital divide). In Germany, recent data on media usage show that among age groups 14-50) almost 90% use internet, the usage declines rapidly beyond the age of approx. 50+ years.

Age group	2001	2005	2010
14-29	63.4	82.8	95.8
30-49	48.0	71.2	87.1
50+	15.6	30.5	49.6

Table 4: % of internet users in different age groups 2001, 2005 and 2010
(from: Schröder et al., 2011)

Based on the results of a telephone interviews ($N=1000$) on internet behaviour among German users of all ages (Schröder et al., 2011), the authors propose a typology characterizing the attitude and behaviour towards internet use.

- **Digital outsiders** (28 %), average age 65, have little access to the internet and low skills for computer usage.
- **Occasional internet users** (28 %), average age 45, usually have a computer, a printer and in most cases internet access at home. They have the basic skills necessary for internet search, email and text processing and sometimes use the internet for these activities. However, they prefer the conventional media.
- **Job-related internet users** (7 %), average age 45, spend two or more hours per day using the internet, mainly email, word processing and information search.
- **Trend driven users** (20 %), average age 37, have a private computer and equipment. Many of them also have internet access with a smartphone. They are participating in the social web and play computer games.
- **Digital professionals** (12 %), average age 39, have extensive knowledge of computing and use the internet on the job as well as at home for communication and information seeking.
- **The digital vanguard** (5 %), average age 34, is characterized by higher formal education and income. The members of this group spend 10 hours per day with computers, for work as well as entertainment (Schröder et al., 2011, p. 18)

These results need to be enriched with characteristics of diabetes self-management per age (if evident) and will be relevant for characterising the personas in EMPOWER and of use for the storyboards

5.4 Gender differences

In the literature three major themes of gender research²⁰ are relevant to eHealth projects. On the one hand, the issues of “gender and technology” (e.g. reflection of gender stereotypes in

¹⁹ Country Brief: Turkey. Available at:
http://ehealth-strategies.eu/database/documents/Turkey_Countrybrief_eHEstrategies.pdf

the technology; mutual relationship between technology development and gender roles), the issues of “technology and health” (e.g. gender dynamics involved in design and use of ICTS in health care; different use of media and attitude towards technology) and, on the other hand, the issues of “gender and health” (e.g. gendered use of technology in health care; gendered health issues) (see Balka et al. 2009). Chronic diseases, especially diabetes, are not necessarily biological sex-specific diseases, however, the following three aspects relevant for EMPOWER will be discussed:

- gender difference in use of internet / health application and different attitude towards technology,
- gender-different interests in health information and internet communication behaviour, and,
- the gender-different approach towards interpreting web-based presented mathematical information (e.g. graphs and figures) as part of health literacy (numeracy).

5.4.1 Usage and attitude towards the internet

Unfortunately the European scoreboard statistics are not prepared yet to collect gendered data on European internet usage. However, statistics from Denmark (2009) point for example to a gender difference in “knowing about” and “using of” social networking sites and popular services and provide us with a rather stereotypical picture:

“The most significant ratio is found in the use of Trendsales (M-W: 10-90). Women also outnumber men in the use of Facebook (but not in knowing of), twittering (M-W: 33-67), but in this case with very low and insignificant number in total), MSN, and I-form, while more men than women use MySpace, LinkedIn, YouTube, Flickr, Music services, „den blå avis” and Wikipedia. There are no equals and the ratios range from (M-W: 45-55) to the above mentioned (10-90)” (Finnemann et al., 2012, p. 25).

	Know M/W	Use M/W
Facebook	50/50 m = w	45/55 w
Den Blå avis	50/50 m = w	54/46 m
YouTube	52/48 m	62/38 m
MSN	52/48 m	45/55 w
Wikipedia	55/45 m	57/43 m
Myspace	57/43 m	62/38 m
Music services (last.fm, iTunes, - pirate sites)	62/38 m	62/38 m
I-form	40/60 w	27/73 w
Trendsales	31/69 w	10/90 w
Twitter	60/40 m	33/67 w
LinkedIn	57/43 m	57/43 m
Flickr	70/30 m	64/36 m
None of these	42/58 w	45/55 w

Table 5: Social network sites and popular services ('know of' and 'regular use').
Gender differences in knowing about and using social media in Denmark. Gender Distribution. N=1710
(from: Finnemann et al., 2012)

A survey of PEW internet research targeting gendered internet use, shows the following results (Fallows, 2005; survey data from observations between March 2000 and September 2005):

²⁰ Note that the term “gender” is used both for the biological sex of male and female persons and for the social construct of gender (e.g. social roles, gender roles or gender identity). See Online Encyclopedia WIKIPEDIA. <http://en.wikipedia.org/wiki/Gender>

- *“Women are catching up in overall use and are framing their online experience with a greater emphasis on deepening connections with people.*
- *The percentage of women using the internet still lags slightly behind the percentage of men, however, women under 30 and black women outpace their male peers. Unfortunately, older women trail dramatically behind older men.*
- *Men are slightly more intense internet users than women. Men log on more often, spend more time online, and are more likely to be broadband users.*
- *In most categories of internet activity, more men than women are participants, but women are catching up.*
- *More than men, women are enthusiastic online communicators, and they use email in a more robust way.*
- *Women are more likely than men to use email to write to friends and family about a variety of topics: sharing news and worries, planning events, forwarding jokes and funny stories.*
- *Women are more likely to feel satisfied with the role email plays in their lives, especially when it comes to nurturing their relationships. And women include a wider range of topics and activities in their personal emails. Men use email more than women to communicate with various kinds of organizations.*
- *Men are more avid consumers than women of online information. Men look for information on a wider variety of topics and issues than women do.*
- *Men are more likely than women to use the internet as a destination for recreation. Men are more likely to: gather material for their hobbies, read online for pleasure, take informal classes, participate in sports fantasy leagues, download music and videos, remix files, and listen to radio.” (Fallows, 2005, p.II-V).*

All in all, Fallows (2005) concedes that “men and women are more similar than different in their online lives, starting with their common appreciation of the internet’s strongest suit: efficiency. Both men and women approach with gusto online transactions that simplify their lives by saving time on such mundane tasks as buying tickets or paying bills. Men and women also value the internet for a second strength, as a gateway to limitless vaults of information. Men reach farther and wider for topics, from getting financial information to political news. Along the way, they work search engines more aggressively, using engines more often and with more confidence than women.(...).Women are more likely to see the vast array of online information as a “glut” and to penetrate deeper into areas where they have the greatest interest, including health and religion. Women tend to treat information gathering online as a more textured and interactive process – one that includes gathering and exchanging information through support groups and personal email exchanges” (ibid).

5.4.2 Interest and search behaviour for eHealth topics

The interest for dealing with medical and health search in the internet differs slightly between men and women. Whereas the access gap is closing somewhat in recent time (73% of men and 75% of women 2011go online, see US data by Fallow, 2005; Fox 2011). However, living in a family, 86% of online women search and are interested in using web-based information for health issues, compared with 73% of online men.

“Online women significantly outpace online men in their pursuit of information about specific diseases or medical problems, certain treatments or procedures, doctors or other health professionals, hospitals or other medical facilities, food safety or recalls, drug safety or recalls, and pregnancy and childbirth. Not a single topic included in the survey attracts more attention from men than from women” (Fox, 2011:15).

Interesting for EMPOWER is that in particular more women are interested in using internet information for specific diseases.

Health topic	Sex			Education level			
	All internet users	Women	Men	Some high school	High school grad	Some college	College grad
	N=2065	N=1198	N=867	N=122	N=552	N=563	N=813
Specific disease or medical problem	66	74	57	45	54	70	77
Certain medical treatment or procedure	56	63	48	32	44	60	67
Doctors or other health professionals	44	50	36	26	31	43	58
Hospitals or other medical facilities	36	41	30	21	27	35	47
Health insurance, including private insurance, Medicare or Medicaid	33	34	32	13	27	34	42
Food safety or recalls	29	32	26	17	21	33	36
Drug safety or recalls	24	28	19	15	17	26	30
Environmental health hazards	22	22	23	21	15	23	28
Pregnancy and childbirth	19	24	13	19	15	21	19
Memory loss, dementia, or Alzheimer's	17	19	14	14	12	20	18
Medical test results	16	18	14	7	11	16	23
How to manage chronic pain	14	15	13	12	10	18	16
Long-term care for an elderly or disabled person	12	13	9	13	7	13	14
End-of-life decisions	7	7	7	2	5	9	9
Another health topic not included in the survey	28	31	25	10	17	33	37
At least one of the above topics	80	86	73	62	70	83	89

Table 6: Health topics searched, differentiated by gender. N=3001
(from: Fox, 2011)

5.4.3 Gender-specific differences in numeracy

Very often gender-specific differences in competence are often attached to factors of access frequency or the successful usage of certain services. These differences are not so important anymore, since the advent of cheap computers and mobiles (see previous section for access). Schelhowe, a professor for gender and digital media research at the University of Bremen, claims a differentiated approach, to being examined with young “digitalized” persons and in schools:

“Not through quantity but through the quality of access to digital media, [...] is shown how the relationship of the genders in schools and beyond in the processes of societal practice develops” (Schelhowe cited in Aufenanger, 2009, p. 21).

She found out that the traditional view on “the degree of familiarity” and “experience of technical usage” characterizing computer use and media do not necessarily lead to a reflexive usage. In her studies, she showed that *“technical know-how represented only a section of media competence and had little influence on the development and facilitation of other dimensions like reflexive abilities, communicative abilities and social interaction”* (see Schelhowe (2003): Digitale Medien in der Schule – Doing Gender. Beitrag für die Fachtagung „Schwimmen lernen im Netz cited in Aufenanger, 2009. However, although girls are more competent in reading (e.g. the handling of texts on different requirement levels:

identify information, interpret using the text and to reflect etc.), they scored less in interpreting numerical tests.). According to the study “... *the greatest and most consistent differences between the genders are to be found in reading. In all PISA participating countries the girls recorded significantly better test results than the boys, but scored less in interpreting non-linear texts like graphs, tables and diagrams* .(.)

“With 15 year olds it was shown, taking into account various kinds of texts, that girls performed much better at handling literary or continuous texts. However, the difference decreases considerably with discontinuous texts (e.g. tables, diagrams, maps)” (Aufenanger, 2009; n.p.)²¹

In educational science and pedagogy it remains still unclear, which factors, for example genetics, cultural context, educational setting etc., influence the often empirically observed performances differences in mathematics between boys and girls (see Preckel et al., 2008). Some critics even maintain that this perceived stereotype amounts to a self-fulfilling prophecy and lowers the performance.

Measuring and interpreting data is of utmost importance as part of the self-management of diabetes. Therefore for the EMPOWER project it might be relevant to be aware of gender-differences not only in usage and attitude, but also in related needed competences, e.g. technological competence for technological devices and numeracy skills for measuring and interpreting personal data to derive to good decisions and conclusions for individual diabetes self-management.

It might be useful to cater for gender-specific design in related EMPOWER functions. Needed are creative ways of support female patients in their self-management tasks, which involve numeracy skills, e.g. by automated oral or textual interpretation of glucose meter and graphs.

5.5 The issue of digital divide in EMPOWER

5.5.1 Current state of European digital divide

“Digital divide” generally refers to a very low rate of ICT use and of digital competences among specific groups, such as senior citizens, migrants or households with low compared with other user groups (Dijk, 2008). It is related to the idea of “e-inclusion”, meaning that everyone should take part in the advantages of an Information Society. Although the section before showed a decline in the differences of access rates to computer and internet in previous years (due to lower costs), the OECD acknowledges that some groups still remain in digital disparities (OECD, 2011). The study by Montagnier and Wirthman (2011), “Digital Divide: From Computer Access to Online Activities – A Micro Data Analysis” showed, the following results:

- “Low income is the single most important factor for non-access to a computer and to the Internet. On average, the odds that a high-income household in Europe has access to a computer and to the Internet are over 4 times higher than for a low-income household.
- The presence of children is the second most important factor for the access to a computer and to the Internet: on average, the odds for a household with one or more children in Europe are up to 3.9 times higher than for a household without children.

²¹ Based on Media Perspektiven. Basisdaten. Daten zur Mediensituation in Deutschland 2001. Frankfurt am Main, Dezember 2001. See also : TIMSS Study (OECD): TIMSS (Trends in International Mathematics and Science Study), which measures each fourth year the knowledge in mathematics and science. International reports: http://timssandpirls.bc.edu/TIMSS2007/intl_reports.html

- *Living in a town in Europe increases the odds to have access to a computer and to the Internet by over 30% as compared to living in the countryside.*
- *Age and economic inactivity are by far the most important factors for having never used a computer or the Internet. The odds are over 4 times higher for European inhabitants aged 65-74 years and up to 2.6 times for those out of the labour force. (Low) income, gender (female) and (lack of) children do play a role but their effect is smaller.*
- *Becoming unemployed is the most important factor for stopping using the Internet. The odds that a European inhabitant has not used the Internet over the last 3 months are about 2 times higher if he is unemployed or out of the labour force.*
- *Education is the most important determinant of the intensity of Internet use. The odds that an individual uses the Internet everyday increases by 2.4 times in Europe and by 3.6 times in Korea if he has a university degree and above.*
- *Being a student is the second most important determinant of the intensity of Internet use – the odds that a student uses the Internet every day are 2 times higher both in Europe and in Korea.*
- *The third factor explaining the intensity of Internet use is income in Europe (the odds are over 70% higher for the high-income households) and broadband access in Korea (the odds are 2 times higher for households with a broadband connection).*
- *Young age and higher education are the main determinants for the scope of Internet use in Canada, Europe and Korea.” (Montagnier & Wirthmann , 2011, p. 4).*

A study from the PEW Internet Project and California HealthCare Foundation on people living with chronic conditions such as diabetes or high blood pressure reported that this group is significantly less likely to have internet access. However,

“once online, they are just as likely as everyone else to look for health information. (..) 64% of adults living with at least one chronic condition have internet access, compared with 81% of adults who report no chronic conditions. Yet once online, 83% of internet users living with chronic conditions say they look online for health information, compared with 77% of internet users living with no such conditions. However, internet users living with chronic conditions are keen to gather health information online, particularly about specific diseases, treatments, health insurance, and drug safety or recalls. They outpace or match other internet users on nearly every topic (except pregnancy issues)” (Fox, 2011, p. 11)

Recent survey data from the Pew Internet Project and the California HealthCareFoundation show that adults living with chronic disease are significantly less likely than healthy adults to have access to the internet:

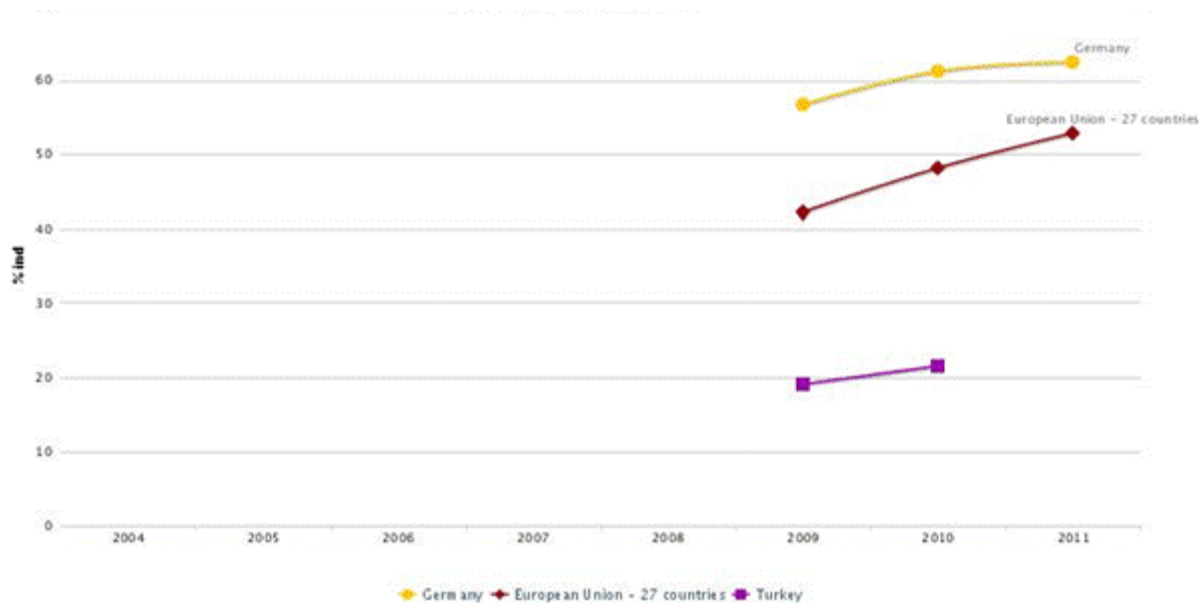
- 81% of adults reporting no chronic diseases go online.
- 62% of adults living with one or more chronic disease go online.

Additionally, people managing multiple diseases are less likely to have internet access:

- 68% of adults reporting one chronic disease go online.
- 52% of adults living with two or more chronic diseases go online.

These findings are in line with overall trends in public health and technology adoption

The European Scoreboard data showed that disadvantaged people, e.g. jobless, chronic ill or retired early are at least once a week online (sometimes borrowing computer or in an internet-café).



Graph 19: % of disadvantaged people who are regular internet users (at least once a week)

Definitions and scopes:

% of disadvantaged people who are regular internet users (at least once a week);

Disadvantaged people are defined as individuals having at least one of the following characteristics: aged 55-74, those with a low level of education (ISCED 0-2) and/or out of the labour market (unemployed, inactive or retired).

Regular use is defined as having used the internet at least once a week, in the last three months.

Figures are calculated based on available microdata.

(from: Eurostat - Community survey on ICT usage in Households and by Individuals)

5.5.2 Needs and demands by younger senior citizens

For EMPOWER the existence of the digital divide among younger and older senior citizens is of interest, since the average diabetes patient of type 2 is 55 years and older. This large group of potential EMPOWER users are called “younger senior citizens” and they are also a heterogeneous population, which includes very different subgroups according to socio-economic, cultural and geographical variables. Common to them is that they

“grew up in the 1940s and 50s, in a pre-digital age, and they suffer from various limitations that impair their embrace of digital technologies. Although the majority of Europeans aged 65 and over are open-minded towards new technologies and many have already gained hands-on experience with a computer, their full acquaintance with these technologies is limited by factors that prevent accessibility to ICT resources” (see Mordini et al. 2009: 8).

According to Mordini et al. (2009), strategies to bridge the digital divide are - from a technological perspective:

- *“the development of lower-cost and highly accessible technologies*
- *the creation of applications that engage and motivate individuals to interact with ICT because it enhances their personal lives and their roles within family and community.*
- *Meeting the physical needs of senior citizens as well as those who may be less educated and uncomfortable or unfamiliar with the traditional desktop computing environment which has become the hallmark of current day ICT.”* (Mordini et al. 2009:5)

Many EU projects aim at developing strategies, materials and policies to include senior citizens, such as the EU Project - Digital Engagement of Senior Citizens at: www.seniorsproject.eu. This project identified the following differences in learning needs of senior citizens: “The learning needs of seniors differ as they:

- learn technology differently from those of us who have more or less grown up with computers
- have different learning styles
- have different physical issues (poorer vision, mobility problems e.g. arthritic hands);

The findings are that older learners engaged in ICT learning

- are more likely to undertake short non-award vocational courses - aim is to gain skills rather than qualifications.
- increasingly turn to community training providers for vocational and personal training.
- prefer learning in an informal learning environment, in small classes or groups.
- need slower paced, low intensity training and often prefer self-paced learning.
- take increasing responsibility for their training and learning and for sourcing learning which meets their needs, constraints and learning-style preferences.
- are often independent learners - self-directed and with a clear idea of their own purpose for undertaking training".²²

Finally, it has become apparent from pilot projects and usability evaluations in eHealth and related fields (e.g. Feuersinger, 2008: Internet für Senioren: Anspruch und Wirklichkeit seniorengerechter Webseiten: www.seniorkom.at) that special aspects of usability help to bridge the digital divide. The SeniorLearning platform, suggests to take care with:

- Visual Design: Avoid the use of serif, novelty, and display typefaces. Use 12 point or 14 point type size for body text. Use medium or bold face type. Present body text in upper and lowercase letters. Use all capital letters and italics in headlines only. Reserve underlining for links.
- Scrolling : Avoid automatically scrolling text.
- Color: Avoid yellow and blue and green in close proximity as these colors and juxtapositions are difficult for some older adults to discriminate. Use dark type or graphics against a light background, or white lettering on a black or dark-colored background. Avoid patterned backgrounds. Warm colors and harmonic color schemes are more suitable than cold colors and strange color combinations...etc.
- Buttons and Styles: Buttons should be logically arranged. They should be large enough (the same applies to symbols and text used for them). An easy to read font, etc.
- Language and Terminology: Present information in a clear and familiar way. Use the active voice. Write short, straightforward sentences, etc.

5.6 Implications for the EMPOWER project

- In EMPOWER the concept of health literacy is strongly connected to digital competence and media literacy. In EMPOWER, we aim focusing on what potential users of EMPOWER services, supporting chronic disease management need to know (knowledge), being aware of how to do (competence), being able to do it (show how) and doing it (action).
- Digital competence is more than only read and write with the computer/media. It involves the "confident and critical use of information Society technology (IST) for work, leisure, learning and communication. It is underpinned by basic skills in ICT: the use of computers to retrieve, access, store, produce, present and exchange information, and to communicate and participate in collaborative networks via the Internet." (see Digital Agenda Scoreboard 2011).

²² Source: EU project Report: Digital Digital Engagement of Senior Citizens<. ICT pedagogy strategies for engaging senior citizens in the information society.

- Digital competence can be measured by different characteristics: by the rate of access to computer and internet as pre-requisite; by a positive attitude and willingness to use the technical devices needed for EMPOWER and by the actual usage (daily, weekly, monthly; from reading information via web, use e-mail to be part of an online community or to produce and publish e-content (via a CMS-system, blog-system).
- In Europe the access of ICTs (computer and internet) has considerably increased by 2011 (almost 90% of households in Germany; 45% in Turkey). Shift in media usage from TV to devices with internet access, from stand-alone computer to lap-top, I-Pads and I-Phone or mobiles. However, the shift varies with age.
- ICT uptake of general practitioners, especially data exchange and use in patient-doctor relation is currently modest, but with rising trends.
- In Europe 27, 32% of internet users have low level skills (e.g. only read information via web, search eHealth info), 30% have medium level skills (e.g. posting a message to a chat or social network platform; excel and graphs developments and interpretation) and 10% have high level skills (e.g. producing e-content).
- Gender differences: the difference between male and female attitude towards technology/ internet is becoming minimal; women are more interested in searching for eHealth topics, esp. about chronic care knowledge; women use more online communication tools and platforms; men are more likely to use internet as a destination for recreation. Young students show different performances in numeracy skills, necessary for measuring and calculating diabetes parameters and outcomes. There is a need for creative – seamless – support of EMPOWER functions for which users need numeracy skills (e.g. automation of measuring and interpretation process; oral and text support for graph interpretation).
- The digital divide, low rate of access, ICT skills and positive attitude towards EMPOWER technology is of considerable concern, since a majority of diabetes patients is beyond 50+, lower income and lower educated. However, having no access is not a barrier anymore.
- Younger senior citizens have the need for different usability (screen design, script, haptic devices etc.)

6 Conceptual framework of web-based patient empowerment

In the following the conceptual framework of the EMPOWER project will be described. Based on concepts from health behaviour literature a model was developed to understand the underlying processes of patient empowerment.

6.1 Main concepts for Patient Empowerment

Patient empowerment and *health literacy* are two prominent concepts in health behavior literature. They are considered to be related with several health behaviors and health outcomes and are therefore focal for the development of public health interventions.

Empowerment can be defined in general as a “*process by which people gain mastery over their lives*” (Rappaport 1987) and can be therefore applied to different disciplines. However a common basis for every discipline is that in order to improve the quality of their lives in every aspects the individuals should be motivated to change at a personal, social and organizational level. As a result empowerment is a relational construct, as it is for example in doctor-patient communication, which is associated with several other concepts, and implies problem solving skills (Israel et al. 1994, Schulz et al. 1995).

Starting from the management literature the concept of empowerment inherited two meanings, which are particularly important for the realm of health (Wall et al. 2002). The first one is denoted as “psychological empowerment”, and refers to employees’ subjective feelings of empowerment—specifically feelings of perceived competence to perform tasks well, feeling influential in their work role, feeling that the work is important, and feeling free to choose how to execute tasks (Conger & Kanungo 1998, Spreitzer 1995, Thomas and Velthouse 1990). A second meaning, often called “role empowerment” or “situational empowerment” (Logan and Ganster 2007), refers to objective practices involving the delegation of responsibility to employees in order to give them decision-making authority. Empowerment in this sense encompasses practices such as job enrichment, self-managing teams or autonomous work groups. Research has linked both of these forms of empowerment to improved employee performance and satisfaction.

In the field of health, and in relation with health behavior, the concept of empowerment is named as patient empowerment (Rappaport, 1987; Rappaport, 1981; Zimmerman & Rappaport 1988), even if this includes individuals who are not necessarily patients. Patient empowerment is conceived as the patient’s participation as an autonomous actor taking increased responsibility for and a more active role in decision making regarding his or her health (Schulz & Nakamoto, 2011).

It can be argued that the patient may not be willing to take a more responsible role towards his/her health, and this argument highlights the psychological dimension of patient empowerment. In this respect indeed patient empowerment implies feelings of power, control, self-esteem, which lead the patient to value autonomy and the interest to take a participatory role in their healthcare. This perspective underscores the importance of the volitional dimensions of empowerment. A patient who is empowered is a person who use the information s/he gets, and tries to make sense out of it and to use it in the best way possible for her/his health. From this capacity to make sense out of all kind of personal and external resources the strong connection with health related behaviors of an empowered patient is derived.

Most of the programs on patient empowerment which are presented in the literature deal with an increased self-management by improving the access to services, the ability of patients’ to manage disease, and their health outcomes. As stated by the British Expert Patient program, the vision should be that “many more patients with chronic diseases are well informed about their condition and medication, feel empowered in their relationship with health care professionals, and have higher self-esteem. Thus, the programs take as an intermediate goal both situational and psychological empowerment of the patient.” However, the mechanics of the program rely heavily on education including improved patient knowledge (ergo literacy) regarding their health condition (Tyreman 2005).

Spreitzer examined the management context, and noticed that increasing employee empowerment means to increase employees’ perceived capacity and willingness to do what they can be assumed to be able to do. Linking this assumption to health means that it is reasonable to expect that a patient gains the expertise to participate in decision making regarding his/her healthcare. But in the case of psychological patient empowerment, this assumption is not necessarily true. Increasing patient empowerment means to increase their willingness to become more autonomously involved in health care decision but we cannot assume they have the necessary expertise. *This expertise is the core of the concept of health literacy.*

Even though they are related, health literacy and empowerment have to be distinguished, which has huge implications for health communication research and practice. One of those is the conceptualization and measurement of these concepts as two distinguished concepts. A proposed operationalization of patient empowerment is the following.

Operationalization of psychological patient empowerment

The operationalization of psychological patient empowerment is still an issue, since literature shows few attempts in operationalizing it. Thomas and Velthouse (Thomas and Velthouse 1990) proposed a conceptualization in the management field, which is operationalized by Spreitzer (Spreitzer 1995). He identifies four constructs that constitute empowerment: meaningfulness (or relevance), self-efficacy (or competence), self-determination (or choice) and impact. To summarize those constructs in proposition we could say: “I feel that doing this is relevant for me”; “I am able to do this”, “I can choose between different ways”, and “I can make a difference.” Schulz and Nakamoto (Schulz and Nakamoto 2011) translated these constructs to the health realm and included:

- „*Meaningfulness (or relevance)* which refers to the value of the activities, judged in relation to the individual’s own ideal of life. Meaningfulness is about the individual experiencing the feeling that what he or she does is meaningful and worth investing energy in. If the patient does not consider his/her activities as being relevant for his own quality-of-life, this will result in resignation, apathy or disengagement. On the other hand, higher levels of relevance are believed to result in commitment and involvement.
- *Self-efficacy (or competence)* is a key cognitive component of social cognitive theory (Thomas and Velthouse 1990, Bandura 1977, Gecas 1989). Self-efficacy is the belief in one’s capabilities to produce desired results by one’s actions. Without efficacy, people have little incentive to act. Referring to the degree to which a person can perform task activities skillfully when he or she tries, the concept has been widely investigated in social psychology, in motivational theories as well as in cognitive theories which conceptualize self-efficacy in terms of expectancies and perceptions of control . Research based on Bandura’s theory has shown that self-efficacy has beneficial effects in different health domains such as smoking addiction (DiClemente et al 1985), alcohol and drug abuse (Newcomb and Harlow 1986, Seeman and Anderson 1983), increasing pain tolerance (Neufeld and Thomas 1977) as well as eating disorders (Rohrer et al. 2007). Rohrer et al. showed that patients who are confident about their ability to manage their health will have better health in comparison to more dependent patients.
- *Impact* means that the accomplishment of a task is perceived to make a difference in the scheme of things. Thomas and Velthouse’s (1990) conceptualization of impact is derived from work in the areas of locus of control (Rotter 1966). The more impact individuals believe they have, the more internal motivation they should feel.
- *Self-determination (or choice)* refers to a decision that is characterized by autonomous initiation and is self-determined. It presupposes a distinction between an intentional behavior where people want to act in a way that would yield certain outcomes and a kind of behavior that is pressured and coerced by intra-psychic or environmental forces. Only the former represents a true choice (Deci and Ryan 1987, Deci 1975, Ryan and Deci 2000). Greenfield et al. demonstrated that a guided form of patient involvement in health decision making improved outcomes as well as involvement and preference for involvement (Greenfield et al 1985).

All the components of this operationalization refer to subjective experience of empowerment, and its force as a motivation for acting. This is essential to distinguish empowerment from the concept of health literacy, which is rather the knowledge and the ability to use it. Health literacy abilities can be clearly distinguished by empowerment since they are not motivating per se. However since both, empowerment and health literacy, together contribute to health behavior change it is important to clarify and measure also this other concept.

Health literacy stems from the general concept of literacy, which is the ability to read and write (Oxford Dictionaries, April 2012). Correspondingly, the Ad Hoc Committee on Health

Literacy defines health literacy as a “constellation of skills, including the ability to perform basic reading and numeric skills required to function in the health care environment” (Ad Hoc Committee on Health Literacy, 1999: 553). Conceptually, health literacy has moved from functional skills in the medical setting to being a multidimensional concept that involves more advanced skills. Nutbeam (2000), for example, proposes a three-tiered concept of health literacy distinguishing between functional health literacy, interactive health literacy, and critical health literacy. Schulz and Nakamoto (2005) stress the importance of knowledge as part of health literacy. In addition to basic reading and numeracy skills, their multidimensional concept of health literacy comprises *declarative knowledge* (factual knowledge related to health issues to be able to learn how to approach a health condition), *procedural knowledge* (“know-how” to apply factual knowledge and use health information in a specific context), and *judgment skills* (the ability to judge on the basis of factual knowledge necessary to deal with novel situations). In the context of diabetes, declarative knowledge includes, e.g., the knowledge of blood glucose and the availability of tools to measure it. On the other hand, procedural knowledge entails how and when to measure blood sugar level.

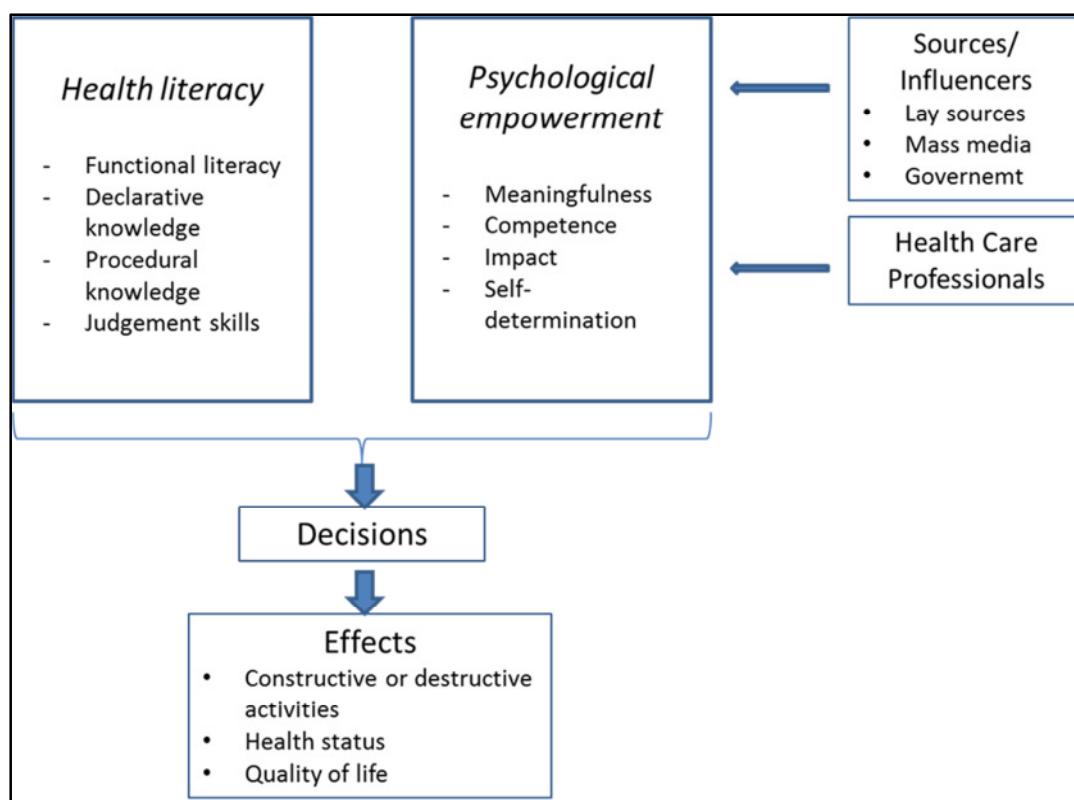


Figure 5: Health Literacy and Psychological Empowerment
(from: Schulz & Nakamoto, 2012)

Those concepts are all part of a model of health literacy and empowerment (Schulz and Nakamoto, 2012), which constitutes the theoretical background of EMPOWER project, thus serving as the basis for the evaluation of the pilot application of the prototype (**Fehler! Verweisquelle konnte nicht gefunden werden.**).

6.2 User Characteristics: An analysis in view of the proposed framework

In the following the results of the focus groups with diabetes type 2 patients in Ingolstadt, Germany are discussed.

In March 2012 two focus group with patients and one focus group with doctors were conducted. The discussions took place at rooms of GO IN Germany and patients were

recruited through the office of a general practitioner. The doctor's assistants called the patients and invited them directly to participate in the focus groups.

Doctors were recruited through snowballing contacts.

The first focus group which took place during the evening hours consisted of 8 participants of whom were 6 male and 2 female.

The second group consisted of 10 participants, including 6 female and 4 male participants.

The age ranged from 60 to 79.

The focus group with doctors consisted of 7 doctors, including 6 general practitioners and 1 ophthalmologist.

One discussion lasted for 90 minutes and was facilitated by an USI researcher. Further, a co-facilitator, also from USI, was present to support the moderation. The focus group discussions were taped and later transcribed. The full set of transcripts was then analyzed.

At a first step an inductive method was used to identify topics.

Once these topics had been identified a rather deductive method was used. In the light of Nakamoto and Schulz' proposed model on patient empowerment the transcriptions of the focus groups are analyzed. The analysis also draws from input given by doctors in a third focus group at the same setting.

Further, the analysis was supplemented by the analysis of interviews conducted with Turkish patients and doctors. This was done in order to account for differences in culture and health care systems, as the pilot application will be validated in Germany and Turkey respectively.

Each sub-chapter refers to one component of the model. Each component and their related constructs are used as reference points to analyze patients' discourse.

The main and most „tangible“ topics that emerged throughout the discussion were: Nutrition, physical activity, monitoring blood glucose levels, use of technologies, hypoglycemia, social expectations and social support (Table 7, Table 8).

6.2.1 Psychological Empowerment

6.2.1.1 Meaningfulness: „I feel that doing this is relevant for me“

Nutrition

The topic of a healthy diet was a theme that continuously came up and is not surprising as diabetes type 2 is often framed as an outcome of bad nutrition and a disease which requires changes in diet.

Since it was such a prevalent topic in the discussion, it seemed to be a topic of high relevance to the patients. Following the right dietary guidelines were meaningful to them in the sense of being able to lower their blood glucose levels.

Nevertheless, people also deviated from dietary guidelines, rather following their own patterns, in order to keep their blood glucose levels low.

„When I get up early in the morning I have to measure, then I see the sugar and decide what to have for breakfast.“ (Male Participant - FG 1)

„I realized that when you eat normally it is better with the sugar than paying attention to eat little because then my sugar is in most of the cases higher. So I eat wholemeal bread and then alternating musli or the other day wholemeal bread...“

(Female Participant - FG 2)

Physical Activity

With regard to sports, in particular men mentioned that they already were physical active before they were diagnosed with diabetes. Physical activity seems to be rather relevant in terms of overall health than with regard to the condition they are suffering from.

On the other hand, also men, indicated physical activity as being useful in weight reduction in order to better handle their diabetes.

Women seemed to perceive sports as being less relevant in order to treat their condition. They agreed on its importance but seemed to agree because they learned so from their doctors and other sources rather than because of their own experience.

Hypoglycemia

Patients stressed their concerns regarding hypoglycemia. Patients described extensively their experience with it and in both groups the topic of integrating an emergency function on a mobile phone came up.

It is to assume that people who feel the immediate effects of hypoglycemia perceive its managing and handling more relevant than unseen long-term effects caused by high blood glucose levels.

With regard to long-term relevance, a doctor mentioned the importance of using pictures in order to make patients more aware of the possible long term outcomes in untreated diabetes.

6.2.1.2 Competence (self-efficacy): “I am able to do this.”

Nutrition

The focus groups revealed two different groups with regard to what one may name “nutritional self-efficacy.” One group showed to be less able to refrain from eating sweets, such as cake or chocolate. The group of “sweet-tooth” indicated that they were less able to abstain from sweets.

“When I eat chocolate or something today, then I just eat it, I can do it.”
(Male Participant – FG1)

”I also have to live. When I get started, I cannot just eat a piece of it, I need a whole chocolate bar.”
(Male Participant – FG2)

The group of “salty tooth” on the other hand indicated that they never had the urge to eat sweets or did not have any problem to cut on these things when diagnosed with diabetes.

”I can hold myself back from sweets. That is not a problem. I have everything under control. There are no difficulties.”
(Female Participant – FG2)

Use of technology

In both focus groups only very limited support for the use of technology was found. Participants articulated that they considered them being either “too old” or that the usage of mobile devices and internet would be more suitable for younger generations.

One participant mentioned that special training would be needed for that.

Men showed to be a bit more experienced than women in using computers, even though it was stressed that they did not particular comfortable with them and rather used it for easy tasks, such as writing and internet.

One participant mentioned that his wife rather uses it and that he preferred to get the information from the internet in printed form.

Arguable participants, in particular women, seemed to lack enough self-efficacy with regard to the use of technologies in the realm of diabetes care.

6.2.1.3 Impact: “I can make a difference.”

Physical Activity

As mentioned above participants indicated that they perceive physical activity as being meaningful and relevant to them. However, especially with regard to short-term outcomes, in particular women did not express that sports would allow them to better control their disease. They understand it as a means of reducing weight or keeping the blood sugar level down in the long run. But for the short term participants expressed worries about hypoglycemia and possible consequences, such as being weak, trembling and passing out or how to accurately manage their physical activity in order to reach satisfying results.

"If someone has overweight, then he can lose weight and continuously reduce blood sugar but when I do sports then my blood sugar rises. You do not get any information on this for example. If one would have a gym teacher next to oneself, one could better control it."
(Male Participant – FG 1)

Monitoring Blood Glucose

Women who use insulin to treat their diabetes seemed to be more likely to frequently and thoroughly monitor their blood glucose levels and keep track of them. As opposed to women who are not yet on insulin therapy, they seem to think to be in better control of the development of their disease by trying to continuously observing the measurement results.

"Yes, I got specifically the booklet where I write it down. And in addition to it I let them (Doctors) put the HbA1c values down order to have an overview whether it goes down."
(Female Participant – FG2)

"[...] every day. Early in the morning I write it down." (Female Participant – FG2)

Men on the other hand showed to be less likely to keep track of the blood sugar levels in a written form. They nevertheless indicated that they keep track by checking it on the blood glucose monitoring device.

"I save it. I am always interested in the last 30 days." (Male Participant – FG1)

"I can go back to 100 (times measured) using my glucose meter." (Male Participant – FG2)

Quality of Life

A theme that emerged throughout the discussion was the importance to accept the disease as such and to arrange oneself with it, accepting it to be part of one's life.

Especially men seemed to be less worried about different phases they may encounter during their disease and emphasized the need of accepting it.

However, it became evident that patients rather saw the actions they took as incremental steps in order to enhance their situation rather as keeping the situation stabilized. Individual actions were seen to be detached from the overall condition, rather solving one-time problems. This became particular evident with the monitoring of blood glucose levels. Patients had difficulties in interpreting the results with regard to long-term outcomes rather than relating it to immediate effects and behaviors (such as, "what I am allowed to eat now?" or "what did I do wrong?").

"This (measurement result) can't be right! What did I do wrong?"
(Female Participant – FG1)

"And when I have so high results early in the morning, then I get so angry with myself and also with my environment..."
(Female Participant – FG2)

6.2.1.4 Self-Determination (choice): “I can choose between different ways.”

Social Expectations

In particular women expressed concerns regarding the interaction with other people taking into account their disease. A problem that emerged were in particular social gatherings in which one has to refuse eating certain things for dietary reasons.

„... One is invited very often and then (they say) ‘Do you want a piece of cake?’” (Female Participant – FG 1)

Besides the decline of food, patients also expressed the perceived problems of how to communicate to peers that they are suffering from diabetes.

„In the beginning my friends and acquaintances did not even know for years that I had diabetes. And then (they) always say: ? ‘Eat another piece of cake or take this still.’“ (Female Participant – FG2)

Further, people expressed their worries injecting insulin in public places or measuring blood sugar levels. Either because of environmental circumstances (using public toilettes, searching for a parking spot) or because they may have to let strangers know about their situation in order to have some privacy.

The table (Table 7) on the following page sums up the results of the focus group according to the different constructs of psychological empowerment. Short statements in first person try to capture and simplify the identified issues in the discourse, and should serve as exemplary metaphors of people’s thoughts.

Psychological Empowerment			
Meaningfulness	Competence	Impact	Self-Determination
<p>↑ Nutrition</p> <p><i>To follow dietary guidelines is meaningful to me.</i></p>	<p>↔ Nutrition</p> <p><i>"I need my chocolate" vs. "I can abstain from sugar"</i></p>		
<p>↑ Hypoglycaemia</p> <p><i>In order to guarantee immediate quality-of-life, I have to avoid hypoglycaemia.</i></p>	<p>↓ Technologies</p> <p><i>I do not have the skills to master technology.</i></p>	<p>↔ Monitoring Blood Glucose</p> <p><i>Women: "Keeping track has an impact." Vs. "Men: "Keeping track does not make a difference"</i></p>	
<p>↔ Physical Activity</p> <p><i>I wish I could see how physical activity affects me in the long run.</i></p>		<p>↔ Physical Activity</p> <p><i>Physical activity is a means to help me to manage my weight.</i></p>	
		<p>↓ Quality of Life</p> <p><i>All the actions I take, do not have an impact on the overall disease, it rather helps me to get from one day to another.</i></p>	<p>↓ Social Expectations</p> <p><i>The environment I am in changes my behaviour.</i></p>

Table 7: Focus Group Results - Psychological Empowerment – Arrows indicate importance given to each of the topics in light of the construct used to analyze it.



The research leading to these results has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under grant agreement No 288209, EMPOWER Project.

6.2.2 Literacy Components

6.2.2.1 Declarative Knowledge: (factual knowledge)

The focus groups revealed that participants seemed overall to have a general understanding and knowledge about the treatment of diabetes and its related necessary lifestyle changes.

Nutrition

Nevertheless, the discussion revealed also that patients do not necessarily show a coherent knowledge. While discussing, people exchanged opinions on what and how to eat and did not always agree on what and how to eat.

Some people, especially women, raised more questions about the right choice of food.

Blood Glucose Monitoring

With regard to measuring their blood glucose levels, people seemed to be able to understand what the results meant and whether they refer to a high or low blood glucose level.

6.2.2.2 Procedural Knowledge (or know how):

Nutrition

Participants highly valued the diabetes training on nutrition. Those ones who already participated in these classes expressed feelings of being able to better manage their food intake. It was mentioned that during the classes patients learn how to measure food intake in a simpler way which showed to be particular useful in everyday situations.

Doctors expressed their concerns regarding the lack of the repetition of newly learned information, in particular with regard to stays in medical spa (please see section 6.2.3.2)

Monitoring Blood Glucose

People seem to be able to put learned information into practice but the discussion also revealed some worries about translating declarative knowledge into procedural knowledge. Most participants know how to measure blood glucose level but there seemed to be a lack of understanding what the right patterns in measuring BG were, such as time and frequency.

“I always hear measuring but no one tells you how to measure and when to measure.”
(Male Participant - FG 1)

Further it was indicated that the results of the measurements are sometimes not fully understood at first sight but with time people draw their own conclusions where these results may have come from, e.g. stress or physical activity.

Using Technologies

Doctors agreed that the usage of technologies might not be appropriate for the older generation of type 2 patients but younger ones could be a good target.



6.2.2.3 Judgment Skills

Listening to oneself

One participant extensively described how she found out that eating tomatoes would hamper her blood glucose levels. She stressed the importance of listening to oneself. A topic that was also stressed by other participants, e.g. developing own strategies with regard to food intake. Independently from what doctors have them told or any other form of official suggestion, patients try to interpret measurement results with regard to their behaviors and try to adapt those in accordance. Thus, taking actions based on what they already know and on own their personal experience.

“It is exactly like this. I try it..... In the beginning I also have (had) 30 units. That is not possible, always so little (low blood sugar). Then I always used less, now I inject 4 units per night. And then sometimes nothing at all.“

(Male Participant – FG₂)

6.2.3 Sources/Inferences

6.2.3.1 Lay sources

Life Partners

When asked about the most important relationships in order to cope with their disease, patients referred often to their partners. Either husbands or wives both were considered to be helpful support.

“My wife completely changed the diet. In this respect I could always rely on her.”

(Male Participant - FG 1)

“ Yes I also have my husband. He also supports me, he observes me.”

(Female Participant - FG 2)

One female participant nevertheless mentioned the difficulties of her husband to understand and also accepting that his wife is suffering from diabetes.

„My husband does not believe me that I am sick. [...] He only wants to eat fatty (foods). And always... when I make vegetables, I have to make potatoes for him. And when I make pasta, he also does not eat any pasta or rice, only potatoes. Then of course you get upset. And then it is enough.”

(Female Participant - FG₂)

6.2.3.2 The mass media, government & health professionals

Knowledge Acquisition in general

Participants indicated to get information from doctors and through educational classes as well as from the DMP.

Some participants indicated a lack in diabetes training (as health insurers would not pay enough). The doctors, as revealed in the discussion with them, also agreed this on. Doctors saw a lack of responsibility on the side of the health insurers in order to communicate diabetes training and also called on their part to better integrate their programs in accordance with doctors.

Most patients indicated that they liked the information they got from the DMP as well as from the classes.

Another topic that came up was that patients learned a lot during the stay at a medical spa and indicated that they were happy with how and the amount of information that was given to them.

The discussion with the doctors on the other hand revealed skepticism regarding the learning effect in medical spas (cures). A doctor mentioned that patients take up the habits for a while but then will eventually forget about it. Further, patients are not able to translate learned things into daily life. The sustainability of this new knowledge was questionable. One doctor mentioned the importance of repetition. In this case newly learned things have to be repeated, something that is not accounted for by the spas.

Nutrition

From the patients' perspective in particular the training courses as well as the stay in the medical spa were perceived as being helpful.

Medication

Patients showed trust in their doctor concerning medication. One female patient mentioned that she also appreciates the information given by the health insurance and the possibility to go with this information to her doctor in order to talk about it with him.

6.2.4 Limitations

The results of the focus group discussion have to be evaluated carefully as it has to be taken into account that we dealt with very particular groups. Most of the patients shared the treating physician and the discussion took place in a setting which was also provided by the physician. Further, patients were directly recruited by the doctor and his assistants. Thus, results (as usual for focus groups) should be used carefully with regard to generalizable assumptions.

Health Literacy & Sources/Influencers			
Declarative Knowledge	Procedural Knowledge	Judgment Skills	Sources
↔ Nutrition <i>"What is the right choice of food?"</i>	↔ Nutrition <i>"I think I am sure what to eat."</i>		↔ Nutrition <i>"I think I have learned a lot but do I remember everything?"</i>
↑ Monitoring Blood Glucose <i>"I understand the meaning of the results."</i>	↔ Monitoring Blood Glucose <i>"I know how to do it but what are the patterns I have to follow?"</i>		↑ Medication <i>"I trust my doctor and the information from the DMP."</i>
	↔ Using technologies <i>"I do not know if I am in the right age?"</i>		
		↑ Listening to oneself <i>"With time, I have learned what is best for me."</i>	↑ The life partner <i>"I trust him/her, she means it well with me."</i>

Table 8: Focus Group Results – Health Literacy & Sources/Influencers – Arrows indicate importance given to each of the topics in light of the construct used to analyze it



The research leading to these results has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under grant agreement No 288209, EMPOWER Project.

6.3 The EMPOWER Project: Fostering self-management in diabetes patients

6.3.1 The context of the EMPOWER project

The EMPOWER project develops *software functionalities*, which aim to support specifically forms of interventions in the process of individual chronic care disease management programmes.

Chronic diseases influence strongly the daily life of patients. Often health-related decisions and actions can and will be done by the patients themselves. Many of these decisions involve routine activities of daily living (e.g. nutrition, physical activity). Hence, patients should be more involved in decisions about their care, health conditions, treatments and their lifestyle. Consequently patient empowerment should integrate multiple concepts that allow patients to effectively self-manage their disease. Self-management and to work out self-management skills should also be a part of education effort. Lorig (Lorig, 1993) defines self-management education as, *“learning and practicing the skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition”*. Lorig (Lorig, 2003) also indicates that self-management programs must also be based on patients’ perceived problems and recommends five major self-management skills as key concepts:

- ◆ Problem solving –this means the teaching of problem-solving skills. This will include problem definition, the generation of possible solutions (e.g. together with friends or care professionals) or the evaluation of results.
- ◆ Decision-making – in order to support persons with chronic diseases in their day-to-day decisions, which they have to make in response to changes in disease conditions. EMPOWER will provide the necessary knowledge, e.g. how do I know whether a symptom is medically serious? Decision-making is based on having enough and appropriate information.
- ◆ Resource utilization – often patients are told about resources but they are not taught how to use them, e.g. the Internet, a library, a community resource guide.
- ◆ Supporting the patient/healthcare provider partnership – up to the first half of the 20th century the primary reason for seeking health care was to treat acute illness. The role of care provider was to diagnose an illness. Since then, chronic diseases have been increasing more and more. Patients of today are more informed about their diseases. They must be able to report the state of their diseases and to discuss it with the health care provider. Against that background the role of the health care provider becomes more that of a professional supervisor.
- ◆ Taking actions in reasonable steps – this refers to skills in learning how to change behaviour, in particular making short-term action plans and carrying them out. Typically an action plan covers a period of 1-2 weeks and is behaviour specific. At the same time it has to be realistic meaning that a person should be able to accomplish the behaviour in the defined period. If on a scale from 0 (totally unconfident) to 10 (totally confident) the answer is 7 or higher, based on self-efficacy theory, there is a good chance that the action plan will be accomplished.

Furthermore, enhanced self-efficacy is one mechanism that is responsible for improvements in health status. Self-efficacy can be fostered by e.g. involving people actively in behaviour change based on action planning or following community behaviours. Self-help groups are excellent examples of social persuasion and how group support can be effective in behaviour change (Lorig, 2008). Patients are social actors, residing in social environments that contain and deliver different types and degrees of support. The concept of social support – defined as resources provided by a network of individuals and social groups (Lepore, Evans, & Schneider, 1991) – and its relation to health had been faced in the past 25 years by a

burgeoning literature (Krokavkova et al., 2008; Helgeson, 2003; House et al., 1988b; House et al., 1988b; Lee et al., 2004). One of the most important functions of social support is the health-sustaining function in that it has a direct effect on the well-being of individuals (Krokavkova et al., 2008; Thoits, 1982). There is strong empirical evidence that social support from family and friends can be helpful for patients in several ways (Johnson et al., 2010). Several studies have shown that both seeking and receiving assistance from other people may have direct effects on health outcomes (Antonucci et al., 2003; Simoni et al., 2006; Parker et al., 2006; Strating et al., 2006; Courneya et al., 2000), other literature suggests that social support has moderating effects on health outcomes such as health status or health service utilization.

Looking at initiatives with focus on patient empowerment there already exists many projects and solutions which typically cover aspects of patient empowerment, e.g. online PHR systems with free account such as Google Health²³ or Microsoft Health Vault²⁴; LifeSensor²⁵, a commercial PHR system; Project HealthDesign²⁶ pursues a new vision for PHRs by integrating observations of daily living into clinical care; health portals such as Diabetes Juvenil²⁷, a Spanish virtual community providing material for training, self-care, news, documentation for diabetes patients; HealthSpace²⁸ a free, secure online personal health organiser of the National Health Service (NHS) in UK; the Danish public health portal Sundhed.dk²⁹ which aims to be a common entrance to Danish healthcare in such a way that everyone has secure access to common information and services; Dokter³⁰ is a Dutch website that offers medical consultations over the internet with expertly qualified doctors; INKA³¹ is a German virtual community of cancer patients. The Swiss website SENACA³² focuses on improving the health literacy of elderly people.

6.3.1 Patient-physician-relationship

6.3.1.1 Identify existing models, strategies, concepts and first experiences and best practice projects

The field of patient-physician relationship has been largely studied. Particular attention has been given to doctor-patient (D-P) communication over the '90s and onwards. This relationship is especially complex as it is an interaction of individuals in non-equal positions. It is often non voluntary, deals with vital important issues, involves emotions and requires cooperation. (Ong et al., 1995). In a context where medicine is growing in complication the interpersonal relationship between doctor and patient is one of the most important aspects.

There are many possible ways to look at D-P communication. A very well-known and shared classification by Roter and Hall (2006) is based on doctor and patient control, and it is represented by the following table (Table 9).

²³ <http://www.google.com/health>

²⁴ <http://www.healthvault.com/Industry/index.aspx>

²⁵ www.LifeSensor.com

²⁶ <http://www.projecthealthdesign.org>

²⁷ <http://www.diabetesjuvenil.com/>

²⁸ <https://www.healthspace.nhs.uk/visitor/default.aspx>

²⁹ <https://www.sundhed.dk/>

³⁰ www.dokter.nl

³¹ <http://www.inkanet.de/>

³² <https://www.senaca.ch/>

Patient control	Physician control	
	Low	High
Low	DEFAULT	PATERNALISM
High	CONSUMERISM	MUTUALITY

Table 9: Types of doctor patient relationships
(from: Roter & Hall, 2006)

One of the most prevalent types of relationship is the one in the upper right cell. *Paternalism* is the relationship where the doctor has high power, meaning that he regulates the agenda and the goals of the visit and therefore the decision making process. Thus, the voice of the patient is largely absent. The underlining assumption of this relationship is that the doctor has all the authority and knowledge and he/she is acting in the “best interest” of the patients. Patients’ knowledge and social status have shown not to have a strong relationship with decision-making preferences, whereas the severity of the illness showed to have a strong relation. The literature shows that when the severity of the illness increased the tendency of patients-physician relationship was to rely more on physicians for decision making.

A second type of relationship is called *consumerism*. This case is the opposite of the previous one, with the patient having a high control and the doctor having low control. The patient sets the goals of the visits and the agenda, and he/she is the only one who takes the responsibility of the decision making process. The name consumerism comes from the metaphor with a regular buyer of a good or a service. The patient knows what he/she wants and uses the doctor as a consultant. Consumerism is a relation that is strictly related with cost reduction. Indicators of consumerism are:

1. Cost consciousness;
2. Information seeking;
3. Exercising independent judgement
4. Consumer knowledge.

This type of relationship is more common in people with higher education and in younger age groups.

A third typology of relationships is called *mutuality*, where both doctor and patient have high control. This is considered to be an optimal situation where each of the participant to the discussion, meaning the doctor and the patient, bring their own strengths into play. The dialogue is more cooperative and it holds in itself a great therapeutic potential. Mutuality seems to be the optimal relationship. Brody (1980) identified four steps for encouragement of mutuality by physicians: 1. establishing an atmosphere conducive to participation, 2. ascertainment of the patients goals and expectations, 3. education of the patient, 4. elicitation of the patient’s informed suggestions and preferences, and the elicitation of disagreements.

The last type of relationship presented by the table above is the *default*, where both doctor and patient have a low level of control. This last typology is the most undesired one because it is poorly functioning and may continue for long time without any good outcome or resolution. It is therefore a good example of dysfunctional situation.

From a socio-cultural perspective of course the second and the third typologies can be considered to be the more modern types of relationships. If the doctor had all the authority in the past because he/she possessed knowledge, nowadays with ubiquitous information and technologies it is more likely that a patient is able to discuss, and to bring his/her own authority into a consultation. The patient is indeed contributing not just with the knowledge acquired by some other sources but also with the personal experience of the illness. Another historical reason for the shift in D-P relationship over the last century is the change of the role of healthcare providers. In the past the patients looked for healthcare providers only in cases of acute treatments, and therefore the role of the physician was to diagnose and to treat. With the rise of chronic conditions in the 20th century the reasons for and the contents of medical consultations changed, and consequently the role of the physician (Lorig & Holman, 2003).

What makes D-P communication particularly interesting for the context of healthcare, and for other related disciplines, is the important association with health outcomes. It has been proven that there is a positive relation between D-P communication and health outcomes. This positive relation is maybe not due to a direct impact, but we can rather assume that an effective D-P relationship have an indirect impact on patients' health. As Street (Street et al 2009) pointed out unfortunately there are some lacks in research that make impossible for now to understand more about what kind of communication process generates positive health outcomes, and also how this is related to a more general socio-cultural context. Assessing that D-P communication can lead indirectly to better health outcomes means that there is a mediated route through *"proximal outcomes of the interaction that could then affect health or that could contribute to the intermediate outcomes that lead to better health"* (Street et al., 2009, p. 297). In his model Street (2009) individuated seven of what he called "indirect pathways". These pathways are:

1. Access to care;
2. Patient knowledge and shared understanding;
3. Enhancing the therapeutic alliance;
4. Enhancing patients' ability to manage emotions;
5. Improving family and social support;
6. Enhancing patient empowerment and agency;
7. Higher quality decisions.

This last list highlights the importance of considering D-P relationship as a fundamental part of any self-management programme.

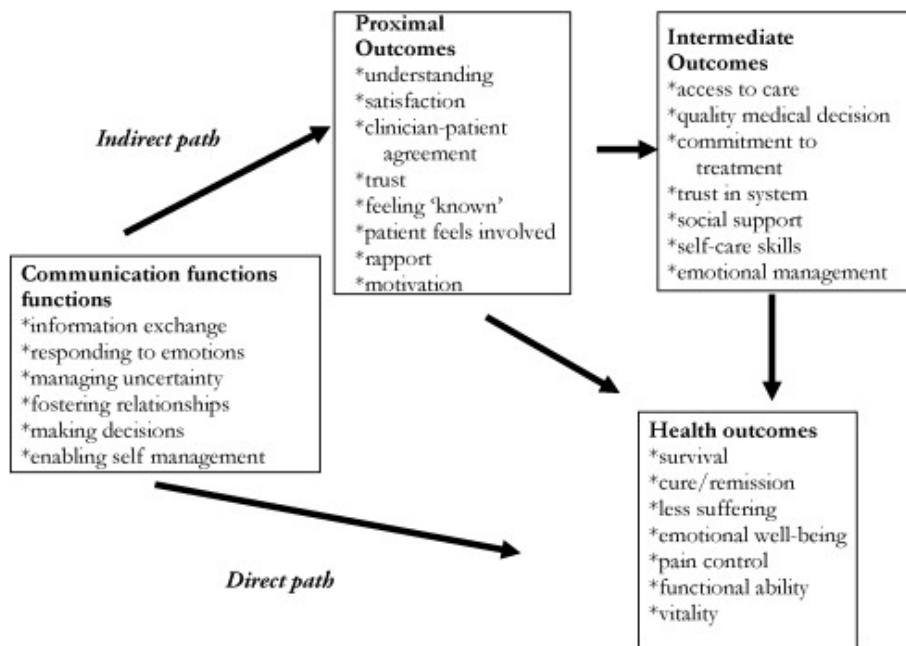


Figure 6: Direct and indirect pathways from communication to health outcomes
(from: Street et al., 2009)

6.3.1.2 Drivers and enablers

Starting from the model of Street and colleagues (2009) the drivers and enablers of an effective D-P communication are the proximal outcomes, which are the first step of an indirect path to health outcomes. Essential to an effective communication are: mutual understanding, satisfaction, clinician-patient agreement, trust, feeling “known”, feeling “involved” (from the patient side), rapport, and motivation. Essential antecedents of proximal outcomes are knowledge (at different levels), listening and communication skills, and time.

6.3.1.3 Inhibitors

Two are the main factors which can hamper doctor-patient relationships are time constraints and the lack of willingness to engage in an engaging relationship. The first has to deal with practical matters, which are difficult to avoid, while the second has to deal more with personal characteristics, which can be trained. For both doctors and patients having time constraints for consultation is affecting the possibility to establish a good relationship, because of a lack of opportunities. On the other hand as for any other relationship both the participants would be willing to be engaged, otherwise this won't become engaging.

RELEVANCE FOR EMPOWER:

- Patients with serious illnesses need the authority of the doctor, and have the need to rely on a professional figure. EMPOWER supports patients with different needs.
- Providing diabetes-relevant information in order to foster understanding of diabetes-relevant aspects and mutual relationships is an important aspect for chronically ill patients.
- Time constraints, in particular on the side of the physician, should be taken into account when designing the EMPOWER functionalities.
D-P relationship can foster empowerment, therefore lead to better health outcomes

6.3.2 Problem solving & decision making

6.3.2.1 Identify existing models, strategies, concepts and first experiences and best practice projects

Three are the dominant approaches to decision making in health:

1. Informed decision making

The informed decision making, or patient choice or consumer model of medical decision-making, differ drastically from the paternalistic. It is opposed to that as it is for consumerism and paternalism in the model of Roter and Hall (2006). In this case it is the patient who has the main authority over the decision. Regardless to what is happening during the whole consultation, the final decision among the alternatives has to be taken by the patient. "This model allows for patients not only to make choices, but to choose options against their own best interest—as long as they are well-informed." (Sandman & Munthe 2009)

2. Paternalistic approach to decision making

The paternalistic approach to decision making directly descends from the type of D-P relationship described above. The assumption of a paternalistic approach to decision making is that the health care professional in general is acting in the best interest of the patient. The roots of this approach stands in the Hippocratic ideal of medical practice. This kind of approach is more likely to fail to take into account the patient's perspective and therefore to ignores his/her perceived needs. This approach excludes the vision of the autonomous patient, the patients is rather something that need to be handled. (Sandman & Munthe 2009)

3. Shared decision making (SDM)

Charles et al. (1999) portrayed SDM as something that, as the name suggests, in the first place is being shared or involves sharing. Secondly SDM implies consensus: the objective of SDM is to reach a mutual agreement upon something (e.g. a treatment). Charles and colleagues describe this process in the following chronological steps:

- a. At a minimum, both the physician and patient are involved in the treatment decision-making process.
- b. Both, the physician and the patient, share information with each other.
- c. Both the physician and the patient take steps to participate in the decision making process by expressing treatment preferences.
- d. A treatment decision is made and both the physician and patient agree on the treatment to implement

It has been shown that problem solving skills have a central role in the capability of taking decisions and most of all in improving patients adherence, which is a central issue in chronic diseases. In her article of 2003 Hill-Briggs (Hill-Briggs, 2003, p. 189) proposes the following model (Figure 7) of problem solving for diabetes self-management, which encompasses problem solving skills but brings together also other important dimensions:

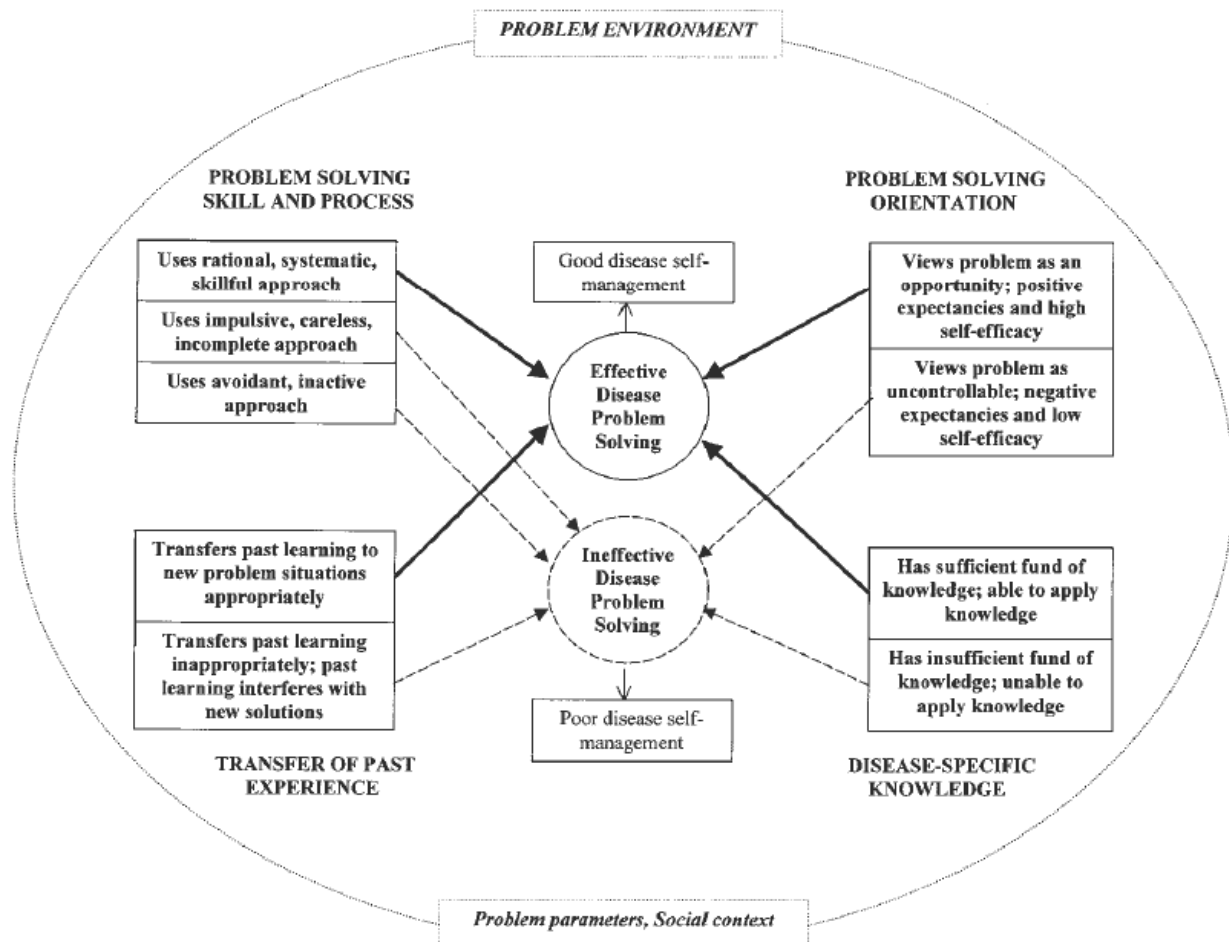


Figure 7:

An integrated problem-solving model of chronic illness self-management.

The model illustrates problem-solving components from the fields of cognitive psychology, educational/learning theory, and social problem-solving theory as adapted to disease self-management.

(from: Hill-Briggs, 2003, p. 189)

6.3.2.2 Drivers and enablers

As it is shown by the model of Hill-Briggs there are four main conditions necessary for the problem-solving in chronic illness self-management. First of all problem-solving skills. Literature on diabetes shows that effective problem solving involves a rational process of sequential steps, such as the ones described by IDEAL problem-solving strategies: Identify the problem, Define the problem, Examine alternative solutions, Act on solutions in the context of daily living, and Learn from results. The second component of the model is problem-solving orientation. This component deals with the concept of self-efficacy. A third component is disease-specific knowledge. Since disease related knowledge by itself hasn't shown to improve adherence, the combination with problem solving skills could possibly make a difference. The last component is the transfer of past experience. This refers to the ability of the patient to use past experiences as a source for the organization of problem solving when facing a new problematic situation. Learning from the past experience means therefore to build a set of problem-strategies that can be adapted to different types of problems, even new ones. On a theoretical level the transfer of past experience is essential to problem solving, but little has been done regarding this process in the field of diabetes (Hill-Briggs, 2003).

6.3.2.3 Inhibitors

As opposed to drivers and enablers for problem solving there are three main inhibitors that can be identified: (1.) Lack of disease related knowledge, (2.) Lack of education, (3.) Lack of self-efficacy.

RELEVANCE FOR EMPOWER:

- SDM of Charles et al. (2009) have been developed for acute conditions, and it has to account for differences in chronic condition.
- In most cases diabetes is a lifelong illness and patients have to make a lot of disease-relevant decisions in their daily life. Hence, problem solving skills and the decision making process as suggested in the model of Hill-Briggs is an essential qualification for diabetes patients.

6.3.3 Resource utilization

2.2.3.1 Identify existing models, strategies, concepts and first experiences and best practice projects

Lorig and Holman identified the core self-management skills in the field of chronic disease. The first two have just been explained, whilst the third is summarized by the citation bellow.

“A third core self-management skill is how to find and utilize resources. Many programs tell participants about resources but do not teach participants how to use the phone book, 800 numbers, the Internet, the library, and community resource guides. In addition to teaching people how to use resources, self-management includes helping people seek these out from many sources. When looking for a resource, most people will call only one at a time and wait for information. If that does not work, they try another. However, for best results, it is important to contact several potential resources at the same time as if casting a net for information. This skill is basic but often overlooked in traditional health promotion and patient education programs.” (Lorig and Holman, 2003, p. 2)

A self-management programme has therefore not only to provide patients with the appropriate tools for the management of their disease, but also to educate them how to use these tools. The patient should learn how to use what he has at his disposal, to make sense out of it, and ultimately to be able to integrate these practices into his/her daily life.

Guicciardi and colleagues (2006) found out that the primary language spoken is a determinant of who utilizes particular services and resources. This finding underlines the importance to pay attention to the development of culturally sensitive resources that can be accessed by different ethnic groups. Moreover these resources should take into account the different literacy level of the patients, thus making use of other kind of media when necessary (e.g. audio-visual resources for low literate people). A relationship between age and the number of resources utilized has also been showed by Guicciardi and colleagues (2006): the older a person is the fewer are the resources he/she utilizes. Moreover they also are less akin to look for additional resources, maybe for accessibility and comfort reasons. The conclusion of their study (Guicciardi et al. 2006) describes a proactive approach to self-management education as the one that not just connect patients to resources, but also teaches them how to find and use these resources.

2.2.3.2 Drivers and enablers

In order for the patients to have the resources they need, and therefore to make them meaningful and useful to them, it is important to assess their needs. Afterward it is necessary to educate them to use the resources, and to check for usability and availability of these resources. In line with what Guicciardi and colleagues (2006) found, resources should also be designed appropriately for age, language and cultural differences.

2.2.3.3 Inhibitors

The inhibitors for resource utilization in the field of chronic disease self-managements are similar conditions of what stated above. First of all (1.) a lack of education to use the resources, (2.) scarce availability, and (3.) presence of resources that do not respond to the real need of patients. Moreover the lack of monitoring, and consequently the lack of feedback to the patients.

RELEVANCE FOR EMPOWER:

- Provide the patients with the tools they need, starting from their own need assessment
- Educate patients to make sense of the tools, to use them, and to integrate them into their daily life
- Check periodically the usability and the usefulness of the resources (helpfulness of resources)
- Development of adaptive resources, meaning resources that should adapt to the personal history and the actions of the patients

6.3.4 Changing behaviour

6.3.4.1 Identify existing models, strategies, concepts and first experiences

The consequences of suffering from a chronic disease such as diabetes are not confined to medical aspects. Suffering from a chronic disease may also change life roles (e.g. increased self-control of diabetes-relevant parameters, changing eating habits or the demand of increasing physical activities) and suffering from a chronic disease often requires changing existing behaviour patterns. There already exist some behaviour change models tailored for health-related behaviours, such as

- Health Belief Model – suggests that your belief in a personal threat together with your belief in the effectiveness of the proposed behaviour will predict the likelihood of that behaviour. It is also stating that individuals will alter health-related behaviour according to the perceived severity of the threat to their health (Chen & Land, 1986).
- *I-Change Model* – is a phase model including several theories (e.g. Bandura's Social Cognitive Theory) and assumes that at least three phases in the behavioural change process can be distinguished:
 - (1) *Awareness* – of a particular problem in a person is the result of accurate knowledge and risk perceptions of the person about his own behaviour
 - (2) *Motivation* – to change a behaviour is regarded to be dependent on a person's attitude (the results of perceived advantages and disadvantages of the behaviour), social influence beliefs (norms of others, behaviour of others, and support of others) and self-efficacy expectations (the perceived ability to perform a particular health behaviour)
 - (3) *Action* - Intentions do not necessarily lead to behaviour. Factors determining action, besides a positive intention, are again self-efficacy, action planning and goal setting.
- The 5 A's model – is used to train health professionals in behaviour change counselling and focuses on the assessment, detection and management of risk factors. The model has an effective approach for behaviour change, particularly in primary health care setting. The 5A's involves a 5 step process that includes:
 - (1) *Assess* – ask about beliefs, behaviour and knowledge

- (2) Advise – provide specific information about health risks and benefits of change and give a clear message of encouragement to change
- (3) Agree – collaboratively set goals based on patient's interest and confidence in their ability to change the behaviour
- (4) Assist – identify personal barriers, strategies, problem-solving techniques and social/environmental support
- (5) Arrange – specify a plan for follow-up (e.g. visits, phone-calls, mailed reminders)

The figure below presents the five elements of the 5A model and summarizes the necessary information parts for a “Personal Action Plan”.

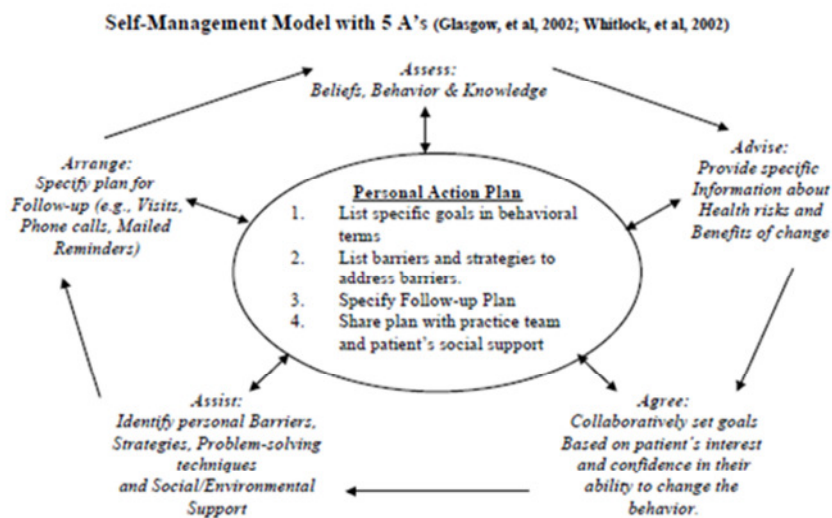


Figure 8:
Self-Management Model with 5 A's
(from: Glasgow et al. (2002), Whitlock et al.(2002):
http://www.improvingchroniccare.org/downloads/3.5_5_as_behavior_change_model.pdf)

6.3.4.2 Drivers and enablers

“We know that people need information to manage their disease, but having knowledge of the facts is not enough for behavioral change,” says Felicia Hill-Briggs, Ph.D., an associate professor in the Division of General Internal Medicine at the Johns Hopkins University School of Medicine and the study's lead author. “When the program stops and support is taken away, the behavior stops and the benefits stop,” she says³³. This diabetes self-management program was successfully evaluated (also in terms of patient outcomes), because it benefited from the inclusion of a “problem-solving” approach (including communication skills, decision making skills).

Behavioural change models aim at explaining the reasons behind alterations in individuals' behavioural patterns with the hope that understanding behavioural change will encourage individuals to develop and maintain healthy lifestyles. Although successful drivers and enablers may depend on an individual's preferences and needs, there are general drivers and enablers facilitating behaviour changes for patients, such as

- Being aware and informed about their disease, about consequences and alternatives
- Identifying needs, barriers, options
- Setting personal goals and implement them following an action plan.

³³ http://www.hopkinsmedicine.org/news/media/releases/new_diabetes_education_program_yields_improved_blood_sugar_control

- Designing information material and diabetes self-management courses on diabetes self-management which are combining diabetes education programmes information, knowledge acquisition AND problem-solving and decision techniques.
- Support behavioural changes with constant feedback (patient-doctor-system), awards and peer communication about achievements.

6.3.4.3 Inhibitors

Changing behaviour patterns sustainably is mostly not an easy task and often requires a lot of time and insistency, not only from the patient but also from medical and other care takers. The patient should be the focus when selecting the appropriate approach by considering his/her condition, lifestyle and psychosocial factors, individual capabilities and barriers. Another important aspect is identifying and acknowledging the patient's readiness to change or the current stage of change in order to provide a personalised treatment plan.

Finally, as stated by the Health Belief Model the severity of the illness often increases the likelihood of changing behaviour patterns. In many cases this is late. Changing behaviour patterns at an earlier stage is clearly more beneficial from both the medical point of view and from the quality of lifestyle. Increasing awareness at an early stage of an illness is crucial.

RELEVANCE FOR EMPOWER:

- Behaviour changes are an essential aspect of self-management and crucial for treating chronic diseases successfully.
- Understanding enablers and inhibitor for changing behaviour patterns are a necessary input for specifying the Self-management Pathways in EMPOWER.
- Designing information material and diabetes self-management courses on diabetes self-management which are combining diabetes education programmes information, knowledge acquisition AND problem-solving and decision techniques.
- Support behavioural changes with constant feedback (patient-doctor-system), awards and peer communication about achievements or disappointments.

6.3.5 Observation of Daily Living

6.3.5.1 Identify existing models, strategies, concepts and first experiences

In 2006, the Robert Wood Johnson Foundation created Project Health Design, which puts patients at the center of eHealth processes by creating prototype health record applications that help people manage their health and guide their decisions. The project found that chronically ill patients stressed the collection and sharing of information that is not typically part of the medical record, such as diet, sleep patterns, medication adherence, and mood, which they termed “observations of daily living” (Jean & Brennan, 2009).

Observations of Daily Living (ODLs) are “patterns and realities of daily life” including but not limited to “diet, physical activity, quality and quantity of sleep, pain episodes, mood” and adherence to medication regimens. ODLs support the idea of people tracking aspects of their health. ODLs may support personal health goals (e.g. monitoring blood pressure) but they can also be person-defined observations. Questions such as whether variations in stress, exercise, and diet affect the blood glucose level have much more relevance to someone who suffers from diabetes than to healthy people. Another example is patients with diabetes who may record their blood glucose levels every day at home, generating data to share with their clinician. That kind of patient-generated data can be a crucial input for medical decision making. ODLs may very well complement biomedical indicators and inform medical decision making by providing a more complete and holistic view of the patient as a whole person.

Typically, ODLs are connected to Personal Health Records (PHR). PHRs are designed for individual users to help them engage in their own health management. The information stored in a PHR can be radically different from Electronic Health Records (EHR). Both should contain accurate data on the patient's current medical status such as lab values and medications but they have different target groups – the EHR for medical and care persons, the PHR for patients - and hence, they are designed for different purpose. For that reason, PHR systems should additionally collect observations and patterns of the patient's daily living such as physical activities, mood, pain episodes, medication adherence and sleep patterns and be able to make personalized recommendations for e.g. minimizing chronic pain or the blood sugar level.

Observations and patterns of daily living are cues that people attend to in the course of their everyday life, that inform them about their health. They are different from signs, symptoms, and clinical indicators and can therefore not be directly mapped to biomedical models of disease and illness. Typically, they are defined by the patient and their families because they are meaningful to them, and help them to self-manage their health and make decisions about it.

The process of collecting ODLs might require a person to express and articulate their health cues – both this input process and the trend reporting can be beneficial. For example Intel Corporation's Mobile Therapy application helps the user to manage stress, improve mental health and reduce the risk of cardiovascular disease. Sports related mobile applications might motivate users toward health goals, especially in a social and "collaborative web" lightly competitive atmosphere, such as GPS-based mobile sports applications that share across social applications and report a runners' routes on a map, their times, and moods. The concept is "improve yourself" and pertains not only running, but many exercise related activities that users can report. The social-competitive actions we make can clearly motivate us to improve health.

6.3.5.2 Drivers and enablers

Mobile devices provide applications that might or might not be directly associated with one's health goals, but clearly can be exploited by healthcare providers or by the patients themselves (e.g. logging/diaries using social apps).

The conference, Mobile Health 2010 Using Mobile Technology to Change Health Behavior, addresses the question how applications can be used to change one's health behaviour. Additionally, a patient does not have only one condition; a patient will have other conditions, some associated with the particular disease, some not or not yet medically proven. For example, ODLs relevant to conditions of diabetes, obesity and depression can be collected and assessed depending on what the healthcare provider or patient determines is best for motivating the patient in achieving their health goals.

Today's mobile applications often can be exploited for achieving one's health goals. Many existing tools are either used as is or specialized for health us to realize our health goals, such as social web, blogging, forums, electronic calendars – people create their spaces for discussing health, recording our planned activities and results – our observations. Logs for diet, exercise, or medication are easily created in electronic calendars or shared in social applications such as Facebook. Texting and messaging have been cited as positive for one's health goals. Texts delivered to mobile devices (phones, watches). Texts can be referenced, collected and used for self-management or for interacting with a health care professional.

6.3.5.3 Inhibitors

Some challenges caused by these innovations are that they create data silos – user access to health related data over many applications causes that lack of semantic interoperability and hence, more data silos, leaving PHR systems to handle the interoperability problems when attempting to aggregate patient data from these applications. Even applications, such

as calendars or blogs could be categorized as Personal Health Applications (PHA) or PHA-like applications. The application marketplace supporting smart phones (e.g. iPhone, Android based) includes many social health related applications, such as Runtastic, to capture ODLs relating to exercise events, including mood.

Collecting observations and data can be burdensome and time-consuming if patients record data on a very detailed level. Patients have to decide which type of data on which level of detail would make sense for them. Hence, the challenge is to increase the collecting and recording of observations of daily living without being a burden for patients, and to assist them in determining the right amount of data collecting. One solution is to gather more observations implicitly rather explicitly. Automatic collection is highly desirable especially with regard to patient monitoring services – compliance monitoring is needed for medications and other observation or activity homework. Using wireless edible sensor technology, doctors can determine whether medications were taken and even when. Because the personal sensor clouds grow and improve patients might do less “homework”, however, to change behavior, some “homework” should not be completely automated. The interaction itself could play a role in behavioral changes.

Fears of mistakes and mishandling the ODL devices and consequently distrust in the accuracy of measurements inhibit the daily use. Difficulties in comparing individual outcomes with the outcomes of peers reduce the regular use.

RELEVANCE FOR EMPOWER:

- ODLs allow patients to gather health-relevant information which are of importance for the patients themselves. The information can take many forms – from quantitative measures of sport activities to qualitative self-reports. Additionally,
- ODLs can also be useful for physicians and provide a more holistic view of the patient's condition and possible unforeseen causes.

6.3.6 E-learning concepts supporting chronic disease self-management competences and skills

6.3.6.1 Identify existing models, strategies, concepts and first experiences and best practise projects (focus on web-based support)

“The most important thing is to design a programme whereby you incorporate learning and motivation into the course of treatment. Patients must have more knowledge about how to deal with their own illness and they also have to learn to react earlier when their condition deteriorates,” Birthe Dinesen (2011), lecturer at the Department of Health Science and Technology at Aalborg University and founder of Telekat³⁴).

“Motivating type 1 diabetic patients to learn carbohydrate counting through a cultural/aesthetic experience – A.C. Bianchi, Italy (Diabetes Education study group <http://www.desg.org>³⁵).

“Patients with type 2 diabetes prefer education based on participation and development of competences over information” (Diabetes Education study group <http://www.desg.org>³⁶).

³⁴ <http://www.epractice.eu/files/Guide%20to%20the%20Patient%27s%20Journey.pdf>

³⁵ <http://www.desg.org/images/desg-easd%20award1.pdf>

³⁶ <http://www.desg.org/images/desg-easd%20award2.pdf>

Many studies have proven that education and training has an impact on self-care of diabetes patients and traditional face-to-face training is provided in clinics or special care centres (e.g. Karakurt et al. 2012, e.g. The Polyclinic's Diabetes Self-Management Education at the Polyclinic - Seattle, Washington³⁷; recognized by the American Diabetes Association). Whereas the publication of diabetes self-management information, guidelines and templates via the internet web has spread in almost all countries and many languages (e.g. US³⁸, National Health Service UK³⁹, National Health Service, Australia⁴⁰, Germany⁴¹, Turkey⁴²), the pedagogical models, training and related e-learning concepts vary considerably.

As E-learning has also developed in the course of the last twenty years from simple E-learning to E-learning 2.0⁴³, the latter means that the advent of the social media and content management tools in a Web 2.0 enables active production of e-content and enhances informal learning via social media, all good pre-requisites for self-directed and self-managed learning.

In literature the concept of self-regulated learning and self-directed learning is understood as "individuals take the initiative, with or without the help of others, in diagnosing their learning needs, formulating their learning goals, identifying human and material resources for learning, choosing and implementing appropriate learning strategies, and evaluating learning outcomes" (Knowles, 1975, p.18). Similar, Gibbons (2002) defines self-directed learning as "any increase in knowledge, skill, accomplishment, or personal development that an individual selects and brings about by his or her own efforts using any method in any circumstances at any time" (Gibbons, 2002, p.2).

In education aspects such as

- flexibility of the learning processes,
- students' control in learning,
- self-observation and self-evaluation

are, in fact, core principles of self-regulated and self-directed learning that need to be incorporated also in the learning process of e-Health applications.

6.3.6.2 Best practices: different types of pedagogical, ICT enhanced settings for diabetes self-management courses

We can distinguish the following types of e-learning concepts and used ICTs in diabetes self-management education:

- *Multimedia publishing of diabetes self-management information and knowhow on diabetes illness and self-management activities:*

³⁷ http://www.polyclinic.com/diabetes_management_and_education-self-management-education-classes;

³⁸ <http://patienteducation.stanford.edu/programs/>

³⁹ http://www.diabetes.nhs.uk/webinars/audit_to_action_webinars/?#sg_anchor_

⁴⁰ Portal with free access on material: <http://www.diabetesoutreach.org.au/consumer/default.asp>;

⁴¹ http://www.deutsche-diabetes-gesellschaft.de/fileadmin/Redakteur/Zertifizierung/Schulungsprogramme/Liste_anerkannter_Schulungs-und_Behandlungsprogramme08_2011.pdf

⁴² See <http://www.turkdiab.org/i/ortak/file/ingyeni.pdf>

⁴³ For defining e-learning see Online WIKIPEDIA: "E-learning comprises all forms of electronically supported learning and teaching. The information and communication systems, whether networked learning or not, serve as specific media to implement the learning process. (..) . E-learning is essentially the computer and network-enabled transfer of skills and knowledge. E-learning applications and processes include Web-based learning, computer-based learning, virtual education opportunities and digital collaboration. Content is delivered via the Internet, intranet/extranet, audio or video tape, satellite TV, and CD-ROM. It can be self-paced or instructor-led and includes media in the form of text, image, animation, streaming video and audio." <http://en.wikipedia.org/wiki/E-learning>

Hereby information on diabetes self-management is published and transmitted via CD-Roms, DVD or web-homepages or platforms for reading alone and/or for printing and discussing in face-to-face workshops. The didactical concept for self-directed learning is worked out minimal. The media format includes e.g. Word docs, power-point slides (see: NOVOMED⁴⁴, FIDAM⁴⁵, 4 steps to control your diabetes life⁴⁶).

- *Blended e-learning*: this is a combination of workshop and online coaching support; Facebook community (See: Course at the diabetes teaching centre, US San Francisco⁴⁷)
- *Blended/hybrid e-learning and assessment*: face-to-face workshops, online coaching phases and informal assessment activities (see: Diabetes Education study group⁴⁸)
- *Online e-learning modules*: these modules are didactically structured as longer learning sequences, including didactically conceptualised activities, exercises, tests, peer discussions and homework etc. (see: e.g. Open University UK: free modules⁴⁹, Online “blood glucose awareness training” (or “BGAT”)⁵⁰).
- *Webinars*: as above, but fixed with a time schedule (1,5hours; direct teacher) (see: e.g. at National Health Service UK⁵¹)
- *Communities of practise and peer learning among diabetes patients*: this form of self-regulated learning is very important for a sustainable form of diabetes self-management. Given the importance of social media and networks as important tool for search for online information and exchange of treatment and self-care experience (e.g. Shaw et al., 2011), one finds examples of building communities of practises of diabetes patients supporting such as, <http://www.facebook.com/meindiabetesblog>.

⁴⁴NOVOMED: <https://www.novomedlink.com/DownloadOptin.aspx?contentid=334>

<http://www.novomedlink.com/diabetes/slide-kits.aspx>

⁴⁵ The FIDAM Forschungsinstitut Diabetes-Akademie Bad Mergentheim offers information and courses for diabetes type1, diabetes type 2; in German and Turkish language
<http://www.diabetesschulungsprogramme.de/templates/main.php?recordID=20>;

<http://www.medias2.de/templates/main.php?recordID=128>

<http://www.medias2.de/templates/main.php?recordID=264>

⁴⁶ 4 steps to control your diabetes life. For download at the website of the National Diabetes Education Program: www.YourDiabetesInfo.org;

USA <http://www.ndep.nih.gov/publications/PublicationDetail.aspx?PubId=4&redirect=true#page2>

⁴⁷ Course at the diabetes teaching center, US San Francisco, <http://dte.ucsf.edu/>; <http://dte.ucsf.edu/workshops-and-classes/class-schedule/>; teaching materials: - <http://dte.ucsf.edu/learning-library/resource-materials/> for download (very interesting the different types of word docs especially for monitoring different log books, Printable Type 1 Intensive Log Book; Printable Type 2 Diet Log Book, Printable Type 2 Comprehensive Log Book, Printable Type 2 Insulin Log Book, Printable Type 2 Intensive Log Book- <http://dte.ucsf.edu/learning-library/resource-materials/>

⁴⁸ Diabetes Education study group:

http://www.desg.org/component/option,com_docman/task,cat_view/gid,33/limit,5/limitstart,5/order,name/dir,DESC/Itemid,61/; very often included are online-quizzes to test the acquired knowledge via an online knowledge – quiz (e.g. <http://www.diabetesinfo.de/wissensquiz.html>)

⁴⁹ http://www.diabetes.nhs.uk/safe_use_of_insulin/safe_use_of_insulin_elearning_module/elearning_course/;

⁵⁰ http://www.diabetesselfmanagement.com/Blog/TaraDairman/isonline_diabetes_education_for_you/

<http://www.interest.bgathome.com/>

⁵¹ http://www.diabetes.nhs.uk/webinars/audit_to_action_webinars/?#sg_anchor_

http://www.diabetes.nhs.uk/safe_use_of_insulin/safe_use_of_insulin_elearning_module/elearning_course/
http://nhsdiabetes.healthcare.co.uk/outside_the_uk.aspx

- *Games and agent-based learning:* example is the diabetes self—management program for very young diabetes 1 type;
<http://www.meduniwien.ac.at/VIEODE/wordpress/information/>
- *Video-Courses:*
Examples of e-learning courses – Type 1
<http://www.bdec-e-learning.com/>
For diabetes care workers -
<http://www.bytsyz.co.uk/elearning/online-courses/diabetes-care/43/>
For diabetes – Type 2
http://www.digital-spirit.de/fileadmin/pdfs/Videokurs-Leben-mit-Diabetes_DE.pdf
Example: digital-spirit
http://www.digital-spirit.de/fileadmin/pdfs/Videokurs-Leben-mit-Diabetes_DE.pdf
http://www.digital-spirit.de/leben_mit_diabetes.html
- *Open educational resources:*
Example: European Health Care Foundation
http://www.youtube.com/watch?v=hnVt0fWak8k&feature=autoplay&list=UUQ2IZYARVDJRBOP_rhgs5OQ&playnext=1;
<http://www.euhcf.org/ausbildungsangebote/basisausbildung.html>
Educational Tools - <http://www.desg.org/content/blogcategory/16/30/>
diab train - <http://www.youtube.com/watch?v=Hm0k0HqDzsg>
- *Digital storytelling for „digital empowerment“* (<http://www.digem.eu/>) Examples:
Storytelling games: <http://www.digem.eu/images/guide/en/Storytelling%20Games.pdf>
- E-learning course platform: eg. Moodle- diabetes prevention manager
Example: Open university – diabetes care
<http://intern.image-project.eu/moodle/login/index.php>
<http://www3.open.ac.uk/study/undergraduate/course/sk120.htm>

6.3.6.3 Drivers and enablers

According to Gucciardi et al. (2008) there is high need to respect usability and accessibility issues for senior citizens, such as

- Regarding different anxiety levels of diabetes patients (difference type 1 and type 2)
- Flexible access hours
- Low costs
- Not too intensive
- Continuous communication
- Use of video as low level media (similar to tv)
- Harnessing open educational resources enables higher rate of access .

6.3.6.4 Inhibitors

- Poor sustainability of educational interventions
- No respect of young senior learning needs.
- High costs
- Low education
- Low motivation (problem with Chronic disease – type 2: less motivation due to low anxiety level)

RELEVANCE FOR EMPOWER:

- Aspects such as flexibility of learning processes, students' control in learning, self-

observation and self-evaluation are core principles of self-regulated learning (SRL) that have been incorporated also in the teaching and learning process of e-Health.

- Diabetes educational programmes are widespread, but ICT use and enhancement varies from simple publishing of diabetes information via web (e.g. download in face-to-face seminar) to more flexible and structured webinars to online courses with online coaching.
- Need for flexible information material (type-wise), high accessibility possibility 24/7, low cost

6.4 Summary of user needs relevant for EMPOWER

6.4.1 Patients` needs relevant for EMPOWER

The following section summarizes the needs of diabetes patients and is based on the results of the literature review and the analysis of the focus groups and interviews. They are presented according to the following headlines, which were identified throughout the study.

1. Sense making in diabetes care
2. Behaviour Change in diabetes care
3. Social Interaction in diabetes care
4. Monitoring in diabetes care.

Only where evidence was striking, further attention was paid to demographics.

A table at the end of the section summarizes the main needs and includes references to the used patient empowerment framework of the EMPOWER project and to the Patient Empowerment Model by Schulz and Nakamoto (2012). Further the table tries to capture in a few keywords possible implementation strategies. Which have to be further investigated.

6.4.1.1 Sense making in diabetes care

Information is the key.

Need: Timely Information

Patients have to make sense out of the things they are experiencing and seeing. Especially patients, who would like to exercise a great deal of control, easily get frustrated about e.g. MBG levels (Chen, 2010).

Women

Women in particular tend to be more frustrated with regard to their results than men. If results are not as expected they tend to ask more often where these results come from. Only with time they make sense out of it. In order to keep frustration levels and possible negative consequences low it is important to provide patients with timely information and possible explanations.

Need: Understanding changes in life routines

In situations in which behavioural patterns deviate from everyday life (e.g. on vacation) patients are not always sure how to handle these situations. Questions, such as how to travel with my disease or what if I have an emergency, are common fears among patients. Thus, people have to understand, either in advance or while experiencing these situations, potentially needed changes in common patterns and how to handle these situations without deviating too much from the normal routine.

Need: Understanding the bigger picture

Patients need to understand their actions as incremental steps feeding into a bigger picture, namely the disease. Short-term goals are reasonable but long-term goals make the patient aware what he/she is going for. It is not sufficient to provide people solely with long-term goals, It is important to provide them also with information explaining the reasoning behind it. For some patients a long-term goal might be to reduce the HbAc1 levels by a certain amount. Depending on the patient this might not be possible. Patients have to be made aware that changes can take time and that actions taken may not always lead to the wanted outcomes.

Turkish Patients

Most of the patients agreed on the above mentioned points but some of the Turkish patient also stressed that they in cases where they feel better, do not necessarily think about their disease and therefore are less compliant and less adherent.

6.4.1.2 Behavior change in diabetes care

Repeating and Reminding.

Need: Understanding behaviour changes

With regard to changes in diet or medication, patients may have the need to understand the logic, if not even the rationale behind it. It is not sufficient to impose changes without handing out explanations for why these changes are needed.

In particular patients with low health literacy levels may have the need for more interactive communication in order to repeat concepts so as to retain information (Schillinger et al., 2003) (see below).

Need: Repetition

In order to foster long-term changes in routines, it is important to repeat newly learned concepts and behaviour patterns. In particular with regard to changes in diet, it seems useful to continue education *also after* diabetes training or stays in medical spas.

Turkish patients

Patients mentioned that there is a particular need for training and mentioned the wish to receive more training on necessary lifestyle changes.

Need: Reminding

With repetition comes also reminding the patient. Whether it is to remind the patient to monitor his/her blood glucose levels or reminding him/her of nutritional fallacies. Reminders have to be shown to lower HbAc1 levels. Further patients tend to forget about measuring their levels in order to be able to guarantee long-term

Need: Personalized Behaviour Changes

Older patients

In particular older patients who developed over years their own behavioural patterns, are concerned that diabetes treatment and care does not take sufficiently into account personal differences. Personalized feedback and recommendations are perceived as being more meaningful to the patient.

6.4.1.3 Social interaction in diabetes care

Inclusion is the key.

Need: The partner, my support.

Women

Especially women with diabetes type 2 have to been shown to heavily rely on their partners. In particular with regard to decision making activities and making sense of results. Husbands were perceived as having the best interest in their wives. Husbands were considered supportive in giving advice based on observation of the wife's behaviour patterns.

Men

Men with diabetes type 2 relied on their wives with regard to cooking and information seeking.

Turkish Patients

From the interviews emerged that group support is important (peers, colleagues) for lifestyle changes. Individual support (relatives, spouse) was rather important for monitoring.

Need: The doctor, my support.

The focus group showed that the doctor's role in managing the disease is of crucial importance to the patients. Not only in prescribing medication but also in giving advice on lifestyle changes his role was considered to be very important. Nevertheless, it has to be kept in mind that the focus group we dealt with was very particular as most of the patients shared the same doctor. A further limitation is that the focus group took place in a setting which was provided by the treating physician.

Turkish Patients

The places where Turkish patients meet their doctors are slightly different. It turned out that some patients meet their doctors at the work place. In general, they were showing the need for a tool that would enhance and foster communication (e.g. reduced distance especially in the countryside, faster communication).

Need: Telling friends.

Women

Women are more likely to be embarrassed about their disease and felt pressure in social gatherings to make people aware of their disease. The focus groups revealed that interaction with people who have similar experience, may be fruitful.

Younger users

In particular mobile phone applications are not yet fully explored with regard to integration of social networks. (Chomutare et al., 2011). Visualizing results and sharing information as integral part of the platform may be a useful tool to consider, especially with regard to younger users.

Need: Share Experiences

In the focus group discussion it became apparent that there is a need for diabetes patients to talk about their experiences and to share those with other people. This may be a need derived from the feeling that patients have to make sense out of what they are experiencing and the actions they are taking. During the interaction with other people they learn that problems they may face are very common problems among diabetes patients and make them feel more at ease when confronted with problems.

6.4.1.4 Monitoring in diabetes care

Need: Understanding Monitoring

Even though patients seem to be very well aware of the importance of their medical parameters (e.g. blood glucose levels), but there seems to be less awareness of the relevance to regularly monitor these parameters. These monitoring procedures may even go beyond solely watching and writing down blood glucose levels but also include the monitoring of behavioural patterns, such as sport activities or eating behaviour. People do

not necessarily seem to understand the patterns of and reasons for monitoring. In particular, if no effects can be observed or they are not aware of the importance patients are more reluctant to keep track of these.

Need: Affordable and easy to handle devices

In the focus group it became apparent that besides affordable products, such as blood glucose meters and the test stripes, but patients are also looking for devices that are easy to handle and are able to ease the burden of monitoring. This includes (semi-)automated process of handling, collecting and archiving data (ODLs).

Turkish Patients

In comparison to German patients Turkish patients showed to have less often a blood glucose meter at their disposal. Thus, they need to go to the doctor's office, hospital or ask peers to use theirs.

Sense-Making in diabetes care

Need	Health Literacy and Psychological Empowerment Model	EMPOWER	Keywords
Timely Information	Impact Meaningfulness Declarative Knowledge	Reminders, Alerts Evaluation Decision Aids	Monitoring Prompt Feedback
Understanding changes in life routines	Self-determination Judgment Skills	Recommendations and Goals Information Material Decision Aids	Information Feedback Mechanisms
Understanding the bigger picture	Meaningfulness Impact	Recommendations and Goals Information Material	Short- and long-term goal setting

Behavior Change in diabetes care

Understanding behaviour changes	Meaningfulness Impact	Recommendations and Goals Information Material Decision Aids	Information Interaction
Repetition	Declarative Knowledge Procedural Knowledge	Reminder Action Plan	Information Active Involvement
Reminding	Declarative Knowledge Procedural Knowledge	Reminders	Information Reminder
Personalized Behaviour Changes	Meaningfulness	Recommendations and Goals	Personalization Personalized Information

Social Interaction in diabetes care

The partner, my support.	Sources/Influencers	Patient Consent Information Material	Interaction
The doctor, my support.	Sources/Influencers Declarative Knowledge	Health Actor Services Personalized Recommendations	Interaction
Telling friends.	Self-Determination	Online Community Self-help group	Facebook, Twitter, etc.
Share Experiences	Sources/Influencers	Self-help group Online Community Information Material	Connect with other diabetes patients.

Monitoring in diabetes care

Understanding monitoring	Meaningfulness Impact	Recommendations and Goals Action Plan ODL Evaluation Information	Monitoring Prompt Feedback Personalized information
Affordable and easy to use devices	Self-Determination Declarative Knowledge	Information Online Community	Product information

Table 10: Patients` needs relevant to empower

6.4.2 Doctors' needs relevant for EMPOWER

In the following the most important needs of doctors with regard to web-based diabetes management will be presented. These needs were drawn from the previous literature review and the analysis of the focus groups.

Need: Effectiveness and Efficiency

In order to develop in accordance with the patient a treatment plan that involves mutual understanding based on diagnosis, best practices and understanding of the (development of the) disease, doctors need to have the most important information ready. This means a prepared patient that keeps track of his behaviour and has the ability to communicate behavioural patterns.

Time constraints and growing workload on the doctors' side create the need for streamlined information. Information has to be structured and not be overloaded. Information given to the doctors should be as compact as possible.

Turkish Doctors

One doctor mentioned that he would need a tool that would allow him to communicate faster with his patients. He already gave out his telephone number to those people he seemed to be most in need of it.

Need: Involvement of other specialists

Often patients and doctors themselves are not aware when to include other doctors in the care taking process. Doctors may assume that patients go directly to ophthalmologists when dealing with acute eye problems. And vice versa patients may assume that their treating physician will refer him/her to a specialist (e.g. podiatrist) in case needed. Unfortunately, there still seems to be a lack regarding this issue and there is a need to connect and enhance communication (if not even shared decision-making) between different specialists in order to enhance a patient's treatment plan and guarantee the optimal use of resources,

Need: Whom to talk to in the family

In the focus group doctors articulated the need also to include family members in the treatment of the diabetes patient. Thus, it is of importance to them to understand whom exactly to include. For an elderly patient his/her life partner may be important, as in the case of a married male patient his wife might be in charge of cooking. Doctors understand what role the direct environment can play in diabetes patients' self-management behavior and therefore would like to actively like to involve family members in the treatment of their patients.

7 Identification of user behaviour patterns

7.1 Objective

The design of e-Health technology and software, is a complex development process, because the adoption of such applications involves multiple stakeholders: patients, general practitioners, treatment educators, supportive caregivers and friends, self-help advisors and coaches, administrators of disease-management programmes (DMP) hospital staff and/or providers of the ICT-solution. Moreover, studies have shown that the use of such devices by elderly patient groups is rather minimal (LeRouge et al., 2011). Therefore, this section aims at:

- (1.) Examining the "*Persona Method*" and its guiding principles as one specific user-centered approach for software development in the context of developing eHealth applications (section 6.2.1-6.2.4),
- (2.) Secondly, proposing *elements for a persona description*, specifically useful for chronic care and patient empowerment solutions (section 6.2.5), and,
- (3.) Thirdly, proposing steps needed for identifying, categorizing and creating useful personas descriptions and use scenarios for the EMPOWER project (section 6.3).

Finally, the result will be a matrix on short sketches of different EMPOWER personas, which should be discussed within the EMPOWER project consortium and used as an instrument for focusing on the user goals and needs while designing the proposed software application.

The persona method, developed by the interaction designer Alan Cooper (1999; 2003⁵²), is a research-based, user-centred approach to software development, which aims at condensing user needs and requirements prior and during the design and development processes on the bases of research data. It has only very recently become popular in the design of eHealth applications and has been applied either alone or in combination with other user requirement analysis methods, such as system analysis, creative-walk-through, task analysis, usability testing. Velsen (2012) points to a few eHealth projects, which have developed persona descriptions and scenarios, for example for the *development of electronic patient records* (see Bredies, 2009), for a *public website with cancer-related information* (Goldberg, 2011), for a *digital assistant for nurses* (Spinhof & Calvi, 2006), for a *handheld device to monitor*

⁵² See <http://www.cooper.com>

chronic heart failure (Villaba et al. 2007) and for the *development of a smart-phone based application for diabetes self-management for elderly people in urban and rural areas of China* (Velsen et al., 2012, p. 1).

"Personas can be the linking pin in the development process of eHealth. They serve as lively summarizations of user groups, can inform design, and finally, inspire problem analysis activities with stakeholders. Therefore, we can only encourage eHealth developers to look seriously into the possibilities for utilizing personas in their development processes." (Velsen et al., 2012; Center for eHealth Research, & Disease Management, University of Twente).

"Without any research to back assumptions, it's easy to end up with a product built for what designers think the users are like, rather than what the users really are like. It's the difference between reading about someone and actually meeting them, between fantasy and reality. The best personas are really conceptual models, which help you to digest the user research in a coherent way. They put a name and face to an observed pattern of behavior." (Saffer, Dan 2005: *Persona Non Grata*. Adaptive Path blog, August 17, 2005, <http://www.adaptivepath.com/ideas/essays/archives/000524.php>)

7.2 The persona method in eHealth projects

7.2.1 Purpose of the method⁵³

Personas are a method to keep designers and developers focused on the users when determining appropriate functionality, prioritise features, design interaction interfaces, etc. Personas can help

- to develop the EMPOWER prototype in concentrating on designing for a manageable set of personas knowing that they represent the needs of many users
- to develop empathy with users for which the application is designed for,
- filter personal stereotypes and concentrate on behaviour and motivations, which occur typically within a broader range of users, while still being able to take respect of individual patient needs and motivation strategies,
- to avoid traps of building what users ask for rather than what they will actually use,
- to prioritize design efforts and make better design decisions for the EMPOWER tools and services (e.g. structure and presentation of functionality, content and sensory elements,
- to develop EMPOWER use scenarios, and,
- to focus the evaluation of the software in the adoption process of pilots (see Geser, 2011; Cooper et al., 2007; Olsen, 2004; Calabria, 2004).

The graphic below depicts the iterative design process, involving directly users and their characterised profiles and behaviour patterns.

⁵³ This section roots on the Salzburg Research Handbook of Methods (Geser, 2011: 205-214).

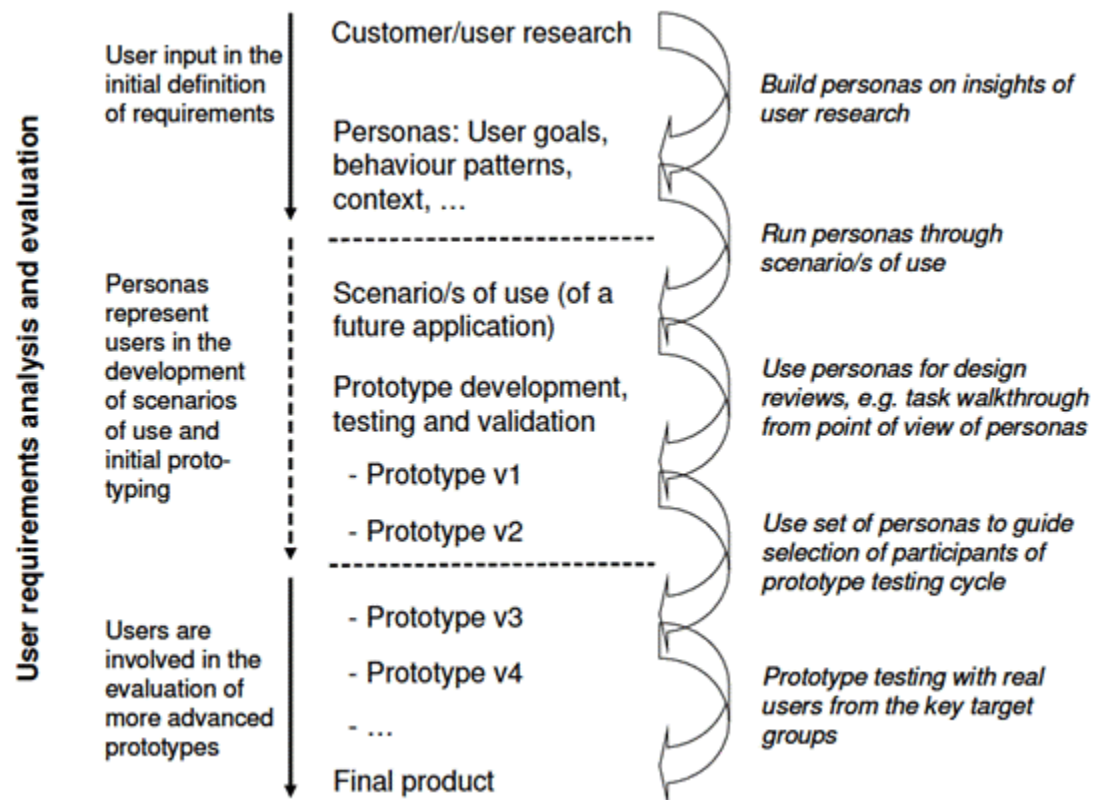


Figure 9: Using personas in continuous user requirements analysis and evaluation.
Geser G. (2011: 205). Handbook of methods.

7.2.2 Characteristics of personas and guiding principles

7.2.2.1 What is a persona?

A persona is a profile of a user of a product or service under development. The profile is synthesised from insights of research on target user groups but does not present an average, generalised or stereotypic user. Rather, the persona provides designers and developers with a description of an individual person with specific motivations and goals as well as context and behaviour when using the product or service (e.g. an ICT application). By designing for personas whose goals, contexts and behaviour patterns are well understood, it is possible to satisfy the needs and requirements of the broader user groups they stand in for. For an ICT application such as an information portal, typically a small set of personas is necessary in order to cover the different goals, behaviour patterns, attitudes and skills of the relevant user groups (Geser, 2011, pp. 206).

7.2.2.2 Characterisation of personas and behaviour patterns

As will be later illustrated in detail (section 6.2.5.), personas are characterised by “do-goals” as well as “be-goals”:

- “Do-goals” are motivated by pragmatic personal or professional needs to accomplish certain tasks,
- “Be-goals” are motivated by needs such as being related, being competent, being autonomous. “Be-goals” are also called experience goals as they describe how people want.

Personas represent behaviour patterns, not lists of tasks or duties like in a job description. What is important is how personas will go about certain tasks and what skills they have to complete them. Behaviour patterns are best described with short stories of what the

personas will do in order to achieve their goals. Such stories help in organising and sharing information from user surveys or what people have said in interviews, for example,

- what functions of an application will be most important to them,
- how they talk about tasks (e.g. what terminology they use),
- what information they need at which points,
- can they focus on one thing at a time or are there a lot of interruptions,
- who else is involved in certain tasks.

Adding quotes about goals and tasks, motivations and attitudes, etc. can help designers to hear the voice of the persona (Geser, 2011: 206-207).

“Fiction based on research can communicate useful knowledge. Watching a character succumb slowly to a dementia over several episodes of ER, one feels one understands the disease better. If the portrayal is based on real observation and data, it could inspire the design of technology to support sufferers”. (Grudin, Jonathan 2006: Why Personas Work: The Psychological Evidence).

7.2.2.3 Sources of information

The elaboration of personas is based on insights from user research, i.e. input from participants gathered with methods such as site visits, focus groups, interviews, etc. Then the personas are used to test scenarios of use of and envisaged application and initial. In EMPOWER the sources of information will be derived from desk-research, three focus groups in Germany (two patient groups-,diabetes type 2, and one focus group with general practitioners, March 2012) and interviews with doctors and patients from Turkey (conducted in June 2012). The focus groups will be complemented with individual interviews with stakeholders (esp. patients, self-help group advisors, doctors, administrators of disease management programmes).

7.2.2.4 Different types of personas

The method proposes to distinguish different “user models” (=personas). Personas represent common needs and requirements of different groups of users in terms of their goals and behaviour patterns. In order to provide a useful set of personas, the different personas must be based on important differences in why and how people do something. Olsen distinguishes the following types of personas:

- *Primary personas (PP)*

These users are also called “focal users” and will constitute the prime target group of the EMPOWER tools and services. They stand in the focus of the core design activities and decisions of the software development team. According to Cooper et al. (2007), there can be only *one primary persona per interface* for an application, but it is possible for some applications to have multiple distinct interfaces, each targeting at a distinct primary persona (2007: 104). The latter case is often the case in eHealth information systems, in which different users act on the same data, but work with separate interfaces (e.g. clinical, financial, private). In EMPOWER the focus lies on diabetes patients (e.g. type 1 diabetes, type 2 diabetes and pre-diabetes and on general practitioners supporting them (see work plan).

- *Secondary personas (SP)*

These users also use the EMPOWER tools and services, but their goals and needs do not differentiate very much from that of the primary personas. However, they may have specific additional needs, which should be taken into account, when designing the application. In eHealth projects we can distinguish here also diabetes patients (e.g. female patients with gestational diabetes; people at risk), consultants of self-help groups, clinical staff, administrative personal of disease management programs).

- *Tertiary (supplementary) personas (TP)*

User personas that are neither primary nor secondary personas are called “tertiary” or “supplementary” users. They use the EMPOWER services, however, only on a very limited scale and intensity. Examples in EMPOWER might be medical experts cooperating with the prime general practitioner, such as optician, dermatologist etc. who might use the paper

based results provided by the patient. Further examples could be patients or doctors who are not authorized to do so (e.g. a patient who would not be recommended for self-treatment, e.g. because of severe multiple diagnosis/heart; unskilled personnel in praxis) or unskilled care givers and friends.

- *Affected (served) personas (AP)*

These persons are different from the three groups above, since they do not use the EMPOWER prototype themselves, but are directly affected by it. Personas may be built for example for e.g. parents of kids with diabetes type 1; partners of patients with diabetes type 2; diabetes education trainers). These are important personas, and are treated like secondary personas (see Cooper et al., 2007:106).

- *Excluded (negative) personas (EP)*

The project does not design for these persons (=non-users). It is not necessary to provide a full description, because these users are not served for. However, it is important to have clear for whom the project does not work. Cooper et al. suggest to exclude early adopters of technology ("ICT freaks"). Patients and/or clinical staff with no access, no skills and unwillingness to use ICTs;

- *Customary personas (other stakeholders) (CP)*

For this group, there is no need to create personas. However it might be useful to identify their goals, amount of influence on the usage, amount of knowledge needed to support EMPOWER; degree of involvement of usage of others; possible conflicts with other stakeholder. Stakeholders in EMPOWER could be: pharmacies, insurance companies (private), public health authorities, self-help group associations, patient friends etc.

7.2.2.5 Differentiation between types of personas

In an eHealth project it may be one of the most difficult tasks to identify and decide about distinct personas appropriate. Each persona should clearly represent a different user group that shares the same or similar goals, motivation, skills and behaviour pattern. To identify such groups one should look for similar social and professional backgrounds, level of experience in a subject domain and ICT use, similarities in interaction styles and information seeking behaviour, context of use, such as relaxed or under pressure, usage patterns (e.g. frequency and intensity of use), and shared stories of critical aspects of tasks and information needs. In order to create a useful set of personas the most distinct differences between user groups must be identified. Such distinct differences that clearly belong to one user group should be used in the definition and description of an individual persona. In a number of interviews with members of a target group, one participant will often be the inspiration for the persona. A set of personas may be characterised

- by a strong primary persona and some secondary personas, often based on tasks,
- a matrix of personas based on two core orthogonal variables that distinguish the most important target user groups,
- a collection of personas, differentiated by key characteristics of target user
- groups, or
- a spectrum, based on 1-2 strongly related characteristics" (Geser, 2011, p. 210).

7.2.2.6 Amount and prioritisation

The precise number of personas (set of personas) is assessed differently. Cooper (2007) suggests only one primary persona per interface, Calabria (2004) suggests four to five personas in total. The general principles are the not too many and no extreme persona description.

"When creating personas, it's easy to create too many personas to be useful. Typically you want between three and 12 personas of all types (although potentially you can have additional stakeholder minipersonas, if critically needed)." (Olsen, 2004).

The following methods are useful for consolidating personas, as well as understanding the relationships among your personas (from a design perspective). These relationships are also

similar to the relationship among “actors” in the UML notation system used by some programmers.

- Personas resembles: similar to another persona (may be able to satisfy personas with a similar design)
- Personas serves as a special kind of : for example: “full-time sales clerk” and “temp sales clerk” are both specialized versions of “sales clerk”
- Includes: More useful for role-intensive personas, for example: an editor includes the roles of “editing,” “proofreading,” “fact checking” and “production scheduling.”

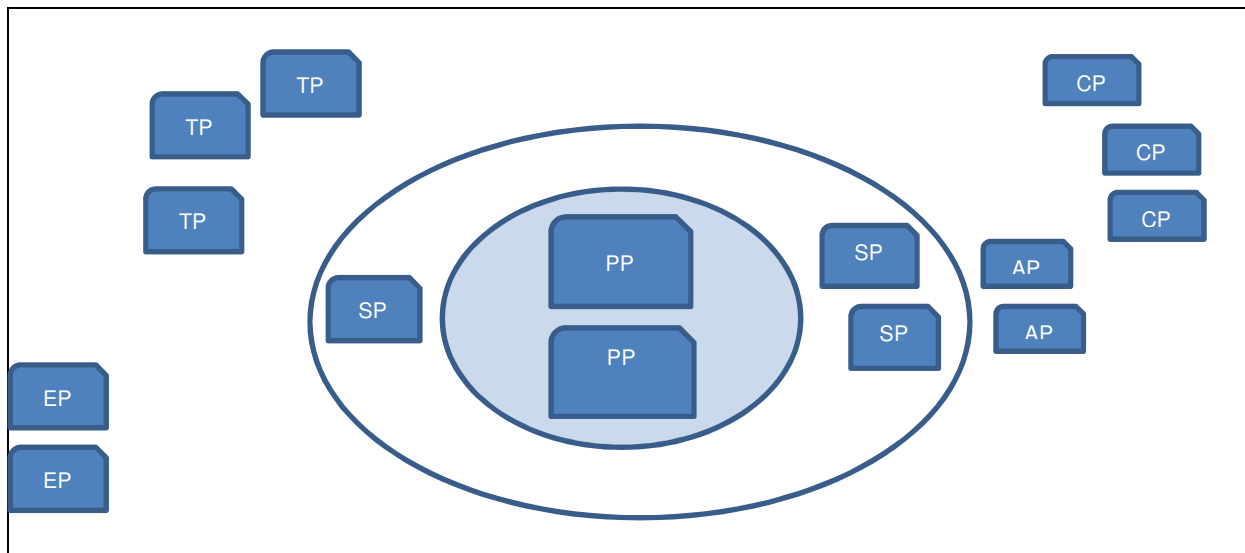


Figure 10: Sketch of a possible set of personas (SRFG/vhp 2012)

7.2.2.7 Validation of personas

“Before personas are used to scrutinize scenarios of use of a future application and review initial prototypes, first they must be validated themselves. This can be done by presenting the personas to real users to see if they can recognise themselves; or reviewing the personas with others who have first-hand experience with real users such as field service people, user support personnel or trainers. Business representatives will want to have the personas also tested against market segments. Moreover, each persona must demonstrate that they function as realistic individual character as well as provide a good coverage of a target group. Finally, in a relatively short time the design team should feel that the personas provide them orientation and guidance in decision making about functions, features, interfaces, etc”. (Geser, 2011, p. 210).

7.2.3 Steps in developing personas⁵⁴

It is advisable to follow the different steps of a persona developing process, as summarized below (see Nielsen, 2007):

Step 1: Finding the users

Questions: Who are the users? What do they do with the system? How many are they?

Methods: Quantitative data collection; statistics; desk-research;

Outcome: EMPOWER study D.2.1.1. Section 4. Chronic Care Management

⁵⁴ Source: Nielsen, L. (2007)

Step 2: Building a hypothesis

Questions: What are the differences among the users?
Methods: Analysing material, grouping the users, identifying and naming the groups
Outcome: EMPOWER pre-study D.2.1.1.- 7.37.3.1

Step 3: Verifications

Questions: Identify data for personas: likes/dislikes, inner need values;
Data for situations: area of work; work conditions; health conditions, health biography
Data for scenarios: work strategies and goals; information strategies and goals; health management goals
Methods: Qualitative data collection
Outcome: EMPOWER focus groups; single interviews;

Step 4: Finding patterns

Questions: Dose the initial group hold? Are there other groups to consider? Are all equally important?
Methods: Categorization
Outcome: Description of categorisation;
Will be done in EMPOWER pre-study D.2.1.1.- 7.3

Step 5: Constructing personas (avoid stereotypes)

Questions: Ask for biographic background, demographic and psychographic background; health biography, health care behaviour, emotions and attitudes (towards technology), personal traits
Methods: Categorization
Outcome: Description of persona categorisation; Will be done in EMPOWER study.
D.2.1.1.- 7.3

Step 6: Defining Situations

Questions: What are the needs of this persona? What are the situations?
Methods: Analysing data for situations and needs.
Outcome: Catalogue of needs and situations;
Will be done in EMPOWER Deliverable D 8.1.1. User requirements for pilots.

Step 7: Validation and Buy-in

Questions: Do you know someone like this?
Methods: People who know of the personas read and comment on the persona descriptions
Outcome: Will be done with transcripts of focus groups, individual interviews;

Step 8: Dissemination of Knowledge

Questions: How can we share the personas within the project organisation?
Methods: Posters, meetings, e-mails.
Outcome: Will be done in EMPOWER project meetings (beginning in June 2012)

Step 9: Creating Scenarios

Questions: In a given situation, with a given goals, what happens when the persona uses the technology?
Methods: Posters, meetings, e-mails etc.
Outcome: Will be done in the task for storyboard, use case development in late 2012.
(see EMPOWER Deliverable D 8.1.1.).

7.2.4 Elements of a persona description

This section provides firstly a general overview of the most important when characterising the persona. Then, secondly, it will add specific elements, which are highly relevant in the context of eHealth application development. For the EMPOWER project it is particularly important to aim at targeting goals and needs for chronic care and diabetes applications.

7.2.4.1 General features of a persona description

In literature there exist a number of categories to best describe personas. One of the most concise one can be found in the work of Olsen (2004). A useful persona description for a software designer should entail:

- Name
- Photo
- Biographic background: socio-demographic, psycho-graphic, webographic profile
- Goals, needs and attitudes
- Specific knowledge of application domain
- Context of use of EMPOWER tools and services
- Interaction characteristics of use
- Information characteristics of use: how to present appropriate contents
- Persona relationship to EMPOWER prototype and vice versa
- Technology attribution and ownership
- Communication (style and partner)
- Accessibility issues
- Emotional issues

7.2.4.2 Specific health care behavior and cognitive patterns of perception

In order to identify user goals and needs for eHealth applications, it is suggested to research on the following issues characterising health care behaviour and cognitive perception (applications (see LeRouge and Ma, 2010: 4):

- Level of health care information seeking (active learning)
- Propensity to avoid health care (care seeking/outcome expectancy)
- Trust in medical professionals (outcome expectancy)
- Physical activity level
- Level of involvement in health care decision making (locus of control)
- Care support infrastructure (spouse, family, doctor, friends)
- Perceived challenges to self-management
- Self-management capabilities (overcome barriers, suitable methods, achieve goals, obtaining support, coping)
- Current level of compliance
- Self-efficacy to provide self-care
- Involvement in family health (motivation/risk perception)
- Level of being health proactive (self-regulation/ self-efficacy)
- Health price concern (resource allocation)
- Health quality concern (outcome expectancy).

In the first round of EMPOWER focus group (Germany), some of the above elements have been already researched during the focus group and interviews. The following issues were tried to be raised (see interview guidelines, ANNEX):

- Personal and social factors (age, stage in life cycle, very basic: What is “The diabetes patient”?)
- Activities – What type of diabetes patient and role in programme has the user? (prime: patient; secondary: doctors)

- Attitudes – How do the users think about a disease management programme and the use of web services for it?
- Attitudes – What type of education and training do the users have in using the web-based diseases management programme?
- Motivations – Why is the user engaged in the diseases management programme?
- Skills- What skills does the user have in using a web-based diseases management programme?
- Cultural factors (culture, subculture, class – in particular with regard to Germany and Turkey).

The study from LeRouge and Ma (2010) on common goals and needs of diabetes patients in China identified the following common traits for elderly patients, such as

- Empty nesters
- Good at self-initiating follow-up doctor visits
- Understand the need to adjust lifestyle (i.e., diet, exercise) to manage diabetes
- Environment of system use: hospital, home, and community centers
- Diabetes management is a hassle (28 on a scale of 40 with 40 being “no problem”)
- Co-morbidities
- Potential for system use - peak after diagnosis and when diabetes educational outreach not readily available
- Wish for better health care quality of community hospitals; hope there are more health specific community resources to utilize (see LeRouge and Ma (2010:5).

7.2.4.3 Template for eHealth applications

This section provides a template for elements needed as input for the description of personas, specifically for eHealth applications. Based on research results from the focus This should be of use, when sketching the EMPOWER set of personas and the story boards (D 8.1.1.).

Name	<ul style="list-style-type: none"> • <i>German, Turkish name; if no cultural preference maybe use a neutral one (English; to be discussed);</i>
Photo	A photo or drawing (to be discussed, because of need to avoid stereotypes in picture)
(Health) Biographic background	<ul style="list-style-type: none"> • <i>Socio-demographic profile:</i> Age, gender, family size, family life cycle status (e.g. single, married, young, with/without children, widow, grandchildren), income, housing, occupation (professions, unemployed, retired), education (highest level of school degree: secondary school, high school, university; intellectual abilities, skills of the user). • <i>Psycho-graphics:</i> Social class (working class, middle class, upper middle class), social network role (central connector, boundary spanner, information broker, specialist); personality and self-image (compulsive, gregarious, authoritarian). • <i>Health biography:</i> Diabetes diagnosis; diabetes detection; learning style for health behaviour (games, language etc.), acceptance of health innovation (early adopter, majority, laggard). • <i>Webographic profile:</i> tenure of online usage, amount of online usage (hours per day, week/month); type of IT usage (mail, facebook, sms) connection speed, specific online behaviour. • Life-style traits • Interests, hobbies, read media • Geographic profile (prototype for specific regions); • Urbanicity (urban, suburban, rural).
	<p>This section is very important and should include a short description of personal goals, attitudes, beliefs (conscious and subconscious).</p> <ul style="list-style-type: none"> • <i>Experience goals:</i>

Goals, needs, health beliefs attitudes	<p>Experience goals help describe how a persona wants to feel while using a product. These goals provide focus for a product's visual and aural characteristics, its interactive feel—such as animated transitions and the snap ratio of a physical button—and its industrial design by providing insights into persona motivations that express themselves at the visceral level.</p> <ul style="list-style-type: none"> • <i>End goals:</i> End goals describe what a persona wants or needs to accomplish. A product or service can help accomplish such goals directly or indirectly. These goals are the focus of a product's interaction design, information architecture, and the more functional aspects of industrial design. Because of the influence of behavioral processing on both visceral and reflective responses, end goals should be among the most significant factors in determining the overall product experience. • <i>Life goals:</i> Life goals describe a persona's long-term desires, motivations, and self-image attributes, which cause the persona to connect with a product. These goals form the focus for a product's overall design, strategy, and branding. For example: "Be attractive, popular, or respected by my friends." This type of goal needs to be adapted in eHealth and should include life goals related to the chronic disease! • <i>Health beliefs:</i> Type of information seekers on health information (contentwise: health treatment, nutrition and healthy diet; prices); type of health decision maker (alone/self- medication, with family, compliant to doctor) ; Type of patient-doctor relationship: pro-active; re-active patients (decisions by family are followed; see doctors only with serious complications) • <i>Attitudes:</i> General attitude towards technology and ICTs/mobiles (favourable, unfavourable, conservative); general attitude towards eHealth devices; • <i>Usage goals:</i> What do users really want to accomplish regardless of the specific tasks they use to reach the goal. • Emotional goals Usually unstated, these are emotional overtones accompanying specific usage goals, which when satisfied cause a product to resonate with users. While these are most obvious in consumer-facing products, these can be just as important for internal applications. • Motivations: Why do they want to accomplish usage goals, emotional goals and "big picture" goals? Since goals can broaden quickly, be specific to the context in which they'll be using the product. • <i>Needs in self-management of diabetes related to work and leisure activity:</i> Be specific to the context in which they'll be using the envisaged application: • <i>Work activities of a typical day/ week/ year:</i> description when at work or in retirement; • Leisure activities of a typical day/week /year; description when not at work; • <i>Frustrations related to self-management of diabetes in context of work and leisure activity:</i> What's causing pain with how they do things now? Where are roadblocks? Where are workarounds being used? Often users are so used to these sorts of things they won't raise them. Also look at broader issues beyond the system for opportunistic enhancements. • <i>Trigger(s) for action/ resistance:</i> What prompts them to do the task? General description, use task analysis for details; Roadblocks for inaction or resistance
Knowledge of application domain (chronic care / diabetes self-management)	<ul style="list-style-type: none"> • <i>Knowledge about diabetes and consequences</i> • <i>Diabetes self-management competence (deal with illness / activities / manage emotions)</i> • <i>Health literacy</i> • <i>Digital competence(includes ICT skills)</i> <p>Critical indicators for EMPOWER devices have to be discussed;</p>
Criteria of proficiency level has to be discussed	<p>Indicators for computer and ICT skills (Olsen, 2004<:9):</p> <p><i>Novice</i></p> <ul style="list-style-type: none"> • Very goal and task oriented • Don't want to learn, simply want to do • Domain experts will use existing mental models – which may not fit the new product

	<ul style="list-style-type: none"> • Domain novices have to simultaneously learn the product and the domain • Fear of failure, fear of the unknown • Focus on accomplishing real work • Impatient with learning concepts rather than performing task • Theoretical understanding only – no practical experience. <p><i>Advanced beginners</i></p> <ul style="list-style-type: none"> • Typically 80 percent of users never move beyond this stage • Includes infrequent users • Includes frequent users who only do a few tasks • Can now perform several tasks well, although they learn what they need to and ignores the rest • Focus on accomplishing real work • Impatient with learning concepts rather than perform tasks <ul style="list-style-type: none"> • Domain experts are impatient learners. They will likely try to make sense of interface to accomplish goals by themselves or with peer's help. Only if stumped will go to documentation or outside help. • Randomly access tasks • By adding more and progressively more complicated tasks, they begin to develop an empiricallybased mental model (which may or may not be accurate) • But not comfortable troubleshooting and often unsuccessful at it • Typically self-ratings will overstate skill levels (they don't know what they don't know) <p><i>Intermediates (aka "competent performers")</i></p> <ul style="list-style-type: none"> • Focus on performing more complex tasks that require many coordinated actions • Ability to plan how to perform a complex series of task to achieve a goal • Willingness to learn how tasks fit into a consistent mental model of the interface • Interest in solving simple problems by applying a conceptual framework to diagnose and correct errors. <p><i>Experts</i></p> <ul style="list-style-type: none"> • Focus on developing a comprehensive and consistent mental model of the product functionality and the interface • Ability to understand complex problems and find solutions • Interested in learning about concepts and theories behind a product's design and use • Interested in interacting with other expert users. <p>Source: Competency descriptions based on "User and Task Analysis for Interface Design," JoAnn T. Hackos and Janice C. Redish, 1998 Pgs. 76-87 http://www.amazon.com/exec/obidos/ASIN/0471178314/interactionby-20/104-7330305-6449509.</p>
<p>Diabetes self-management activity</p> <p>and</p> <p>context of use of EMPOWER services</p>	<p>Specify the chronic disease context in which the application is used by persona.</p> <ol style="list-style-type: none"> 1) <u>Health related issues</u> <ul style="list-style-type: none"> • Change health behavior • Monitor, document and interpret vital and other diabetes-relevant parameters • (e.g. vital signs, blood sugar, sport activities, mood) • Make appropriate decisions • Incorporate diabetes-relevant activities into daily routines • Use EMPOWER services at the point of individual need • Continual use of EMPOWER • Communicate data and share experiences • Preferences and resistance to behavior changes • Support others • Privacy 2) <u>General context of use</u> <ul style="list-style-type: none"> • Task context • User's role • User's responsibilities • Benefits sought • User's preference for interacting with others • Surrounding environment • Description of the location(s) where usage occurs, including: places – workstations vs. outdoor café; • Use and movement of space – how people move in and around the space as they do things.

	<ul style="list-style-type: none"> • Tols – hardware, software, others (in-baskets, address books) • Artifacts – Things that may be created, modified or passed around to support what they're doing • Device constraints Desktop connection vs. PDA, connection speed, etc. • Security • Traceability • Confidentiality/privacy • Flexibility of task • Operational risk/Safety Is the user involved in a high-risk task? • Reliability and availability of product • Robustness of product • Scalability • Capacity • Trustworthiness • Legal • Standards • Technological interactions • Maintenance • does the persona have to maintain and/or troubleshoot the product? • Transition issues • Documentation • Remember-ability • Power and efficiency in use • Error tolerance • Satisfaction
Interaction characteristics of use	<ul style="list-style-type: none"> • Frequency of use: how often will the persona take on this role? ("Role" is the role they have interacting with the product – not their job title or occupation.). • Regularity of use: is the product used on a regular basis or is usage more sporadic? Specify time periods. • Continuity of use: Is interaction with this role essentially continuous or is it more intermittent? If intermittent, be detailed about what happens. • Intensity of use: Is usage concentrated into bursts or batches, or is it more evenly distributed? • Timeliness: How quickly do things need to be done? How quickly does the product need to respond to a request or situation? • Complexity: How complex are the interactions within this role? • Predictability: Are the interactions within this role more or less predictable? • Web-specific usage scenarios session lengths and behavior with an information site: quicky, just the facts, single mission, do it again, loitering, surfing.
Information characteristics of use How to present appropriate content?	<p>How to present the content?</p> <ul style="list-style-type: none"> • Level and volume of information needed • Flow of information • Information volume • Information complexity • Modes (visual, text, audio) • Clarity of presentation
Communication (style and partner)	What person does he/she likes best for supporting in a disease management programme?
Accessibility issues	<ul style="list-style-type: none"> • Physical abilities/disabilities • Mental abilities/disabilities • Assistive devices used
Emotional issues	<ul style="list-style-type: none"> • Perceived experience of using EMPOWER: feel of independency, sense of security, confidence, power;

Source: Nielsen (2007); Olsen (2004)

7.2.5 Examples of personas description for eHealth application

Appendix B – Sample Personas

Rural Patient**personal profile**

Ms. Qi is a 68-yr old grandma lives in a farming village in Sichuan Province in southwest China. Her three grown children all moved away to work in big cities. Ms. Qi and her husband have been raising their granddaughter since she was a little baby. Ms. Qi was diagnosed with diabetes three years ago. She had been feeling tired for a long time and had drastically lost a lot of weight before she sought care. The lab work confirmed diabetes; her blood and urine glucose levels were pretty high. In fact, the doctor told her that perhaps she might have had diabetes for several years by then.

After trying various health products, Ms. Qi's blood glucose level was still out of control. During a third hospital stay in two years, she was put on insulin. Although it took her a while to learn how to inject insulin on her own and it's troublesome to take two shots a day, Ms. Qi trusts that her doctors will prescribe the best medicine for her.

To manage her diabetes, Ms. Qi also tries to eat less. Like many older Chinese, Ms. Qi loves eating the comfort food congee for dinner. She reasons that compared to a bowl of steamed rice, a bowl of congee contains less rice. Ms. Qi cooks bitter squash dishes often and drinks a bowl of bitter squash juice everyday, since she heard from a couple of other diabetics in the village that bitter squash is good for diabetes patients.

The village clinic owns a glucose meter. However, Ms. Qi only had her glucose measured there a couple of times, because her fingers became so painful from all the piercing. Ms. Qi feels that she can tell when her glucose level is high or low by how she feels, so testing blood glucose at the clinic is kind of unnecessary and costly. Ms. Qi's daughter left them a cell phone after getting a new model. Ms. Qi was initially intimidated by the phone, but her granddaughter is helping her to become more comfortable with using the phone. Whenever she gets some free time, Ms. Qi likes watching soap operas on TV.

Shufen Qi 齐淑芬

"I want to see my granddaughter grow up and get married."

**background**

- Lives with her husband of 40 years and a 7-yr granddaughter
- Husband feels diabetes is just a part of getting old
- Very limited education, finished primary school, never used computer

attributes

- Unaware of the importance of monitoring of blood glucose level on a regular basis
- Trusts diabetes information she encounters blindly
- Dependent on close ones for health care decision for self
- Has a lot of misconceptions about diabetes
- Fearful of and minimal interest in technology

user needs

- Correct and trustworthy information about diabetes self-care basics
- Assistance in managing diet
- Corrections on current misconceptions
- Improve awareness of the potential seriousness of diabetes complications

Urban Patient**personal profile**

Mrs. Shuxin Gao, a 63-yr retired account, lives with her husband in a comfortable 3-bedroom apartment in Beijing. With a family history of diabetes, Mrs. Gao was first diagnosed with gestational diabetes in 1974. Starting her mid 50's, Mrs. Gao tried to control her blood glucose through diet, but this did not work and she switched to oral medications. In 1998, Mrs. Gao's retina suddenly started bleeding, eventually she lost her left eye because diabetes induced glaucoma. She is now on insulin.

A few years back, many primary hospitals in Beijing started offering health seminars. Mrs. Gao likes attending the diabetes seminars. Although the seminars often present too much information each time for her to digest and remember, she enjoys making friends with other diabetes patients. Unfortunately, Mrs. Gao is not able to attend those seminars as often as she would like because commuting to the seminars takes a lot of time. Through the seminars, she has mastered the basic knowledge of diabetes and her blood glucose level are pretty much under control.

Mrs. Gao tests her blood glucose level often, at least once every three days. She learned from the seminars that she should record her glucose test results to see how she is doing over a period of time. Mrs. Gao only occasionally uses the log booklet that the glucose meter company provided, as it is such a hassle writing things down each time. Mrs. Gao knows that diet is important, but struggles with managing her diet during frequent family meals with her children and grandchildren and especially when they go out to eat. Mrs. Gao often forgets what or how much she ate hours later when she tries to write down what she ate in her log. Mrs. Gao enjoys group ribbon dancing in a nearby park every morning.

Ms. Gao carries her cell phone around so her husband who suffers hypertension can reach her easily. She likes to exchange short messages with her son who lives in Shanghai and only comes home for major holidays.

Shuxi Gao 高树新

"I want to help other diabetics."

**background**

- Lives with her husband of 38 years, both have stable pension
- High school graduate with an accounting certificate
- Enjoys cooking, knitting, and learning how to play poker games on computer with her husband

attributes

- Outgoing and warm hearted
- Has a clear goal in diabetes management and likes to plan ahead
- Feels empowered by diabetes knowledge she has accumulated over the years and wants to share with others
- Avid information seeker (e.g., nutrition, healthy diet)
- Decision maker for the family regarding health care

user needs

- Easy and portable way to log and track daily diet, glucose levels, and exercise.
- Better access to enjoyable diabetes education approved by her doctors.
- More time and individualized attention from her providers
- Assistance to make diabetes self-management more convenient and fun at an affordable cost

7.3 Persona development for EMPOWER

7.3.1 Determination of target groups

Hypothesis: Differentiation of potential EMPOWER target groups - Diabetes patients

<i>Type of potential EMPOWER user</i>	<i>(Health) Biographic background</i>	<i>Goals, attitude and health beliefs</i>	<i>Needs</i>	<i>Specific knowledge and proficiency for using EMPOWER services</i>	<i>Diabetes self-management activity and context of use of EMPOWER services</i>	<i>Information and interaction characteristics of use</i>	<i>Emotional characteristics of use</i>
Patients diabetes type 1	Age, gender, family status, educational levels, social class	<i>Experience goals:</i> To feel treated individually; to feel self-confident and do not be ashamed because of disease; feel save;	Need for information in a timely manner	Knowledge about diabetes and consequences	Change lifestyle	Level and volume of information needed	Perceived experience of using EMPOWER (feel of independency, sense of security, confidence, power)
Patients with diabetes type 2	Diabetes diagnosis (type 1, type2, pd, gd); Detection (short/long experience) and diabetes relevant body characteristics	<i>End goals:</i> Improve blood glucose level; reduce weight, change nutrition, follow diabetes diets, increase physical activities; Cope with chronic disease	Need to understand the big picture of a chronic disease and changes in behavior pattern	Diabetes self-management competence (deal with illness / activities / manage emotions)	Monitor, document and interpret vital and other diabetes-relevant parameters (e.g. vital signs, blood sugar, sport activities, mood) Make appropriate decisions	Flow of information Information volume Information complexity Modes (visual, text, audio)	
Pre-diabetes patients (pd)	Other health problems (hypertension, depression, stress, comorbidity, etc.)	Coping/non-coping; high level of frustration	Understand the long-term consequences of a chronic disease; e.g. what test results and other medical measure mean for me, including awareness of possible diabetes complications	Health literacy Digital competence ----- Novice user - using EMPOWER services in a simplified way;	Incorporate diabetes-relevant activities into daily routines Use EMPOWER services at the point of individual need	Clarity of presentation	
Patients diagnosed with gestational diabetes (gd)	Work/retired Europe (particularly Germany, Turkey) Lifestyle (sportive, walking /sedentary) Family status (e.g. married, partnership; divorced/widow; living alone)	<i>Life goals:</i> Live my "normal" life as much as possible; <i>Health beliefs:</i> Type of health information seeker; type of patient-doctor relationship (Active/ re-active/ inactive patients; compliant/non-compliant; <i>Attitudes towards ICTs:</i> General attitude towards	Need to train and repeat activities; get support in reminding exercises Need to share and exchange experiences and for social support Reduce cognitive needs for complying with treatment (think less, e.g. for data monitoring and interpretation) Have fun for changing diet.	Advanced user – basically using all EMPOWER services, but with a reduced set of options Expert user– using EMPOWER services intensively and in a complex way	Continual use of EMPOWER Communicate information and share experience Support others Privacy ----- Type of interactions for social support: Alone/ practitioner/ with self-help group coach/DMP-programme Where: at home/	Frequency of use (daily/weekly/monthly) Regularity of use (low/high) Continuity of use Timeliness (speed of responding to data) Control of interaction Web-Usage type (1min.-60min sessions)	

		<p>technology e.g. ICT/ Internet/ mobile (favourable/ non-favourable)</p>	<p>Get a reward for change and compliance</p> <p>Understanding the necessity of keeping track of vital and other diabetes-relevant parameters</p> <p>Access to diabetes information/ education relevant for the patients personal needs</p> <p>Connect quickly to trustworthy medical / diabetes support experts</p> <p>Low costs for treatment (affordable)</p> <p>More time for personal medical advice</p> <p>More cooperation among different medical disciplines (internist, eye specialist, orthopedist, dermatologist, psychologist etc.)</p> <p>No/less frustrations with software applications</p> <p>Less pain with insulin injection</p>		<p>friends/restaurant/ praxis</p>		
--	--	---	---	--	-----------------------------------	--	--

Hypothesis: Differentiation of potential EMPOWER target groups: Doctors, dietician and self-help group moderators

<i>Type of potential EMPOWER user</i>	<i>(Health) Biographic background</i>	<i>Goals, attitudes and health beliefs</i>	<i>Needs</i>	<i>Specific knowledge and proficiency for using EMPOWER tools and services</i>	<i>Supporting diabetes self-management activity and context of use of EMPOWER tools and services</i>	<i>Information and interaction characteristics of use</i>	<i>Emotional characteristics of use</i>
General practitioner	Age, gender, family status Work Education (diabetes education) Europe (particularly Germany, Turkey)	<i>Experience goals</i> Be time-efficient	Need for support of efficient and effective treatment (e.g.) Individually required analysis and treatment Contact to other specialists	Diabetes competence Competence how to foster the patient's self-management Digital competence	Have a quick overview about the patients current health status (e.g. charts about vital signs, blood sugar, physical activities, upcoming problems) Increasing quality of care Seamless integration with existing GP software / HIS ----- How: alone/ co-operation with other doctors Where: praxis/ at home/	Level and volume of information needed about patient data (EHR, PHR), diabetes guidelines as input for recommendations Flow of information Information volume Information complexity Modes (visual, text, audio) Clarity of presentation ----- Frequency of use (daily/weekly/monthly) Regularity of use (low/high) Continuity of use Timeliness (speed of responding to data) Control of interaction Webusage type (1min.-60min session)	Perceived experience of using EMPOWER (feel of independency, sense of security, confidence, power)
Clinical medical expert		<i>End goals</i> Effective and efficient diabetes treatment Reduce medication Consulting with other specialists <i>Life goals</i> Support qualitative disease management <i>Usage goals</i> Increase the patient's compliance Fostering patient – physician communication (e.g. shared decision making, personalised treatment and goals) Share experience <i>Health beliefs</i> Understand patients in their resistance to change behavior; human weakness; need to find their trigger to change (not too much/less). Have an honest relation to the patient.					

			eye with capillary changes).				
Dietician	Age, gender, family status, work, Education (diabetes education)	Inform and train about nutrition and food Reflect and share experience with patients	patients interested in the training	Competence regarding nutrition and diabetes diet Training skills Knowledge/competence how to support self-management	Communicate information and share experience		Perceived experience of using EMPOWER (feel of independency, sense of security, confidence, power)
Self-help group moderator / coaches	Age, gender, diabetes detection and diagnosis (Y/N), work, retired Educational levels	Facilitate the communication among diabetes patients and the exchange of information and experiences	Active participants for the online self-help group Persons who are willing to share experiences about diabetes	Diabetes competence Digital competence Knowledge/competence how to support self-management	Communicate information and share experience		Participants who are willing to share information

Hypothesis: Differentiation of potential EMPOWER target groups: parents, partners, stakeholders, excluded personas

Type of potential EMPOWER user	Additional type of personas						
Parents of young diabetes patients; Close care givers in relationship (partners)	Affected personas	<p>To be discussed, if there is need to fully describe them;</p> <p>According to Cooper et al (2007: 106), they should be treated as secondary personas.</p>					
Early eHealth adopters ("ICT freaks") Patients and/or clinical staff with no access, no skills and unwillingness to use ICTs;	Excluded personas	<p>To be discussed: These target groups do not need a persona description, but it should be clear who we are NOT designing for.</p> <p>ICT personnel of clinics; "ICT-freaks"</p> <p>Patients and doctors with no access to ICTs and very low digital competence</p>					
Pharmacies, insurance companies (private), public health authorities, self-help group associations, patient friends etc.	Customary personas (other stakeholders)	To be discussed					

7.3.2 Categorization of the set of EMPOWER personas

1. Categorization and short characteristics of EMPOWER Personas: Patients

Nr.	Type of Persona	Name Photo	(Health) Biographic background	Goals, attitudes, health beliefs	Needs	Specific knowledge and proficiency for EMPOWER	Diabetes self-management activity and context of use for EMPOWER
1	Primary	Fritz Maier	Age 59; married, working as civil servant Diabetes type 2, pills treatment; neuropathical problems Diagnosed: 2 y. Urban area	Wants to increase and ensure high quality for long-term treatment (esp. balance of blood glucose level); “no hypos anymore” Pro-active disease manager Open minded towards ICTs; skeptical in privacy and security issues	Personalised treatment Timely feedback Repetition and reminders	Advanced EMPOWER user Experienced in disease management; clear understanding about consequences Medium level digital competence due to ICT use at work; Occasional internet user at home	Daily monitoring, interpretation, archiving; monthly reporting and individualized goal setting with practitioner and/or specialists (esp. physical exercises); Managing EMPOWER system while on business trips as well. Updates and reminders on action plan; repetition of information
2	Secondary	Nilüfer Aymaz	Age 35, married; nursery teacher at maternity leave; diabetes type 2; gestational diabetes due to pregnancy; Urban area	Wants to avoid premature birth and become a more informed patient Passive follower Favourable ICTs attitude, but little experience	Assistance in general disease management Accurate information for her doctors as base for decision-making and goals	Novice EMPOWER user Little experience in disease management; Low-level digital competence; little access to and experience of ICTs use; occasional internet user at home;	Daily monitoring; monthly reporting and interpretation with (esp. diet) with practitioner and/or specialists (e.g. gynaecologist); Updates and reminders on action plan; repetition of information

3	Secondary	Maria Huber	Age 21; single; Student; Diabetes type 1; Urban area	Wants to decide herself on her treatment and balance of blood glucose level Change from passive follower to pro-active disease manager; Favourable ICTs attitude	Assistance in decision making	Expert EMPOWER user Very experienced in general disease management, but little experience in decision making (only with support of parents) Medium level digital competence; little media literacy on information quality and privacy ; trend-driven internet users	Daily monitoring, interpretation, archiving; monthly reporting and decision-making with general practitioner home/ study location; and/or specialists, Updates and reminders on action plan; repetition of information
---	-----------	-------------	---	--	-------------------------------	---	---



2. Categorization and short characteristics of provisional EMPOWER persona types - doctors, dietician and self-help group moderators

Nr.	Type of Persona	Name/ Photo	(Health) Biographic background	Goals, attitudes, health beliefs	Needs	Specific knowledge and proficiency for EMPOWER	Diabetes self-management activity and context of use for EMPOWER
	Primary	Dr. Paul Schmid	<p>Age 45;</p> <p>Work: middle-sized group praxis (30% diabetes patients over 55; mainly type 2)</p> <p>Special diabetes education</p> <p>Germany</p>	<p>Become more competent in long-term diabetes treatment</p> <p>Pro-active doctor</p> <p>Favourable ICTs attitude</p> <p>Wants to foster patient's compliance and self-management</p>	<p>Have a quick overview of patients current health status</p> <p>Identification of the patient's personal triggers to DSM.</p> <p>Identification of social support for DSM</p> <p>Updates and repetition of diabetes self-management guidelines</p> <p>Needs seamless integration with existing GP software/ Health information system</p> <p>Need for time-efficient control for reminding patients</p>	<p>Participant of a diabetes self-management education course</p> <p>Advanced EMPOWER user</p> <p>Job-related PC/Internet user</p>	<p>Provision of personalized recommendations based on patient data (EHR/PHR)</p> <p>Support of patients self-management competences and compliance</p> <p>Trained on the disease management tool of EMPOWER</p>

FP7-288209 EMPOWER

5	Secondary	Mr. Ahmet Yilmaz Ms. Ayse Öztürk	Age between 35-45; Work: diabetes day clinic (100% patients with diabetes; all types) Special diabetes education Turkey	As above	As above	As above	As above
---	-----------	-------------------------------------	---	----------	----------	----------	----------


7.3.3 The description and verification of personas set

Type of Persona	Primary persona – EMPOWER patient-user diagnosed type 2; middle-age, pro-active patient; medium-level digital competences; urban area, work; occasional internet user	
Name	Fritz Maier, age 59, male, works as a civil servant	
 <p>stockphoto.com</p>	<p>“I want to get a grip on my diabetes.”</p> <p>“I want to feel save in having no “hypos” in the future anymore.”</p> <p>“As long as the (blood glucose/ BG) levels are ok, I feel good.”</p> <p>“I want to unlock the value of ICTs for feeling save on my sugar levels and for reminding me about what to do”.</p> <p>“I need to constantly repeat newly learned information on diabetes self-management.”</p> <p>“I count on the support of my family and friends.”</p>	
	<p>Background</p>  <p>stockphoto.com</p> <ul style="list-style-type: none"> • Married, lives with his wife and his almost grown up daughter (21) in a 4-room city-flat; one son (29) lives abroad for studying; • Works as civil servant; middle class income; • Education: high school education; vocational training / training on the job; medium-level of digital competences; occasional internet user; • Hobbies: biking (since first diabetes diagnosis), meeting friends and grill for them; cars, cinema and travelling; • Has some knowledge of cooking, but his wife does the grocery and she is concerned/ decides about his diet. He is fond of drinking beer. 	
Health Biography	<ul style="list-style-type: none"> • Diagnosed with diabetes type ten years ago; takes oral anti-diabetic pills; high blood pressure level; • In the beginning diabetes training helped to stabilize health condition (took up walking and biking). He has bought a glucose meter and a digital scale at home. He infrequently transfers the data into the paper-based Diabetes Passport. • Since two years he suffers from dry and burning feet and diabetic neuropathy was diagnosed. The feet problems get worse with time and recently the wound healing process is failing and a diabetic foot ulcer develops. He now is regularly visiting a podiatrist for foot care and foot inspections are done every 3 months. 	
Attributes: Goals, attitudes, health beliefs	<ul style="list-style-type: none"> • Experience goal: Shortly after the diagnosis, he has taken part in a three weeks training course on diabetes. Now he knows how to use a 	

glucose meter, but he has forgotten a lot of the given information on the interpretation and necessary actions already. He still tries to self-monitor his blood glucose levels, but forgets it sometimes. And would appreciate some kind of reminders. He finds it difficult to do that on business trips or on because his daily routine is interrupted by such events. He also feels insecure about the food/beer composition in restaurants when dining out or on holiday. With the EMPOWER services he handles his data more often and comprehensively and feels safe in avoiding hypo-glycemic events.

- *End goal:*
He wants to increase the observation of his blood glucose level and hence and the quality of his treatment with the EMPOWER services; he wants to increase the accuracy of the recorded data for the blood glucose level and get clear guidelines what to do.
- *Life goal:*
He wants to cope better with his diabetes as part of his daily life; He wants to continue his work routine as good as possible and enjoy his life. With EMPOWER he wants to share his positive experience with other diabetes patients, but has little/no time for face-to-face self-help groups (due to work responsibilities).
- *Health belief:*
He is an informed patient who has gained a clear understanding, why he has to do record his glucose levels. He visits his general practitioner regularly and also the recommended specialists;
- *Health behavior change/ decision making:*
Enjoys grilling, dining out and drinking beer. He has troubles with being strict on keeping his diet. He rather takes more insulin directly and enjoys himself. He follows the advice of his wife with the diet.
- *Attitude towards ICTs:*
He is open-minded towards the use of technology, especially in case of emergency. However, he is concerned about privacy and security issues of his health data. He has no experience in social media networking but is using a smartphone for work.

<i>Needs and desires</i>	<ul style="list-style-type: none"> • Wants to have more time with doctor to discuss his treatment; wants individualized attention and treatment plan. • Wants to put more focus on physical exercises • Needs easy to use ICTs to archive data on his BG levels, to calculate on it and to remind him what to do. • Needs feedback for changing his action plan (exercises, diet) in a timely manner. • Needs to repeat the training lessons and be reminded to follow his diet plan and exercise plan. • Needs regular information and reminders on his action plans. • Needs access to information also for his wife, supporting him in his decision making and preparing meals adapted to his diabetes diet. • Wants to share his experience with other diabetes patients, but has little time for face-to-face self-help group meetings.
<i>Specific knowledge and proficiency for EMPOWER services; Context of use of EMPOWER services</i>	<ul style="list-style-type: none"> • <i>Advanced user:</i> He uses EMPOWER for exchanging information with his medical professionals and the PHR system for recording blood sugar, blood pressure and other ODLs. Additionally, he is using the food ODL on his smartphone as a useful tool in particular when he is on one of his business trips. • <i>Pro-active manager in diabetes self-management:</i> He is a pro-active manager of his disease, who independently monitors blood glucose and adjusts his self-care regime to maintain metabolic control; he decides about a change of behavior and treatment in cooperation with his doctor and his wife. • <i>Digital competence:</i> He uses the computer at work since many years. He is an “occasional internet user”, has a laptop, printer and internet access at home. He uses the internet minimum once a week at home for Skype-talks with his son, for archiving digital photos and sometimes for playing games (e.g. flight simulation). He can send e-mails, use word processing and graphs; knows how to assess quality of internet (health) information. He does not use internet-banking, because of his privacy concerns.
<i>Narrative Persona Description</i>	Health biography/ Experience with changing health behavior/ Experience with monitoring processes-ODLs/ IT behavior

Type of Persona	Primary Persona: EMPOWER doctor-user : general practitioner middle-age, trained in diabetes self-management education, medium-level digital competences; group practice in an urban area; job related internet user;
Name	Mr. Paul Schmid / Mr. Ahmet Yilmaz; age 45
 Stockphotos.com	<p>“My patients are all different. I want to take the patients as they are.”</p> <p>“I want to support my patients in their lifestyle changes. I motivate my patients not to give up”.</p> <p>“I want to achieve an honest relationship with my patients.”</p> <p>“I use the ICTs to increase the effectiveness and efficiency of the treatment of my diabetes patients”.</p> <p>“I use the ICTs to have more time for individualized treatment of my diabetes patients”.</p>
Biography	<ul style="list-style-type: none"> • Experience as general practitioner since 15 years in a middle-sized group practice; situated in the city. • 1/3 of his patients are suffering from diabetes; but most of them have other diseases too. The average age of his diabetes patients is 55 plus, but he has young patients with type 1 as well. • Is in loose contact with other specialists, needed for diabetes treatment (eye doctor, podiatrist, dietician). • Attended a special course for diabetes education for patients.
Attributes: Goals, attitudes, health beliefs	<ul style="list-style-type: none"> • <i>Experience goals:</i> Feels more competent and successful in treating his diabetes patients with the support of EMPOWER services (e.g. by having a structured and efficient dialogue; using visualized information, sustainable treatment decisions). • <i>End goals:</i> wants to treat his patients efficiently; wants to find out the personal triggers for each patient to change life-style and health behavior with EMPOWER services; wants to increase communication with supporting partners (decision maker on diet in family etc.); wants to have a better patient-doctor relationship (honesty) ; structured and efficient dialogue; visualized information). Wants to lower costs for his practice (minimize training by diet assistance); • <i>Life goals:</i> Wants to provide care and treatment of high quality; wants to foster the patient’s compliance and self-management • <i>Health beliefs:</i> Treatment has be based both on diabetes standards and personalized needs of the individual patient.

	<ul style="list-style-type: none"> • <i>ICT attitude:</i> favourable; has a practice software; little experience with ICT support in direct consultation yet. • <i>Emotions:</i> Sometimes he finds it difficult to transfer general information about diabetes into the personal context of the patient. Giving additional information and repeating information can sometimes be time-consuming.
Needs and desires	<ul style="list-style-type: none"> • Support for efficient and effective treatment in individually required patient analysis and treatment. • Have a quick overview about the patients current health status (e.g. charts about vital signs, blood sugar, physical activities, upcoming problems) . • Quick identification of whom to include in the patient's diabetes self-management process, esp. decision process, dieting and training process (e.g. family, partner). • Quick identification of individual triggers supporting the health behavior change process of patient best. • Need for good communication and information at all levels: doctor-patient; doctor-care giver; general practitioner-diabetes specialists. • Need for time-efficient control / coaching (e.g. semi-automatic support via SMS) for reminding the patients on his/her actions. • Need for interoperable and secure software exchanging patient data automatically with EMPOWER . • Need an easy-to-use access to EMPOWER system. • Need a seamless integration with existing GP software / HIS.
Specific knowledge and proficiency for EMPOWER services; Context of use of EMPOWER services	<ul style="list-style-type: none"> • <i>Advanced EMPOWER user:</i> He uses the Disease Management tool of EMPOWER that provides personalized recommendations based on the patient data (EHR data from his GP software, PHR data from the patients EMPOWER PHR system) • <i>Pro-active doctor:</i> Employs a dietician part time to have her trained the diabetes patient. He has flyers about diabetes self-management in the practice waiting room • <i>Digital competence:</i> He is a "Job-related internet user", uses the PC only in the office and has e-mail, word processing; information search competence. He uses the mobile phone for emergency; he has his assistance use the phone for text-messaging/SMS reminders.
Narrative Persona Description	<i>Adapt description to doctor</i>


Type of Persona	Secondary persona – EMPOWER patient-user: diagnosed type 2 and gestational diabetes; follower in diabetes self-management, low -level digital competences; urban area, work; occasional internet user
Name	Ms. Nilüfer Aymaz, age 35
	"I have a good reason to change."
	"I want to share my concerns with others"
Stockphotos.com	
Health Biography	<ul style="list-style-type: none"> • Diagnosed with diabetes type II two years ago (symptoms: increased thirst, increased hunger, irritation and dramatic weight loss without exercise); she takes antibiotics pills and monitors a blood glucose levels with a free glucose device from the clinic. • She suffers from hereditary diabetes. • She was diagnosed at a special clinic in Ankara (Numune Hospital) and there her data were entered in the clinic system (EHR); she gave her consent to also record her data in a special Personal Health Record system (eSaglikKaydim). Since she became pregnant, she had to see another specialist (gynecologist) and she changed from pill treatment to use an insulin injection. Now she needs to monitor her parameters even more often, to do non-exhaustive exercises and to follow a special diet.
Background	<ul style="list-style-type: none"> • Married; lives with her husband and his family in a house in Ankara. • Before maternity leave she worked as a nursery teacher. • Education: High school level; had problems in mathematics; • Hobbies: singing, cooking, watching movies and knitting.
Attributes: Goals, attitudes, health beliefs	<ul style="list-style-type: none"> • Experience goal: Shortly after the diagnosis, she has given a glucose meter from her doctor. She does not know exactly what the levels she has to record really mean, but her symptoms improve since she started the pill treatment and keeps the diet. She trusts her doctors and follows the instructions. With the eSaglikKaydim/EMPOWER services she feels protected, especially because of the given problem of a premature birth.

- *End goal:*
She wants to provide the correct information about her condition for her doctors and expects them to tell her what to do in a timely manner.
- *Life goal:*
She wants to be an amiable, heartfelt and good mother and take care of the health and diet problems of her family.
- *Health belief:*
She knows that her family has an inclination for becoming diabetes. However, sometimes she is worried about what she had done wrong to have got diabetes type II at a rather young age.
- *Health behavior change/ decision making:*
She trust her doctors and follows their advice as best as possible. She does not decide on her own, always together with her husband and her mother. She follows the pregnancy course, but there little information about gestational diabetes is given. She likes cooking and knows how to follow the diet instructions. However, sometimes she has troubles to follow them, because of the pressure of friends and family events. There she is expected to cook a lot of food and eat sweets. She feels often ashamed and does not tell her friends about having to use an insulin injection. Therefore she stays at home often.
- *Attitude towards ICTs:*
She is open-minded towards the use of technology, especially in case of emergency. However, she has little experience with the use of a PC, since she does not need it for her work and has no PC for her own. She has a mobile phone and likes text messaging. She has little experience in social media networking.
- *Frustrations:*
She is frustrated with the complicated entrance of the data and with the often interrupted internet connection. She always has to interrupt her data transmission, because her husband needs the PC permanently for work. Furthermore, she has problems in interpretation of the graphs given for the different glucose levels. She sends them directly to the doctor, without concluding an action therefrom.

Needs and desires

- Needs assistance with monitoring, interpretation and archiving of the data
- Needs affordable and easy to use ICTs to archive data on his BG levels, to calculate on it and to remind him what to do.
- Needs feedback for changing her action plan (exercises, diet) in a timely manner.
- Need to repeat the training lessons and be reminded to follow his diet plan and exercise plan.
- Needs regular information and reminders on his action plans.
- Needs access to information for her husband/mother, supporting her in the decision making and co-ordination of the action plans.

<p><i>Specific knowledge and proficiency for EMPOWER services;</i> <i>Context of use of EMPOWER services</i></p>	<ul style="list-style-type: none"> • Wants to share her experience with other diabetes patients. • <i>Novice EMPOWER user:</i> She uses EMPOWER PHR system for medication compliance, recording blood pressure and blood sugar, following the diet and for being reminded about upcoming diabetes tasks and appointments with medical professionals. She uses the basic EMPOWER services, devices via the computer and BG devices; she can get some help from her husband with using an app via a smart-phone; • <i>Passive follower in diabetes self-management:</i> She is a passive follower who follows her prescribed self-care regime, but does not react autonomously to changes in metabolic control;. She does not decide on her own, always together with her husband and her mother. • <i>Digital competences:</i> She has learn how to use the computer at school, but she did not need it anymore at work. She is an “occasional internet user”, has access to a PC , printer and internet access of her husband at home. She uses the internet minimum once a week at home for chatting with friends, looking for children and health-related information in the internet and listening music/TV at Youtube. She does not know how to assess quality of internet (health) information. She prefers watching TV with her family.
<p>Narrative Persona Description</p>	<p>Health biography/ Experience with changing health behaviour/ Experience with monitoring processes-ODLs/ IT behaviour</p>

Type of Persona	Secondary persona – EMPOWER patient user
Name	Maria Huber, 21 student; since 11 years-type 1 with insulin pump; change from “passive follower” to “pro-active manager”; trend-driven internet user;
 <p>Stockphotos.com</p>	<p>“I want to enjoy my life and have fun” “I want to party and chill out with my friends”.</p> <p>“I do not want to lose my feet and eye”. “I ‘m living with diabetes more than half of my life” “I want to share my experience with my diabetes”.</p>
Health Biography	<ul style="list-style-type: none"> • Diabetes diagnosed since she was 11 years old; since then has been applying an insulin therapy. • Knows how to handle the glucose meters devices and the insulin pump; • Changes from the family doctor to another specialist on diabetes and adapts her exercise and nutrition programme. • Every 3 months she has an appointment to discuss her results of the blood glucose level self-measurement and corresponding adjustments in insulin administration.
Background	<ul style="list-style-type: none"> • Single; lives in a student home • Education: High school education; studies music; has to travel often, due to her playing in an orchestra. • Hobbies: music; reading; not sportive
Attributes: Goals, attitudes, health beliefs	<ul style="list-style-type: none"> • <i>Experience goals:</i> to be researched • <i>End goals:</i> to be researched • <i>Life goals:</i> to be researched; • <i>Health beliefs:</i> Until now she was a "passive follower," (a patient who follows his/her prescribed self-care regime, but does not react autonomously to changes in metabolic control, because her parents decided for her what to do. But now she is on her own and needs to change from a passive to a pro-active diabetes manager. She is registered for a self-help group. • <i>ICT attitude:</i> very favourable; fit in social media and networks; not always literate in assessing the quality of internet information; • Emotions: She can cope well with her diabetes. She is used at that.

<i>Needs and desires</i>	<ul style="list-style-type: none"> • She follows the advice of her doctor, but sometimes does not exactly know what to ask at the appointment. Need for structured doctor-patient communication guide. • Needs more training and repetition on decision-making procedures and guidelines. • Low cost device and services affordable for a student. •
<i>Specific knowledge and proficiency for EMPOWER services;</i> <i>Context of use of EMPOWER services</i> <i>Emotions</i>	<ul style="list-style-type: none"> • <i>Expert EMPOWER user:</i> She uses all the EMPOWER services she needs on a high level and on multiple channels – the web for action planning and reviewing, forums, self-help groups and Facebook for sharing information and being in contact with other, the PHR system for her weekly review and update of the actions for the next week and her smartphone for recording data and being reminded about upcoming tasks. • <i>Changes from Follower to a Pro-active manager in diabetes self-management:</i> The change of her study is a big challenge for her. Until now she took all decisions about her treatment together with her parents and her local specialists. Now she move in another city and has to share rely on her own decision making. She is well aware, why she has to monitor her blood glucose levels, but troubles with interpretation and decisions about actions to take. • <i>Digital competences:</i> <i>She is a trend-driven internet user, has a private laptop, internet access via smart phone; participating in social web and plays computer games. She uses the computer at school since many years.</i> • Spends XY % of his income for support material (per year).
<i>Narrative Persona Description</i>	Health biography/ Experience with changing health behavior/ Experience with monitoring processes-ODLs/ IT behavior

8 Recommendations

The following recommendations are based on sound results of the literature review and of the inductive analysis of two focus groups with patients (age range 60+; retired) and one focus group with physicians in Germany (3/2012). The recommendations were further adapted to the findings from the interviews conducted with Turkish patients and doctors. The recommendations should support to keep the focus on the most common needs and requirements of the EMPOWER users: different types of diabetes patients and general practitioners, eventually family care givers, self-help groups or trained nurses.

8.1 Recommendations for the EMPOWER approach

Recommendation 1: Follow a holistic approach in "Patient Empower" for chronic care and diabetes

Technology can support behavioural change best if interventions follow a holistic approach based on a sound behavioural theory (psychological empowerment), information and communication theory (health literacy, digital competence) and medical treatment standards (blood glucose monitoring and treatment). The more active the patient is involved in the decision making regarding his/her health, the more he/she feels empowered (e.g. feeling of power, locus of control, increase in self-efficacy). Moreover, diabetes self-management is just one of the patients' primary life concern as for example he/she is often suffers from other co-morbidities.

A holistic patient-centered intervention /treatment will take into account the patient's full range of chronic conditions, his/her way of life including his/her family, friends and personal living conditions.

Recommendation 2: Foster patient empowerment with "meaningful" interventions

"Meaningfulness (or relevance) refers to the value of the activities, judged in relation to the individual's own ideal of life and determines how much energy and commitment a person invests in changing health behaviour (6.2)." The more relevant EMPOWER services are for patients, the more likely they are to become committed and involved in chronic disease and/or diabetes self-management.

Mind that the perception about "what is meaningful" differs among the actors in the health care system. Formerly, diabetes disease management programmes were conceptualized and implemented by medical and health system experts. The medical aim of diabetes self-management is primarily to avoid later physical risks and to increase medication adherence. The economic aim is to reduce the health system's costs of long-term consequences. However, diabetes patients have a personal agenda, as there are, continuing with their life with as minor changes as possible and successful coping with the "right" glucose level. One of the most used phrase in the focus groups was: "in den Griff bekommen" (to get a grip)

Consider to design "meaningful" services (e.g. patient-centered services, easy monitoring of glucose level and nutrition, relevant information) and promote their relevance.

Recommendation 3: Promote face-to-face interaction and technology supported interaction equally

"IBCT (=interactive behaviour change technology) is most effective when it supports human contact. New interventions should support patients' primary care. Services that are seen as extraneous will not be maintained over time by either clinicians or patients with diabetes."

(Piette 2007; 4.4).

EMPOWER should respect that users need to integrate the EMPOWER services and functions into their real world mediated by internet and other media. EMPOWER should develop and design strategies and services, for example for social support and motivation of online and offline self-help groups.

Recommendation 4: Develop a clear Unique Selling Proposition (USP) for EMPOWER services

In particular doctors, who only have limited time resources, need to be convinced by the benefits and added value of the program. Further, in order to engage doctors up front, the rationale of the EMPOWER prototype should be clearly communicated.

Both, patients and doctors, have to be taught and instructed on the system's benefits (e.g. minimize time for treatment and costs, maximize well-being and quality of life etc) and on how the system works as such.

8.2 Recommendations for EMPOWER services and functionalities

Recommendation 1: Monitor continuously and provide timely feedback

The primary goal of diabetes treatment is to keep the blood sugar level as low as possible and to minimize diabetes risk factors and co-morbidity. A continuous monitoring of the relevant vital signs and behaviour patterns facilitates a complete overview and history of the patient's health status and provides qualified data for feedback. Consider different channels for gathering data, such as web-based or mobile based services.

Feedback should be timely and can be both, an alert for e.g. indicating that the patient has just exceeded a threshold or a trend analysis of e.g. vital signs such as the glucose value.

Recommendation 2: Consider services and strategies supporting newly learned behavior patterns - be repetitive.

Repetition is a necessary method to guarantee that newly learned behavioral patterns are retained. In the long run repetition of information may be a useful tool to foster behavioral change.

Example how: Repetition by sending out reminders (E-Mail, SMS) or pop-ups when logging onto the platform.

Example where: Send out prompts (E-Mail, SMS) with regard to recently read articles and searched topics or on users' former experience with diabetes training.

Teaser example of a diabetes management quiz:

"Daniel, what would you say, which one of these products is lower in sugar? Option A, Option B"

"Julia, do you remember that not only normal fruit juices, but also diet fruit juices can lead to a fast increase in blood glucose levels!"

Recommendation 3: Cater for the need of social interaction.

Social support is a very important need, especially relevant for those patients suffering from feelings of exclusion, frustration, etc. due to their disease. The exchange of experience with other patients on equal terms is a very useful method to foster social support. EMPOWER should cater for offering the possibility to connect with other people who share the same experiences at similar stages of their disease.

Example how: Offer information and contact to self-help groups, by private messaging services and/or off and online-discussion forum and self-help groups. Although, discussion

forums or self-help groups are often self-organising, a moderator would be useful for facilitating discussions and the exchange of experiences.

Make profiles tangible (profile pictures, private information, etc.), add the option of creating groups in which people can verbalize interests independently from given topics in the forum.

Recommendation 4: Get the partner involved and develop services that include both.

Including family members as caregivers into the management of the disease is another important form of social support. Involve especially the partner by handing out relevant information to him/her or allowing multiple access (on patients consent).

Changing cooking/eating behaviour is often the women's tasks. If the husband is the diabetes patient, it is recommendable that the wife is also attending a nutrition training.

Example how: Create accounts specifically dedicated to the partner. Patients can indicate with which partner they want to relate and what kind of information they would like to share with them. Based on the patients preferences partners e.g. will not receive personalized information but information relevant to the partner's health status. If changes in diet are needed, the partner will receive information on dietary changes or if changes on frequency of blood glucose monitoring are needed, the partner may receive information on the importance of monitoring blood glucose.

Recommendation 5: Connect with already existing social networks.

Using social networks, such as Facebook, Twitter, patientslikeme.com are useful tools in order to share information and experiences with other people. Especially people who are information and tech savvy (younger users) may like the opportunity to share information with family and friends. In particular mobile applications have not yet fully grasped the potential of these tools.

Example how/where: Transferring results of pedometers to Facebook while also being connected to the platform may yield different forms of social support going beyond merely family support and may foster peers' understanding of the disease.

For example graphs tracking the latest physical activities and which can be posted or shared on Facebook. "Like" and share options for interesting content.

Recommendation 6: Develop services with "quick" wins for the target groups

The adoption rate of new ICTs by the majority of users increases if an immediate benefit is perceived. As an example the calculation of bread units can be mentioned. In order to foster diabetes patients' mobility e.g. enjoying a restaurant with unknown meals, he/she can be provided with direct and mobile accessible information on the right bread units.

Example how: Cater for real innovative solutions, such as a (semi-) automatic conversion from food in bread units while sitting in a restaurant.

Recommendation 7: Increase the awareness of regular monitoring

Patients may be aware of the importance of medical parameters in order to treat their disease. Nevertheless, there seem to be a lack of awareness with regard to regular monitoring of these parameters. Patients often do not have the feeling that regular monitoring is important for their diabetes care. However, their treating physicians need this information in order develop appropriate treatment plans.

One essential possibility for increasing awareness about monitoring are the goals specified by and with the treating physician. Recommendations of the physician should also refer to explanations and reasons why monitoring is important.

Recommendation 8: Aim at easy to use, almost seamless collection process of Observation of Daily Livings (ODLs)

Patients are subject to constant self-monitoring. They do not necessarily keep up with monitoring and may be even reluctant to continuous monitoring. Motivation in self-monitoring seems to be rather low. Thus, it is important to develop collection processes that are easy to use for the patients and do not demand too much effort from them in terms of utilization and time. Collection should aim at being as automatic (semi-automatic) as possible and to collect information in a seamless manner.

Recommendation 9: Didactical concept of multimedia information and resources for younger senior citizens

The adoption rate of innovative eHealth solutions by younger senior citizens increases by respecting the special needs of younger senior citizens in their learning styles. Elderly learners engaged in IT-based self-managing a disease best learn in a community-based setting in an informal learning environment, by means of slow self-paced learning steps and on the bases of their learning-style preferences (e.g. preference for different senses: sound, video, text). Investigate further the adoption of the principles of "micro-learning" ("small information units on a regular base").

8.3 Recommendations for the information sources in EMPOWER

Recommendation 1: Tell them why.

Patients want to make sense out of what they are seeing. Make an action meaningful to them by considering their need of information. Beginners might need more information and explanations than advanced or expert patients. By way of example provide patients with information on why it is necessary to monitor blood glucose levels.

Example how: Combine reminders (e.g. sms) of blood glucose monitoring with information on blood glucose. Send out reminders combined linked to information why it is necessary (Make it meaningful to them)

Teaser example:

"Good morning, Daniel. Did you already check your blood glucose level today to see how well you're reaching your treatment goals?"

"Hey Julia. How is your blood sugar level today? Did you know that high blood sugar levels can increase stress?"

Recommendation 2: Aim for personalized information.

Personalized interventions were proven to be effective in diabetes care. Over the years, patients have developed their own behavioral patterns and expect from care takers that they account for personal peculiarities. EMPOWER should ensure personalized messages by using personal reference points, such as names, registered habits and behaviors (through diary function).

Additionally, through the analysis of diary entries, goals and profile information, messages can be formulated that either are send out as messages or pop-ups.

Teaser example:

"Dear Daniel,"

"Dear Julia, you surely love strawberries, what about a nice apple today?"

"Good evening Daniel, did you recently observe a personal behavior that you think is useful to deal with your diabetes? The next time you see your doctor, talk about it!"

Recommendation 3: Help to keep track on the "bigger picture" of the course of the chronic disease

It is important to not lose sight of the overall development of the disease. Patients have to be aware that all small actions they are taking are incremental steps in trying to guarantee that the disease is not worsening.

Provide users with meaningful messages. Similar to “Tell them why”, people have to make meaning of results not only in the short-term but also overall.

Example how: Foster the patient’s motivation by e.g. offering historical trends and relate them to the physician’s recommendations. This gives the patient an overview what is going well and what should be optimized.

A “risk calculator” (and diary function) that evaluates the results if a certain behavior would have not been followed.

Recommendation 4: Cater for current, updated information

The attraction of an IT-based social service is enhanced by regular and updated information. Even if diabetes treatment guidelines remain the same, users adhere more to a “living” service

Example how:

Offer RSS feeds for actualization of information of different experiences (e.g. reports from others about their diabetes self-management experiments; good diabetes restaurants, travelling.

Recommendation 5: Provide streamlined and visualized information.

Doctors have little time to extract meaning of information for treatment and change behaviour decisions. Provide concise and streamlined information boxes, avoid redundancies and complicated data procedures.

Example how: Develop an easy accessible dashboard which visualizes the most important information for chronic care.

8.4 Recommendations as regards gender and digital divide issues

Recommendation 1: Be aware of different emotional strategies influencing the use of EMPOWER services

Compared to men women with type 2 diabetes who use insulin to treat their diabetes were more likely to keep track of the blood glucose levels. Diary functions may be useful for elderly women. In particular if doctors’ information (e.g. HbA1c value) is added into these diary functions.

Further, women are more likely to be frustrated by unwanted measurement values than men. Whereas men are more prone to stop measuring, women seem to become rather angry asking for the reasons behind the measurement results.

Thus, it is of major importance to keep in mind these differences when designing the platform.

Example how: Provide motivational messages with explanations why certain values were measured. Provide reminders to men to continue measuring.

Recommendation 2: Develop support functionalities and strategies out-balancing gender-different numeracy skills

The EMPOWER project should be aware of gender-differences not only in usage and attitude towards technology, but also in related needed competences, e.g. technological competence for technological devices and numeracy skills for measuring and interpreting personal data to derive to good decisions and conclusions for individual diabetes self-management.

In practice it may be useful to cater for gender-specific design in related EMPOWER functions. Needed are creative ways of support female patients in their self-management tasks, which involve numeracy skills, for example by means of oral or textual interpretation of data graphs.

Example how: Provide eventually for the use of standardized "Diabetes Numeracy Tests (DNT)", in order to flexibly adapt the "critical" content of EMPOWER resources.

Recommendation 3: Unlock the value of gender-differences in internet based health information behavior

The difference between male and female attitudes towards computer and internet is becoming minimal. However, women are more interested in searching for eHealth topics, esp. about chronic care knowledge and women use more online communication tools and platforms. Vice versa men are more likely to use internet as a destination for recreation. These gender-differences should be acknowledged by the design of EMPOWER services and functionalities, which could lead to higher adoption rates.

Example how: Inclusion of social network platforms could be relevant for integration EMPOWER services in the daily routine.

Recommendation 4: Closely follow all interaction design and usability strategies for senior citizens

The digital divide- low rate of access, low ICT skills and low positive attitude towards technology considerably affect EMPOWER, since a majority of diabetes patients is beyond 50+, has a lower income and is modestly educated. Although the problem of access to ICT is not a primary concern anymore, younger senior citizens have different needs for web accessibility and usability of computer-/internet-based technology (e.g. different screen design, variable scripts, haptic devices etc.). Carefully cater for the needs of younger senior citizens in designing EMPOWER services, online-content and devices (visual design, language and terminology, colors, style and buttons, speed).

8.5 Recommendations for the pilot-implementation of EMPOWER services

Recommendation 1: Cater for accompanying measures to keep pilot-users in the pilot implementation

For an EMPOWER pilot implementation it might be useful to offer an accompanying off-line support, such as an off-line self-help group. To know each other face-to-face would also decrease the barrier for online communication and for exchanging information and hence, the compliance for EMPOWER.

Example how: Dropout rates can be reduced for example with prior information days, buddy principle, assistance of an "EMPOWER-coach"

Recommendation 2: Evaluate beforehand users' levels of empowerment.

Explanation in order to provide the user with a design that fits his/her needs the level of his/her empowerment should be assessed beforehand. This should be done in order to avoid for example to exercise an overly paternalistic approach to someone who has not the need for it.

Recommendation 3: Evaluate (self-evaluation) beforehand users' functional abilities.

Before using the platform the users' functional abilities should be evaluated (e.g. level of literacy, including numeracy skills) in order to provide him with information tailored to his/her

abilities.

8.6 Recommendations for the EMPOWER users

8.6.1 Patients (all types; IT savvy, young senior citizen)

Recommendation 1: Unlock the value of the digital world for your safety and better decisions in diabetes self-management.

According to medical guidelines and study experiences, patients with closer monitoring benefit in their daily life and well-being. Make sure that EMPOWER can help users in unlocking the value of semi-/ automated observation, collection, archiving and interpretation of their blood sugar curve daily. This relieves them from the fear of severe consequences and balance exceptional highs and lows.

Archiving and long-term documentation (average rates) serve better decisions.

Recommendation 2: Consider to hire your personal assistant.

Take the necessary actions for a chronic condition in one's daily life is highly time consuming, and it risks to affect the quality of life. Moreover even when the condition is integrated in a patient's life he/she still risks to forget or even underestimate these actions. A system which can work as a personal assistant, reminding about these actions, storing and offering information, and facilitating communication with relevant persons can serve as a personal assistant.

Patients would be eager to use it properly if they perceive the system as an help, which can ease their lives.

8.6.2 General practitioners

Recommendation 1: Do not follow a "top-down" approach to all patients

Do not deliver instructions to all patients in the same form. A guided form of patient involvement leads to more involvement in self-management of diseases. Managing a change of behavior/lifestyle for diabetes patients sustainably (even beyond a course / training) is easier, if patients are setting the level of their goals for themselves. Patients are the experts about their experience of interrelated factors influencing the relevant "glucose" level. The more impact individuals believe they have, the more internal motivation they should feel. Personalize your treatment suggestions and joint goal settings according to the coping and managing strategy of the patients. Cater for:

"proactive managers," a patient who independently monitors blood glucose and adjusts his/her self-care regime to maintain metabolic control;

"passive followers," a patient who follows his/her prescribed self-care regime, but does not react autonomously to changes in metabolic control;

and "nonconformist" a patient who does not follow most of his/her prescribed self-care regimen (Collins et al.,2009).

Develop and use EMPOWER services, e.g. assessment tests for a of coping strategies , in coaching patients differently in their individual goal-setting.

Recommendation 2: Facilitate integrated care

Typically, diabetes care guidelines suggest following regular consultations with different specialists additionally to the periodical appointments with the general practitioner: eye doctors, orthopedists, skin doctor, psychologists etc.

Support a timely integration of other medical specialists by transferring the patient to them for periodic diabetes-specific examinations.

9 Annex

9.1 Focus groups and interviews – guide

9.1.1 Questioning route focus group with doctors: Ingolstadt 28/03/2012

Overarching Question:

What do diabetes patients need to cope better with their chronic disease as part of their daily life?

Was brauchen Diabetes Patienten, um mit ihrer Krankheit im täglichen Leben besser umzugehen?

How can an IT based system support self-control of diabetes-relevant parameters (such as blood sugar) and behavior changes (such as increasing physical activities) in a way that will motivate diabetes patients and doctors to use it and to benefit from it?

Wie kann ein IT gestütztes System die Selbstkontrolle von Diabetes relevanten Parametern (z.B. Blutzuckerwerte) und Verhaltensänderungen (z.B. Zunahme von körperlicher Bewegung) unterstützen, so dass Diabetespatienten und Ärzte es nutzen und davon profitieren?

Doctors:

What are the mechanisms that doctors deem useful in diabetes patients' disease management and in fostering diabetes patients' self-management including self-control?

Was sind Mechanismen, die Ärzte als nützlich und fördernd für das Krankheits- und Selbstmanagement von Diabetespatienten bewerten?

Do doctors recognize different patient types with different needs with regard to these mechanisms?

Gibt es verschiedenen Patiententypen mit unterschiedlichen Bedürfnissen, die Ärzte ausmachen können?

What are the needs and problems of doctors with regard to the usage of IT-based Disease Management Programs (DMP)?

Was sind die Bedürfnisse und Probleme von Ärzten in Hinblick auf die Nutzung von IT gestützten strukturierten Behandlungsprogrammen für chronisch Kranke/Disease Management Programmen?

	DOCTORS
Welcoming	<p><i>Die Fokusgruppe erklären</i></p> <p><u>Ziel der FG:</u> ist es ein besseres Verständnis davon zu bekommen, welche Rolle der Arzt beim Selbstmanagement eines Diabetespatienten spielt und welchen Herausforderungen er/sie dabei möglicherweise begegnet.</p> <p>Zusätzlich möchten wir besser verstehen was Ärzte benötigen (welche Bedürfnisse sie haben), um Diabetespatienten bessere und persönlichere Empfehlungen zu geben.</p> <p><u>Wer sind wir:</u> Wir sind Forscher der Universität Lugano in der Schweiz, die im Rahmen eines europäischen Projektes gemeinsam mit GOIN zum Thema Diabetes und Selbstmanagement zusammenarbeiten.</p> <p><u>Wie funktioniert eine FG:</u> Wir bringen Experten zusammen, um mehr über ihre Erfahrungen zu lernen und diese gemeinsam zu diskutieren.</p> <p><u>Was werden wir tun:</u> Wir werden die Daten, die wir während der Diskussion sammeln, später transkribieren und analysieren. Damit nichts verloren geht, nehmen wir deshalb diese Diskussion auf.</p> <p><u>Diskretion:</u> ist natürlich in Hinblick auf alle hier anwesenden Personen und besprochenen Themen gewährleistet.</p> <p><u>Praktische Regeln:</u> Die Fokusgruppe wird etwa 1.5 Stunden dauern und jeder ist dazu ermutigt freiheraus zu sprechen. Wir möchten basierend auf Ihren Erfahrungen mit Ihnen diskutieren.</p>
Opening	<p><i>Könnten Sie uns zu Beginn vielleicht einfach ganz kurz erzählen:</i></p> <ul style="list-style-type: none"> - wer Sie sind - seit wann Sie als Arzt praktizieren - inwiefern Sie Erfahrung mit dem Thema Diabetes und Diabetespatienten haben und inwiefern Sie Erfahrungen mit Diabetes Management Programmen haben.
Introduction (2 questions)	<i>Die Sicht des Arztes auf seine Rolle in der Diabetesbehandlung</i>

	<p><u>Einleitung:</u> Noch einmal vielen Dank für Ihre Teilnahme. Da ich keinen medizinischen Hintergrund habe und auch bisher nicht im medizinischen Bereich mit Diabetespatienten gearbeitet habe, würde ich gerne von Ihnen ein bisschen mehr über die Rolle des Arztes bei der Pflege von Diabetespatienten erfahren.</p> <p>1. Deshalb interessiert mich zu Beginn, was Ihrer Meinung nach, abgesehen von seiner fachlichen Kompetenz, die Qualitäten sind, die ein Arzt bei der Behandlung eines Diabetespatienten mitbringen sollte?</p> <p>Nachfrage: Und im erfolgreichen Disease Management/Krankheitsmanagement?</p> <p>2. Was glauben Sie, sind die Dinge, die es einem Diabetespatienten erschweren mit seiner Krankheit umzugehen?</p> <p>Nachfrage: Und welche Qualitäten, Kompetenzen oder Fähigkeiten ermöglichen es einem Patient erfolgreich langfristig mit seiner Krankheit umzugehen?</p>
<p>Transition (2 questions)</p>	<p><i>Charakteristika eines Diabetespatienten aus der Sicht des Arztes</i></p> <p>3. Bitte denken Sie einfach mal an die Diabetespatienten, die Sie im letzten halben Jahr gesehen haben. Wie würden Sie diese beschreiben?</p> <p>Nachfrage: Erkennen Sie irgendwelche Gemeinsamkeiten zwischen verschiedenen Diabetespatienten?</p> <p>4. Konnten sie möglicherweise verschiedene Phasen ausmachen, wie diese Patienten mit ihrer Krankheit umgegangen sind? (z.B. Zielsetzung, psychologische Entwicklung, etc.)</p> <p>Nachfrage: Wir würden Sie Ihre Rolle während dieser verschiedenen Phasen beschreiben?</p>

<p>Key questions (2-5 questions, 10-15 minutes each)</p>	<p><i>Die chronische Krankheit managen</i></p> <p>5. Denken Sie einmal an Ihre täglichen Aufgaben in der Diabetestherapie, welches sind die Informationen, die Sie benötigen um einen Patienten erfolgreich zu behandeln (z.B. medizinische Informationen oder Patienteninformationen)?</p> <p>Nachfrage: Welche Informationen sind für Sie am nützlichsten? /Gibt es bestimmte Leitlinien die Sie befolgen?</p> <p>6. Wenn Sie an die typische Behandlung eines Diabetespatienten denken, welche Empfehlungen geben Sie normalerweise diesem Patienten, damit es ihm möglich ist mit seiner Krankheit tagtäglich umzugehen?</p> <p>Nachfrage: Was raten Sie, um das Selbstmanagement eines Patienten zu verbessern? Gibt es bestimmte Empfehlungen die Sie für besonders effektiv halten?</p> <p>Nachfrage: Nutzen Ihre Diabetespatienten bestimmte (Hilfs)Mittel, um den Überblick darüber zu behalten, ob sie diesen Empfehlungen folgen? (Kontrollieren Ihre Patienten Diabetes relevante Parameter?)</p> <p>Nachfrage: Neben den Routineuntersuchungen, kontrollieren Sie (Ärzte) in irgendeiner Form, ob Ihre Patienten Ihren Empfehlungen nachkommen? (z.B. mit technologischen Hilfsmitteln)</p> <p>7. Für wie erfolgreich beurteilen Sie Verhaltensänderungen bei Diabetespatienten?</p> <p>Nachfrage: Was meinen Sie ist besonders leicht für einen Patienten und was nicht? Können Sie sich vorstellen, warum das so ist?</p> <p>8. Was könnten sie sich vorstellen, welcher Teil Ihrer Behandlung von Diabetespatienten könnte durch IT gestützte Technologien erleichtert werden?</p> <p>Nachfrage: (Welche Probleme haben Sie mit IT-gestützten Dokumentationssystemen erlebt? Was war am frustrierendsten für Sie? Inwiefern können diese Dinge verbessert werden?)</p>
---	---

<p>Ending (2-3 questions)</p>	<p><i>Die Diskussion beenden</i></p> <p>9. Wenn man Sie darum bitten würde Vorschläge für den Aufbau einer technischen Kommunikations- und Informationsplattform für Diabetestherapien zu machen, was wären Ihre Vorschläge?</p> <p>(Wenn man Sie darum bitten würde, Vorschläge für den Aufbau einer personalisierte Anwendung für Diabetespatienten und ihr Selbstmanagement zu machen, was würden Sie vorschlagen?)</p> <p>10. Haben Sie das Gefühl, dass es andere wichtige Dinge gibt, die wir hier noch nicht besprochen haben und die wichtig sind um ein personalisiertes System zur Behandlung von Diabetespatienten aufzubauen?</p>
--	---

9.1.2 Questioning route focus groups with patients: Ingolstadt 27-28/03/2012

Overarching Question:

What do diabetes patients need to cope better with their chronic disease as part of their daily life?

Was brauchen Diabetes Patienten, um mit ihrer Krankheit im täglichen Leben besser umzugehen?

How can an IT based system support self-control of diabetes-relevant parameters (such as blood sugar) and behavior changes (such as increasing physical activities) in a way that will motivate diabetes patients and doctors to use it and to benefit from it?

Wie kann ein IT gestütztes System die Selbstkontrolle von Diabetes relevanten Parametern (z.B. Blutzuckerwerte) und Verhaltensänderungen (z.B. Zunahme von körperlicher Bewegung) unterstützen, so dass Diabetespatienten und Ärzte es nutzen und davon profitieren?

Patients:

What are the mechanisms that help diabetes patients to deal with their condition on a daily, yearly and life-span basis?

Welches sind die Mechanismen, die Diabetespatienten dabei helfen mit ihrem Gesundheitszustand im täglichen Leben, sowie über den Zeitraum eines Jahres und über Ihre gesamte Lebensdauer umzugehen?

What are the needs of diabetes patients with regard to these mechanisms? /What are the problems with fulfilling the needs, specifically with regard to self-control, behavior changes and documentation?

Welches sind die Bedürfnisse von Diabetespatienten in Hinblick auf diese Mechanismen?/Was sind die Probleme die im Zusammenhang mit diese Bedürfnissen entstehen, insbesondere in Hinblick auf Selbstkontrolle, Verhaltensänderungen und Dokumentation (z.B. Diabetes relevante Parameter)?

How can we translate/support these mechanisms within/ by means of a technological environment?

Wie können wir diese Mechanismen innerhalb eines technologischen Umfelds umsetzen?/Wie können technologische Mittel diese Mechanismen unterstützen?

Are there any decision making situations in which information is lacking?

Gibt es Entscheidungssituationen, in denen Informationen fehlen?

	PATIENTS
Welcoming	<p><i>Die Fokusgruppe erklären</i></p> <p><u>Ziel der FG:</u> Einen Einblick in die Situation von Diabetespatienten zu bekommen, um besser verstehen zu können welche Bedürfnisse und welche Hindernisse und Probleme sie in Hinblick auf den täglichen Umgang mit ihrer Krankheit haben. Und was sie brauchen, um Ihr Selbstmanagement und Selbstkontrolle in Hinblick auf ihre Krankheit zu fördern/verbessern.</p> <p><u>Wer sind wir:</u> Wir arbeiten am Institut für Gesundheit und Kommunikation der Universität Lugano in der Schweiz. Wir haben keinen spezifischen medizinischen Hintergrund in Hinblick auf Diabetes und den Umgang damit.</p> <p><u>Warum haben wir Sie ausgewählt:</u> Weil wir an Ihrer Sicht der Dinge interessiert sind und ihre Betrachtungen von sehr großer Wichtigkeit für unsere weitere Arbeit sind.</p> <p><u>Wie funktioniert eine FG:</u> Wir bringen Menschen zusammen, die eine ähnliche Erfahrung gemacht haben oder noch machen, wie in Ihrem Fall den Diabetes, und wir möchten diese Erfahrungen besser verstehen lernen, indem wir darüber diskutieren.</p> <p><u>Was werden wir tun:</u> Wir werden die Daten nachdem wir mit der Diskussion fertig sind transkribieren, das heißt Ihre Gespräche niederschreiben und analysieren, deshalb nehmen wir auch diese Diskussion auf, damit nichts verloren geht.</p> <p><u>Diskretion:</u> ist natürlich in Hinblick auf alle hier anwesenden Personen und besprochenen Themen gewährleistet.</p> <p><u>Praktische Regeln:</u> Die Fokusgruppe wird etwa 1.5 Stunden dauern und jeder ist dazu ermutigt frei heraus zu sprechen. Basierend auf ihren eigenen Erfahrungen möchten wir hier mit ihnen diskutieren, ohne natürlich den anderen zu unterbrechen.</p> <p>Bevor die FG beginnt, würde ich sie kurz bitten den vor Ihnen liegenden Fragebogen auszufüllen.</p>

Opening	<p><i>Fragebogen ausfüllen</i></p> <p>Könnten Sie bitte den kurzen Fragebogen, der auf dem Tisch liegt ausfüllen?</p>
Introduction (2 questions)	<p><i>Die chronische Krankheit aus der Sicht des Patienten</i></p> <p><u>Einleitung:</u> Vielen Dank, dass Sie den Fragebogen ausgefüllt haben und nochmals vielen Dank, dass Sie sich bereit erklärt haben an dieser Diskussionsrunde teilzunehmen. Für uns ist es sehr wichtig zu verstehen wie Patienten mit Diabetes leben, um Hilfsmittel zu entwickeln, die ihnen in ihrem täglichen Leben helfen können und sie dabei unterstützen selbstständig mit ihrer Krankheit umzugehen.</p> <p>1. Denken Sie bitte einfach mal an die Zeit zwischen heute und dem Zeitpunkt an dem Sie das erste Mal gehört haben, dass Sie Diabetes haben, was sind für Sie bisher die größten Herausforderungen gewesen?</p> <p>Nachfrage: Haben Sie es geschafft diese Herausforderungen zu meistern? Erzählen Sie uns doch wie Sie diese gemeistert haben?</p> <p>2. Was glauben Sie welche persönlichen Eigenschaften haben Ihnen besonders geholfen mit Ihrer Krankheit umzugehen?</p> <p>Nachfrage: Und was würden Sie sagen sind die persönlichen Eigenschaften, die sich negativ auf Ihren Diabetes auswirken?</p>
Transition (2 questions)	<p><i>Lebenscharakteristika eines Diabetespatienten (Wie beurteilt der Patient seine Krankheit?)</i></p> <p>3. Wenn Sie an Ihren Diabetes denken, haben Sie das Gefühl, dass Sie durch verschiedene Phasen gegangen sind oder immer noch gehen? <i>(Wie hat sich die Krankheit entwickelt und ist sie Teil Ihres Lebens geworden?)</i></p> <p>4. Wenn Sie an Ihr tägliches Leben denken, wie und wo spiegeln sich diese Phasen wieder?</p> <p>Nachfrage: Sehen Sie, dass dieses Einfluss auf ihr restliches Leben hat (Bsp. im sozialen Bereich wie auch im Beruf)?</p>

<p>Key questions (2-5 questions, 10-15 minutes each)</p>	<p><i>Die chronische Krankheit managen</i></p> <p>5. Denken Sie an einen typischen Tag in Ihrem Leben, was sind die Aktivitäten die sie unternehmen, um mit Ihrem Diabetes umzugehen?</p> <p>Nachfrage: Bei welchen Aktivitäten haben Sie das Gefühl, dass diese am effektivsten sind um mit ihrer Krankheit umzugehen?</p> <p>Nachfrage: Haben Sie das Gefühl, dass Sie erfolgreich waren Ihr Verhalten im Hinblick auf den Diabetes zu verändern? Ist es Ihnen schwer gefallen? Erzählen Sie uns doch, warum es Ihnen schwer gefallen ist? Glauben Sie, dass es etwas gibt, was Ihnen dabei hätte helfen können oder immer noch helfen könnte?</p> <p>6. Nutzen Sie bestimmte (Hilfs)mittel, um Ihren Diabetes zu kontrollieren? Was genau kontrollieren Sie (z.B. sportliche Betätigung, Ernährung, Gewicht, etc.)</p> <p>Nachfrage: Haben Sie das Gefühl, dass es Ihnen möglich ist diese Dinge regelmäßig zu kontrollieren?</p> <p>Nachfrage: Nutzen Sie irgendwelche Hilfsmittel, wie zum Beispiel Ihren Computer oder Ihr Handy oder andere Hilfsmittel, die im Internet zugänglich sind?</p> <p>Nachfrage: Wenn Sie über die verschiedenen Dinge nachdenken, die Sie gerade genannt haben, welche Probleme haben Sie bei der Verwendung dieser Dinge festgestellt? (Warum sollten die Technologien unterschiedlich sein?)</p> <p>7. Denken Sie an Ihr tägliches Leben, gibt es irgendjemand, der Ihnen hilft mit Ihrem Diabetes umzugehen?</p> <p>Nachfrage: Gibt es eine Beziehung, von der Sie sagen, dass diese Ihnen besonders hilft?</p> <p>Nachfrage: Inwiefern ist diese Beziehung nützlich? (Wie oft haben Sie Kontakt mit diesen Leuten? Und wie kommunizieren Sie miteinander?)</p> <p>8. Haben Sie sich jemals selbst langfristige oder auch kurzfristige Ziele gesetzt, um mit Ihrem Diabetes umzugehen und Verhaltensweisen zu ändern?</p> <p>Nachfrage: Setzen Sie sich diese Ziele (Ziele in der Diabetestherapie) allein oder gemeinsam mit jemand anderem?</p> <p>Nachfrage: Haben Sie das Gefühl, dass diese Ziele nützlich sind?</p>
---	---

<p>Ending (2-3 questions)</p>	<p><i>Die Diskussion beenden</i></p> <ol style="list-style-type: none"> 9. Wenn man Sie fragen würde, wie man eine persönliche Anwendung für Diabetespatienten bauen würde, die versucht verschiedenen Technologien miteinander zu verbinden, was würden Sie vorschlagen? 10. Haben Sie das Gefühl, dass es noch andere wichtige Dinge gibt, die in Betracht gezogen werden müssen, wenn man eine personalisierte Anwendung aufbauen möchte, die Ihnen dabei helfen könnte mit Ihrem Diabetes umzugehen und die wir hier noch nicht besprochen haben?
--	---

9.1.3 Focus Groups: Patient Questionnaire

Vielen Dank für Ihre Teilnahme an der Diskussionsrunde zum Thema Diabetes.

Wir bitten Sie den nachstehenden Fragebogen kurz auszufüllen, damit wir uns ein besseres Bild über die Teilnehmer der Gruppe machen können. Alle Daten werden natürlich streng vertraulich behandelt und in anonymisierter Form aufbewahrt, so dass keine Rückschlüsse auf einzelne Personen möglich sind.

Sie sind: <input type="checkbox"/> Weiblich <input type="checkbox"/> Männlich	
Geburtsjahr _____	
Mit wem leben sie zusammen in einem Haushalt? (Mehrfachnennungen möglich)	<input type="checkbox"/> allein <input type="checkbox"/> zusammen mit (Ehe)Partner <input type="checkbox"/> zusammen mit Kindern <input type="checkbox"/> zusammen mit Geschwistern <input type="checkbox"/> zusammen mit Eltern <input type="checkbox"/> zusammen mit sonstigen Verwandten <input type="checkbox"/> zusammen mit anderen Personen
Welchen Diabetes-Typ haben Sie?	<input type="checkbox"/> Typ 1 <input type="checkbox"/> Typ 2
Wann wurde bei Ihnen Diabetes festgestellt? (Bitte geben Sie das Jahr und wenn möglich den Monat an.)	_____
Wie lang ist ihr letzter Besuch beim Arzt aufgrund Ihres Diabetes her? (Bitte geben Sie den Zeitraum in Wochen oder Monaten an.)	_____
Haben Sie bereits einmal, oder nehmen Sie immer noch, an einem Disease-Management Programm oder einem strukturiertem Behandlungsprogramm (z.B. AOK-Curaplan) teilgenommen?	<input type="checkbox"/> Ja <input type="checkbox"/> Nein

<p>Haben Sie schon einmal einer Diabetesschulung teilgenommen (z.B. Ernährungsschulung, Fußschulung)?</p> <p><input type="checkbox"/> Ja <input type="checkbox"/> Nein</p>	
<p>Besitzen Sie ein Handy?</p> <p><i>Wenn ja, wie oft nutzen Sie dieses?</i></p>	<p><input type="checkbox"/> Nein <input type="checkbox"/> Ja</p> <p><input type="checkbox"/> Sehr Oft <input type="checkbox"/> Oft <input type="checkbox"/> Manchmal <input type="checkbox"/> Selten <input type="checkbox"/> Nie</p>
<p>Haben Sie einen Computer zu Hause?</p> <p><i>Wenn ja, wie oft nutzen Sie diesen?</i></p> <p><input type="checkbox"/> Nein <input type="checkbox"/> Ja</p> <p><input type="checkbox"/> Sehr Oft <input type="checkbox"/> Oft <input type="checkbox"/> Manchmal <input type="checkbox"/> Selten <input type="checkbox"/> Nie</p>	
<p>Haben Sie einen Internetanschluss zu Hause?</p> <p><i>Wenn ja, wie oft nutzen Sie diesen?</i></p>	<p><input type="checkbox"/> Nein <input type="checkbox"/> Ja</p> <p><input type="checkbox"/> Sehr Oft <input type="checkbox"/> Oft <input type="checkbox"/> Manchmal <input type="checkbox"/> Selten <input type="checkbox"/> Nie</p>

9.1.4 Guideline for the interviews with Turkish doctors 7/6/2012

<p>Questions for the semi-structured qualitative interview with Physicians in Turkey</p>
<p><i>Introduction</i></p> <p><u>The aim of this interview</u> is to better understand what role the doctor plays in the self-management of a diabetes patient and which challenges he/she may have to face.</p> <p>Additionally: to understand what physicians need in order to specify better and more personalized recommendations for the patients</p> <p><u>We are ICH (Institute of Communication and Health)</u> researchers involved in a European project, with no specific medical background with regard to diabetes and its management. Thus, we need doctors` help to better understand interplay of patients` and doctors` demands and needs.</p> <p><u>How does it work:</u> we will record the interview, if you agree. We will be treating all data anonymously and only for the purpose of the project.</p> <p><u>What will we do afterwards,</u> we will transcribe and analyze data, that is why we need to record</p> <p><u>Confidentiality:</u> on the contents discussed and present persons is guaranteed.</p>
<p><i>Could you tell us:</i></p> <ul style="list-style-type: none"> - your function - since when you are a doctor - your “relationship” with diabetes patients - Experience with diabetes management programs (with/without IT-based treatment documentation, treatment compliance) - Experience with training on diabetes therapy and prevention

1. What hampers patients to cope successfully with their diabetes in their daily life?

Follow up: And which qualities/competences/skills allow a patient to successfully manage his diabetes on the long term?

2. Please think about the diabetes patients you have seen in the last 6 months. How would you describe them?

Follow up: Do you see commonalities between different diabetes patients?

3. Did you see these patients going through different phases when dealing with their diabetes?
(referring to objective setting or psychological development rather than acute vs. stable phases)

Follow up: How would you describe your role during these phases?

4. Thinking about your day to day activity in diabetes care which type of information to you need for a successful treatment (medical and from the patient)?/Are there any specific guidelines you follow?

5. Think about the typical care/treatment of a diabetes patient, what kind of recommendations do you give normally to patients in order to enable them to deal with their condition on a day-to-day basis?

Follow-up: Do your diabetes patients use devices to keep track whether they stick to your recommendations?

6. How successful are behavior changes necessary for diabetes patients?

7. What part of your work in the treatment of a diabetes patient could be facilitated by technology/ IT-based technology?

8. If you were asked to suggest what to take into account for designing an ICT tool directed to diabetes therapy treatment, what would you recommend?

9. If you were asked to suggest how to build a personal diabetes application for patients managing their disease what would you recommend?

10. Do you think there are other important things to take into account when building a personal support system to treat patients suffering from diabetes, and that we did not discuss so far?

9.1.5 Guideline for the interview with Turkish patients 7/6/2012

Questions for the semi-structured qualitative interview with diabetes patients in Turkey
<p><i>Introduction</i></p> <p><u>Aim of the interview</u>: to get an insight on diabetes patients condition in order to understand their needs and perceived barriers to cope properly with their disease during their daily life and what they need in order to foster self-control and self-management</p> <p><u>We are</u> ICH (Institute of Communication and Health) researchers involved in a European project, no specific medical background with regard to diabetes and its management.</p> <p><u>We choose him/her</u> because his/her point of view is essential to what we want to do</p> <p><u>How does it work</u>: we will record the interview, if you agree. We will be treating all data anonymously and only for the purpose of the project.</p> <p><u>What will we do</u>: transcribe and analyze data, that is why we need to record</p> <p><u>Confidentiality</u>: on the contents discussed and on the present persons is guaranteed</p>
<p><i>Fill in the questionnaire <u>(see the separate document of the questionnaire to be translated and printed)</u></i></p> <p>Can you please fill in the short questionnaire you find on the desk?</p> <p><u>Premise</u>: Thank you very much for filling in the questionnaire, and thank you also for your participation. It is really important for us to understand how a patient with a chronic disease lives in order to develop tools that can be beneficial to his life, and help him to self-manage his chronic condition.</p>

1. Let's just think of the time span between now and the first time you heard about your diagnosis, what were for you the main challenges you had to face so far?

Follow-up: Did you overcome these challenges? How did you overcome them?

2. What do you believe, which personality traits helped you to cope with your illness?

Follow-up: And what would you say are the personality traits that are interfering on the other hand?

3. If you think about your diabetes, do you feel that you had to go, or that you are still going, through different stages?
(How did the disease develop throughout their lives and eventually became part of it.)

4. Think about a typical day in your life. What kind of actions do you take to cope with your diabetes?

Follow-up: Which were the actions you felt were most effective for you in order to cope with your diabetes?

5. Are there any specific means that you use to monitor your diabetes? What do you monitor? (e.g. physical data, medicine, nutrition, weight, etc.)

Follow-up: are there any specific IT-based means that you use?

Follow-up: Do you have the feeling that you are able to monitor these things regularly? When thinking about the different means you mentioned before which problems do you encounter?

6. Thinking about your daily life is there somebody that helps you to manage your diabetes; is there somebody who supports you?

Follow-up: in which ways is this relationship useful?

7. Did you ever set yourself short or long term goals to help you to deal with your care and diabetes-related behavior changes?

Follow-up: Do you feel that these objectives are useful for you?

8. If you were asked to suggest how to build a personal diabetes application for managing your disease by different means of technology, what would you recommend?

9. Do you think there are other important things to take into account when designing a personal support system that could help you dealing with diabetes, and that we did not discuss so far?

9.1.6 Questionnaire for the Turkish patients

Thank you for your participation to the interview on the topic of Diabetes.

We would kindly ask you to fill in the following questionnaire, in order to collect some basic information about you. All the data you will provide will be treated in strictest confidentiality, only for the purposes of this research.

Gender: <input type="checkbox"/> Female <input type="checkbox"/> Male	
Year of birth _____	
Where do you live? <input type="checkbox"/> Urban area <input type="checkbox"/> Countryside	
With whom do you live? <i>(please check all that apply)</i>	<input type="checkbox"/> alone <input type="checkbox"/> with my partner (spouse) <input type="checkbox"/> with my children <input type="checkbox"/> with my siblings <input type="checkbox"/> with my parents <input type="checkbox"/> with other relatives <input type="checkbox"/> with other people
What type of diabetes do you suffer from?	<input type="checkbox"/> Type 1 <input type="checkbox"/> Type 2
When was your diabetes diagnosed? <i>(Please write the year and the month)</i>	_____
How long has it been since you went the last time to see your doctor because of your diabetes? <i>(Please indicate in weeks, months or years.)</i>	_____ weeks ago _____ months ago _____ years ago
Did you ever take part in, or are you still part of, a Disease-Management Programme or another kind of Management programme?	<input type="checkbox"/> Yes <input type="checkbox"/> No
If yes, please indicate the name of the programme:	_____

Did you ever take part in a diabetes training, such as courses on nutrition, foot care or physical activity with regard to diabetes? <input type="checkbox"/> Yes <input type="checkbox"/> No	
Do you have a mobile phone? <i>If yes, how often do you use it?</i>	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> Very often <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never
Do you have a computer at home? <i>If yes, how often do you use it?</i>	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> Very often <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never
Do you have a computer at your workplace that is available at your free disposal? <i>If yes, how often do you use it for private reasons?</i>	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> Very often <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never
Do you have an internet connection at home? <i>If yes, how often do you use it?</i>	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> Very often <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never

10 References

- Adaji, A., Schattner, P., Jones, K. (2008). The use of information technology to enhance diabetes management in primary care: a literature review. In *Informatics in Primary Care*, 16: 229-237.
- Ala-Mutka, K. (2011). Mapping Digital Competence: Towards a Conceptual Understanding European Commission Joint Research Centre. Institute for Prospective Technological Studies. http://ftp.jrc.es/EURdoc/JRC67075_TN.pdf [2012-02-22].
- Ali, M., Shah, S., Tandon, N.(2011). Review of Electronic Decision-Support Tools for Diabetes Care: A Viable Option for Low- and Middle-Income Countries?. In *Journal of Diabetes Science and Technology*, 5(3): 553-570.
- Anderson R.M., Funnell, M.M., Fitzgerald, J.T., Marrero, D.G. (2000). The diabetes empowerment scale: a measure of psychosocial self-efficacy. In *Diabetes Care*, 23: 739–743.
- Anderson, R.M., Funnell M.M. (2010). Patient Empowerment: Myths and Misconceptions. In *Patient Education and Counseling*, 79(3): 277–282.
- Antonucci, T. C., Ajrouch, K. J., Janevic, M. R. (2003): The effect of social relations with children on the education health link in men and women aged 40 and over. In *Social Science & Medicine*, 56: 949–960.
- Aristotle, Aristotle : *nicomachean ethics / translation (with historical introduction) by Christopher Rowe; philosophical introduction and commentary by Sarah Broadie* 2002, Oxford: Oxford University Press.
- Aufenanger, S. (2009). Media Competence Approaches in Germany AG Medienpädagogik/Institut für Erziehungswissenschaft, Universität Mainz. http://www.medienpaed.fb02.uni-mainz.de/pdf/media_competence_gender_anger.pdf
- Baake, D. (1997). *Einführung in die Medienpädagogik*. Verlag Niemeyer, Tübingen; 1.Aufl.
- Balas, A., Krishna, S., Kretschmer, R.A., Cheek, T.R., Lobach D.F., Boren, S.A. (2004). Computerized Knowledge Management in Diabetes Care. In *Medical Care*, 42 (6): 610-621.
- Balka, e., Green E., Henwood, F. (2009). *Gender, Health and Information Technology in context*. Palgrave Macmillan.IK.
- Bandura, A. (1977) Self-efficacy: Toward a unifying theory of behavioral change. In *Psychological Review*, 84(2): 191-215.
- Bandura, A. (1986) *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, NJ: Prentice-Hall
- Barrera, M., Glasgow, R. E., McKay, H. G., Boles, S. M., & Feil, E. G. (2002). Do Internet-Based Support Interventions Change Perceptions of Social Support?: An Experimental Trial of Approaches for Supporting Diabetes. In *American Journal of Community Psychology*, 30(5): 637-654.
- Batinic, B. and Appel, M. (2008). *Medienpsychologie*. Springer Verlag.
- Begley, S. (2009) Anatomy of a scare. In *Newsweek*, 153(9): 42-47.
- Bergsma, L.J. (2004) Empowerment education - The link between media literacy and health promotion. In *American Behavioral Scientist*, 48(2): p. 152-164.
- Bergsma, L.J. and Carney, M.E. (2008) Effectiveness of health-promoting media literacy education: a systematic review. In *Health Education Research*, 23(3): 522-542.
- Boekaerts, M., Pintrich, P., Zeidner, M. (2005). *Handbook of Self-regulation*. Academic Press.
- Boren, S. A. (2009). A review of health literacy and diabetes: opportunities for technology. In *Journal of diabetes science and technology*, 3(1), 202-9. Retrieved from <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2769840&tool=pmcentrez&rendertype=abstract>
- Boren, S. A., Gunlock, T. L., Peebles, M. M., & Krishna, S. (2008). Computerized learning technologies for diabetes: a systematic review. In *Journal of diabetes science and technology*, 2(1): 139-46.

- Bostock, D., *Aristotle's ethics* 2000, Oxford: Oxford University Press.
- Bredies, K. (2009). Using System Analysis and Personas for e-Health Interaction Design. In *Undisciplined! Design Research Society Conference 2008*, Sheffield Hallam University, Sheffield, UK, 16-19 July 2008. Available at: <http://shura.shu.ac.uk/464/1/fulltext.pdf> [2012-02-20].
- Brody, D. (1980) The Patient's Role in Clinical Decision Making. In *Annals of Internal Medicine* 93: 718–722.
- Calabria, T. (2004). An introduction to personas and how to create them. Step Two Designs Pty Ltd. Available at: http://www.steptwo.com.au/files/kmc_personas.pdf. [2012-02-05].
- Charles, C., Gafni, A. and Whelan, T. (1999). Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. In *Social Science in Medicine*, 49: 651-661.
- Chen, M., and Land, K.C. (1986). Testing the Health Belief Model: LISREL Analysis of Alternative Models of Causal Relationships Between Health Beliefs and Preventive Dental Behaviour. In *Social Psychology Quarterly*, 49(1), 45–60.
- Chen, Y. (2010). Proceedings of the 8th ACM Conference on Designing Interactive Systems. Take it Personally: Accounting for Individual Difference in Designing Diabetes Management Systems.
- Chiou, S.J., Campbell, C., Horswell, R., Myers, L., Culbertson, R. (2009). Use of the emergency department for less-urgent care among type 2 diabetics under a disease management program. In *BMC Health Services Research*, 9, doi:10.1186/1472-6963-9-223.
- Chomutare, T., Fernandez-Luque, L., Årsand, E., Hartvigsen, G. (2011). Features of Mobile Diabetes Applications: Review of the Literature and Analysis of Current Applications Against Evidence-Based Guidelines. In *Journal of Medical Internet Research*, 13(3):e65.
- Cianciolo, A.T., et al. (2006) Practical intelligence and tacit knowledge: Advancements in the measurement of developing expertise. In *Learning and Individual Differences*, 16(3): 235-253.
- Conger, J.A. and R.N. Kanungo. (1988) The empowerment process: Integrating theory and practice. In *Academy of Management Review*, 13(3): 471-482.
- Cooper, A., Reimann, R. and Cronin, D. (2007). *About Face 3: The Essentials of Interaction Design*. Wiley Publishing. Inc. USA
- Cooper, A. (2003). BLOG: The origin of personas. (1st of August, 2003). Available at: http://www.cooper.com/journal/2003/08/the_origin_of_personas.html.
- Costa, B.M., Fitzgerald, K.J., Jones K.M., Dunning, T. (2009) Effectiveness of IT-based diabetes management interventions: a review of the literature. In *BMC Family Practice*, 10 (72), doi:10.1186/1471-2296-10-72.
- Courneya, K. S., Plotnikoff, R. C., Hotz, S. B., and Nicholas, J. B. (2000). Social support and the theory of planned behavior in the exercise domain. In *American Journal of Health Behavior*. 24: 300–308.
- Deci, E.L. (1975) *Intrinsic Motivation*. New York: Plenum Press.
- Deci, E.L. and Ryan, R.M. (1987) The support of autonomy and the control of behavior. In *Journal of Personality and Social Psychology*, 53(6): 1024-1037.
- DiClemente, C.C., J.O. Prochaska, and M. Gibertini, (1985) Self-efficacy and the stages of self-change of smoking. In *Cognitive Therapy and Research*, 9(2): 181-200.
- Dijk, Jan van (2008). *The Digital Divide in Europe*. Draft. Chapter for *The Handbook of Internet Politics*, Routledge, London and New York, 2008. <http://www.utwente.nl/gw/mco/bestanden/digitaldivide.pdf>
- Dobrev et al. (2008). Benchmarking ICT use among General Practitioners in Europe. Empirica. Gesellschaft für Kommunikations- und Technologieforschung mbH. Brüssel http://ec.europa.eu/information_society/eeurope/i2010/docs/benchmarking/gp_survey_final_report.pdf
- Dogac, A, Hülür, Ü, Çaylan, A. K, Yuksel, M. and Heywood, J. (2010). Country Brief: Turkey. Available at: http://ehealth-strategies.eu/database/documents/Turkey_Countrybrief_eHEstrategies.pdf
- Donohue, J.M., Cevalco, M., and Rosenthal, M.B. (2007) A decade of direct-to-consumer advertising of prescription drugs. In *The New England Journal of Medicine*, 357(7): 673-81.

Dorr, D.A., Wilcox, A.B., Brunner, C.P., Burdon, R.E., Donnelly, S.M. (2008). The Effect of Technology-Supported, Multidisease Care Management on the Mortality and Hospitalization of Seniors. In *Journal of the American Geriatrics Society*, 56(12): 2195–2202.

Fallows, D. (2005). How Women and Men Use the Internet. <http://www.pewinternet.org/Reports/2005/How-Women-and-Men-Use-the-Internet.aspx>

Finnemann, N.O., Jaurt, P., Jensen, J.L., Povlsen, K.K., Soerensen, A. S. (2012). The Media Menus of Danish Internet Users. <http://changingborders.au.dk/>

Fox, S. and Purcell, K. (2011). Chronic Disease and the Internet. US. pewinternet.org.

Fox, S. (2011). Health Topics. At. <http://pewinternet.org/Reports/2011/HealthTopics.aspx>.

Frosch, D.L. and Grande, D. (2010) Direct-to-consumer advertising of prescription drugs. In *LDI Issue Brief*, 15(3): 1-4.

Frosch, D.L., et al., (2007) Creating demand for prescription drugs: a content analysis of television direct-to-consumer advertising. In *The Annals of Family Medicine*. 5(1): p. 6-13.

Funnell, M. M., Brown, T. L., Childs, B. P., Haas, L. B., Hosey, G. M., Jensen, B., Maryniuk, M., et al. (2009). National standards for diabetes self-management education. In *Diabetes care*, 32 Suppl 1, S87-94.

Funnell, M. M. (2006). The Diabetes Attitudes , Wishes , and Needs (DAWN) Study. In *Clinical Diabetes*, 24(4): 154-155.

Gecas, V. (1989) The social psychology of self-efficacy. In *Annual Review of Sociology*. 15: 291-316.

Geser, G. (2011) SRFG Handbook of Methods. Salzburg Research GmbH. Austria.

Gibbons, M. (2002). *The self-directed learning handbook: Challenging adolescent students to excel*. New York: Jossey-Bass.

Glasgow, R. E., Kurz, D., King, D., Dickman, J. M., Faber, A. J., Halterman, E., Woolley, T., et al. (2012). Twelve-month outcomes of an Internet-based diabetes self-management support program. In *Patient education and counseling*, 87(1), 81-92. Elsevier Ireland Ltd.

Glasgow, R.E., Funnell, M.M., Bonomi, A.E., Davis, C., Beckham, V., Wagner, E.H. (2002) Self-management aspects of the improving chronic illness care breakthrough series: implementation with diabetes and heart failure teams. In *Annals of Behavioral Medicine*, 24(2):80-87.

Goldberg L., et al.(2011) Usability and accessibility in consumer health informatics. In *American Journal of Preventive Medicine*, vol. 40,pp. 187-197.

Greenfield, S., Kaplan, S. and Ware, J.E. Jr. (1985) Expanding patient involvement in care. Effects on patient outcomes. In *Annals of Internal Medicine*, 102(4): 520-8.

Grudin, Jonathan (2006). Why Personas Work: The Psychological Evidence. Introduction. In J. Pruitt & T. Adlin, (2006). *The persona lifecycle: Keeping people in mind*: 642-663. Morgan Kaufmann. Mapping Digital Competence: Towards a Conceptual Understanding

Gucciardi, E., Smith, P. L., & DeMelo, M. (2006). Use of diabetes resources in adults attending a self-management education program. In *Patient education and counseling*, 64(1-3), 322-30. doi:10.1016/j.pec.2006.03.012

Heinrich, E., de Nooijer, J., Schaper, N. C., Schoonus-Spit, M. H. G., Janssen, M. a J., & de Vries, N. K. (2012). Evaluation of the web-based Diabetes Interactive Education Programme (DIEP) for patients with type 2 diabetes. In *Patient education and counseling*, 86(2): 172-8.

Helgeson VS (2003). Social support and quality of life. In *Quality of Life Research*,12: 25–31.

Hill-Briggs, F. (2003). Problem solving in diabetes self-management: a model of chronic illness self-management behavior. In *Annals of Behavioral Medicine*, 25(3): 182-193.

House JS, Landis KR, Umberson D (1988a). Social relationships and health. In *Science*, 241:4865. 540–5.

House JS, Umberson D, Landis KR (1988b). Structures and processes of social support. *Annual Review of Sociology*, 14:293–318.

Huh, J., et al. (2010) Direct-to-consumer prescription drug advertising: history, regulation, and issues. In *Minnesota Medicine*. 93(3): 50-2.

Irwin, T.H. (1988) *Aristotle's First Principles*. Oxford: Clarendon Press.

Israel, B.A., et al. (1994) Health education and community empowerment: conceptualizing and measuring perceptions of individual, organizational, and community control. In *Health Education Quarterly*, 21(2): 149-70.

Jackson, C. L., Bolen, S., Brancati, F. L., Batts-Turner, M. L., & Gary, T. L. (2006). A systematic review of interactive computer-assisted technology in diabetes care. *Interactive information technology in diabetes care*. In *Journal of General Internal Medicine*, 21(2): 105-10.

Jaen, C.R. and Brennan, P.F. (2009) Patients Need to Share Data; Technology Can Help. In *Rheumatology News*, 8(12):15-15.

Johnson, V.R., Jacobson, K.L., Gazmararian, J.A., Blake, S.C. (2010). Does social support help limited-literacy patients with medication adherence? A mixed methods study of patients in the Pharmacy Intervention for Limited Literacy (PILL) Study. In *Patient Education and Counseling*, 79: 14-24.

Karakurt, Papatya et al. (2012). The effect of education given to patients with type 2 diabetes mellitus on self-care. <http://onlinelibrary.wiley.com/doi/10.1111/j.1440-172X.2012.02013.x/abstract>

Kardas, P., et al. (2005) A systematic review and meta-analysis of misuse of antibiotic therapies in the community. In *International Journal of Antimicrobial Agents*. 26(2): 106-13.

Knowles, M. (1975). *Self-Directed Learning*. Chicago: Follet.

Krishna, S., & Boren, S. A. (2008). Diabetes Self-Management Care via Cell Phone: A Systematic Review. In *Journal of Diabetes Science and Technology*, 2(3).

Krokavcova M, van Dijk JP, Nagyova I, Rosenberger J, Gavelova M, Middel B, Gdovinova Z, Groothoff JW (2008). Social support as a predictor of perceived health status in patients with multiple sclerosis. In *Patient Education and Counseling*, 73: 159-165.

Lee S-YD, Arozullah AM, Cho YI (2004). Health literacy, social support, and health: a research agenda. In *Social Science in Medicine*, 58: 1309–21.

Lepore, S. J., Evans, G. W., & Schneider, M. L. (1991). Dynamic role of social support in the links between chronic stress and psychological distress. In *Journal of Personality and Social Psychology*, 61: 899–909.

LeRouge, C. and Ma, J. (2010). User Profiles and Personas in Consumer Health Technologies. *Proceedings of the 43rd Hawaii International Conference on System Sciences – 2010*. <http://www.computer.org/portal/web/csd/doi/10.1109/HICSS.2010.426>.

LeRouge, C., Ma, J., Sneha, S., & Tolle, K. (2011). User Profiles and Personas in the Design and Development of Consumer Health Technologies. Special Issue of the *International Journal of Medical Informatics (IJMI)* on IS/IT Applications for the Support of Older People.

Logan, M.S. and Ganster, D.C. (2007) The effects of empowerment on attitudes and performance: The role of social support and empowerment beliefs. In *Journal of Management Studies*, 44(8): 1523-1550.

Lorig K., Ritter P.L., Laurent D.D., Plant, K. (2008). The Internet-Based Arthritis Self-Management Program. A One-Year Randomized Trial for Patients with Arthritis or Fibromyalgia. In *Arthritis & Rheumatism*, 59 (15): 1009-1017.

Lorig, K. R., Ritter, P.L., Laurent, D. D., & Plant, K. (2006). Internet-Based Chronic Disease Self-Management. In *Medical Care*, 44(11), 964-971.

Lorig, K.R. and Holman H.R. (2003) Self-management education: history, definition, outcomes and mechanisms. In *Annals of Behavioral Medicine*, 26(1): 1-7.

Martin, A. (2008). CHAPTER SEVEN: Digital Literacy and the "Digital Society". [Book Chapter]. *Digital Literacies: Concepts, Policies & Practices*, 151-176. Cited in Ala-Mutka, Kirsti (2011: 29).

- Martin, A., Grudziecki, J. (2006). DigEuLit: Concepts and Tools for Digital Literacy Development. In *Innovations in Teaching & Learning in Information & Computer Sciences*, 5(4): 246-264.
- McMahon, G.T., Gomes, H.E., Hickson Hohne, S., Hu, T.M.J., Levine, B.A., Conlin, P.R. (2005). Web-Based Care Management in Patients With Poorly Controlled Diabetes. In *Diabetes Care*, 28, 1624–1629.
- Miller, G.E. (1990) The assessment of clinical skills/competence/performance. In *Academic Medicine*, Supplement, 65: S63-S67.
- Minet, L., Moller, S., Vach, W., Henriksen, J.E. (2010). Mediating the effect of self-care management intervention in type 2 diabetes: A meta-analysis of 47 randomised controlled trials. In *Patient Education and Counseling*, 80: 29–41.
- Montagnier, P., Wirthmann, A. (2011), Digital Divide: From Computer Access to Online Activities – A Micro Data Analysis. In *OECD Digital Economy Papers*, 189, OECD Publishing. <http://dx.doi.org/10.1787/5kg0lk60rr30-en>.
- Montori, V.M., Gafni, A. and Charles, C. (2005). A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes. In *Health Expectations*, 9: 25-36.
- Mordini, E., Wright, D., Wadhwa, K., De Hert, P., Mantovani, E., Thestrup, J., Van Steendam, G., D'Amico, A., Vater, I. (2009). Senior citizens and the ethics of e-inclusion. Springer Science+Business Media B.V. 2009. <http://globalseci.com/wp-content/uploads/2010/05/Senior-citizens-and-the-ethics-of-e-inclusion.pdf>
- Mulder, Martin (2006). Einführung zur Sonderausgabe über Kompetenz. Kompetenz – Bedeutung und Verwendung des Begriffs in der beruflichen Erstausbildung und Weiterbildung. Universität Wageningen. Available at: http://www.cedefop.europa.eu/etv/Upload/Information_resources/Bookshop/468/40_de_mulder.pdf
- Mulvaney, S.A. (2009). Improving patient problem solving to reduce barriers to diabetes self-management. In *Clinical Diabetes*, 27(3): 99-104.
- Neufeld, R.W. and Thomas, P. (1977) Effects of perceived efficacy of a prophylactic controlling mechanism on self-control under pain stimulation. In *Canadian Journal of Behavioural Science/Revue canadienne des sciences du comportement*, 9(3): 224-232.
- Newcomb, M.D. and Harlow, L. (1986) Life events and substance use among adolescents: Mediating effects of perceived loss of control and meaninglessness in life. In *Journal of Personality and Social Psychology*, 51(3): 564-577.
- Nutbeam, D. (2000) Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. In *Health Promotion International*, 15(3): 259-267.
- Nielsen, L. (2007). Ten Steps to Personas. HCI VISTAS, VOLUME-III, 2007-2008 <http://www.hceye.org/HCIInsight-Nielsen.htm>.
- Olsen, George (2004). Persona Creation and Usage Toolkit. Available at: http://www.interactionbydesign.com/presentations/olsen_persona_toolkit.pdf
- Ong, L.M.L., de Haes, J.C.J.M., Hoos, A.M. and Lammes, F.B. (1995). Doctor-patient communication: a review of the literature. In *Social Science and Medicine*, 40(7): 903-918.
- Osborn, C.Y., Satterwhite Mayberry L., Mulvaney, S.A., Hess, R. (2010). Patient Web Portals to Improve Diabetes Outcomes: A Systematic Review. In *Current Diabetes Reports*, 10(6): 422-435.
- Paris, S., Paris, A. (2001). Classroom Applications of Research on Self-Regulated Learning. In *Educational Psychologist*. 36 (2): 89-101.
- Parker RM, Kindig DA (2006). Beyond the Institute of Medicine health literacy report. Are the recommendations being taken seriously? In *Journal of General Internal Medicine*, 21:891–2.
- Piette, J. D. (2007). Bench to Clinic Symposia Interactive Behavior Change Technology to Support Diabetes Self-Management Where do we stand ?. In *Diabetes Care*, 30(10).
- Preckel, F., Goetz T., Pekrun 'R., Kleine, M. (2008). Gender Differences in Gifted and Average-Ability Students: Comparing Girls' and Boys' Achievement, Self-Concept, Interest, and Motivation in Mathematics Gifted Child. In *Quarterly Spring*, 52: 146-159.

Pruitt, John and Grudin, Jonathan (2003). *Personas: Practice and Theory*. Published in: • Proceeding DUX '03 Proceedings of the 2003 conference on Designing for user experiences ACM New York, NY, USA. Available at: <http://research.microsoft.com/enus/um/people/jgrudin/publications/personas/designchapter.pdf>.

Rappaport, J. (1981) In Praise of Paradox - a Social-Policy of Empowerment over Prevention. In *American Journal of Community Psychology*. 9(1): 1-25.

Rappaport, J. (1987) Terms of empowerment/exemplars of prevention: Toward a theory for community psychology. In *American Journal of Community Psychology*. 15(2): 121-148.

Reimann, Robert (2005). *Personas, Goals, and Emotional Design*. BLOG: Published: November 3, 2005 <http://www.uxmatters.com/mt/archives/2005/11/personas-goals-and-emotional-design.php>.

Rohrer, J.E., et al. (2007) Overall self-rated health as an outcome indicator in primary care. In *Journal of Evaluation in Clinical Practice*, 13(6): 882-888.

Roosli, M., et al. (2010) Systematic review on the health effects of exposure to radiofrequency electromagnetic fields from mobile phone base stations. In *Bulletin - World Health Organization*, 88(12): 887-896.

Roter, D. & Hall, J.A. (2006). *Doctors talking to patients/patients talking to doctors: Improving communication in medical visits*. (2nd ed.) Praeger Publishing, Westport, CT (2006).

Rotter, J.B. (1966) Generalized expectancies for internal versus external control of reinforcement. In *Psychological Monographs: General & Applied*, 80(1): 1-28.

Rubinelli, S., et al. (2006) WHAT ARE WE TO THINK ABOUT DIRECT-TO-CONSUMER ADVERTISING? A CASE-STUDY IN THE FIELD OF MISINTERPRETED ARGUMENTATION. In *Studies in Communication Sciences*, 6: 337-348.

Rubinelli, S., Nakamoto, K. and Schulz, P.J. (2008) The rabbit in the hat: dubious argumentation and the persuasive effects of prescription drug advertising (DTCA). In *Communication and Medicine*, 5(1): 49-58.

Russell-Minda, E., Jutai, J., Speechly, M., Bradley, K., Chudyk, A., Petrella, R. (2009). Health Technologies for Monitoring and Managing Diabetes: A Systematic Review. In *Journal of Diabetes Science and Technology*, 3(6): 1460-1471.

Ryan, R.M. and Deci, E.L. (2000) Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. In *American Psychologist*, 55(1): 68-78.

Samoocha, D., Bruinvels, D.J., Elbers, N.A., Anema, J.R., van der Beek, A. (2010). Effectiveness of Web-based Interventions on Patient Empowerment: A Systematic Review and Metaanalysis. In *Journal of Medical Internet Research*, 12(2), doi: 10.2196/jmir.1286.

Sandman, L. & Munthe, C. (2009). Shared Decision Making, Paternalism and Patient Choice. In *Health Care Analysis*, 18(1): 60-84.

Schneckenberg, D. and Wildt, J. (2006). UNDERSTANDING THE CONCEPT OF ECOMPETENCE FOR ACADEMIC STAFF. In: *The Challenge of eCompetence in Academic Staff Development*, Mac Labhainn, I., McDonald Legg, C., Schneckenberg, D., Wildt, J., Galway: CELT, 2006. Released under Creative Commons licence. Attribution Non-Commercial 2.0. <http://www.ecompetence.info/uploads/media/ch3.pdf>

Schillinger, D., Piette, J., Grumbach, K., Wang, F., Wilson, C., Daher, C., Leong-Grotz, K., et al. (2003). Closing the loop. *Archives of Internal Medicine*, 163, 83-90.

Schulz, A.J., et al. (1995) Empowerment as a Multilevel Construct - Perceived Control at the Individual, Organizational and Community Levels. In *Health Education Research*, 10(3): 309-327.

Schulz, P. and Nakamoto, K. (2011) "Bad" literacy, the internet, and the limits of patient empowerment. in *AAAI Spring Symposium Series: Artificial Intelligence and Health Communication*. Stanford, CA, United States.

Seeman, M. and Anderson, C.S. (1983) Alienation and alcohol: the role of work, mastery, and community in drinking behavior. In *American Sociological Review*. 48(1): 60-77.

Simoni JM, Frick PA, Huang B (2006). A longitudinal evaluation of a social support model of medication adherence among HIV-positive men and women on antiretroviral therapy. In *Health Psychology*, 25:74–81.

Spinhof, L., Calvi, L. (2006) "User and task analysis in a home care environment," presented at the 20th international symposium on human factors in telecommunication, Sofia Antipolis, France, 2006.

Spreitzer, G.M. (1995). Psychological empowerment in the workplace: Dimensions, measurement, and validation. *Academy of Management Journal*, 38(5): 1442-1465.

Steed, L., Cooke, D., Newman, S. (2003). A systematic review of psychosocial outcomes following education, self-management and psychological interventions in diabetes mellitus. In *Patient Education and Counseling*, 51: 5–15.

Strating MM, van Schuur WH, Suurmeijer TP (2006). Contribution of partner support in self-management of rheumatoid arthritis patients. An application of the theory of planned behavior. In *Journal of Behavioral Medicine*, 29:51–60.

Street, R.L, Makoul, G., Arora, N.J. and Epstein, R.M. (2009). How does communication heal? Pathways linking clinician-patient communication to health outcome. In *Patient Education and Counseling*, 74: 295-301.

Suter, P.M. and Ruckstuhl, N. (2006) Obesity during growth in Switzerland: role of early socio-cultural factors favouring sedentary activities. In *International Journal of Obesity (Lond)*. 30 Suppl 4: S4-10.

Thoits PA (1982). Conceptual, methodological, and theoretical problems in studying social support as a buffer against life stress. In *Journal of Health and Social Behavior*, 23, 145–59.

Thomas, K.W. and Velthouse, B.A. (1990) Cognitive elements of empowerment: An 'interpretive' model of intrinsic task motivation. In *Academy of Management Review*, 15(4): 666-681.

Tyremen, S. (2005) The expert patient: outline of UK government paper. In *Medicine, Health Care and Philosophy*, 8(2): 149-51.

van Rongen, E., et al. (2009) Effects of radiofrequency electromagnetic fields on the human nervous system. In *Journal of Toxicology and Environmental Health*, 12(8): 572-97.

Van Velsen, L., Van Gemert-Pijnen, L., Nijland, N., Beaujean, D. Van Steenberghe, J. (2012). Personas: The Linking Pin in Holistic Design for eHealth. *Proceedings: eTELEMED 2012: The Fourth International Conference on eHealth, Telemedicine, and Social Medicine*. Available at: <http://www.lexvanvelsen.nl/vanvelsenetal2012.pdf>. [2012-04-10].

Verhoeven, F., Tanja-Dijkstra, K., Nijland, N., Eysenbach, G., van Gemert-Pijnen, L. (2010). Asynchronous and Synchronous Teleconsultation for Diabetes Care: A Systematic Literature Review. In *Journal of Diabetes Science and Technology*, 4(3): 666-684.

Vernier, P. (ed.) (2009). *EuroMeduc. Media Literacy in Europe. Controversies, Challenges and Perspectives*. Brussel. Available at: http://www.euromeduc.eu/IMG/pdf/Euromeduc_ENG.pdf.

Villalba, E. et al. (2007) "User interaction design for a wearable and IT based heart failure system," presented at the 12th international conference on human-computer interaction, Beijing, China.

Wall, T.D., Cordery, J.L. and Clegg, C.W. (2002) Empowerment, performance, and operational uncertainty: A theoretical integration. In *Applied Psychology: An International Review*, 51(1): 146-169.

Wallerstein, N. (2006) What is the evidence on effectiveness of empowerment to improve health? WHO Regional Office for Europe (Health Evidence Network report) Copenhagen.

Wartenberg, D. (2001) Residential EMF exposure and childhood leukemia: meta-analysis and population attributable risk. In *Bioelectromagnetics*. Suppl 5: 86-104.

Wegener, D. T., Kerr, N. L., Fleming, M. A., & Petty, R. E. (2000). Flexible corrections of juror judgments: Implications for jury instructions. In *Psychology, Public Policy, and Law*, 6: 629-654.

Wiedemann, P.M. and H. Schutz, (2005) The precautionary principle and risk perception: experimental studies in the EMF area. In *Environmental Health Perspectives*, 113(4): 402-5.

Zickuhr, Kathryn and Smith, Aaron (2012). Digital differences. Pew Internet Research. <http://www.pewinternet.org/topics/Digital-Divide.aspx?typeFilter=5>

Zimmerman, M.A. and Rappaport, J. (1988) Citizen participation, perceived control, and psychological empowerment. In *American Journal of Community Psychology*, 16(5): 725-50.

Sources published by organizations

European Commission (2011). Digital Scoreboard. http://ec.europa.eu/information_society/digital-agenda/scoreboard/index_en.htm.

European Parliament (2006). RECOMMENDATION OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 18 December 2006 on key competences for lifelong learning (2006/962/EC). Official Journal of the European Union. <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2006:394:0010:0018:en:PDF>

European Commission (2011). Digital Scoreboard.
http://ec.europa.eu/information_society/digital-agenda/scoreboard/index_en.htm.

Health Level Seven International (n.d.). Retrieved June 18, 2012 from Health Level Seven International: <http://www.hl7.org/>

IHE (2011). Retrieved June 18, 2012 from IHE: <http://www.ihe.net/>

OPEN SOCIETY FOUNDATION (2011) Schröder (lead reporter); Uwe Hasebrink, Stephan Dreyer, Wiebke Loosen, and Felix Schröter (2011). Mapping Digital Media: Germany A REPORT BY THE http://www.soros.org/initiatives/media/articles_publications/publications/mapping-digital-media-germany-20111028/mapping-digital-media-germany-20111028.pdf

Robert Wood Johnson Foundation, <http://www.rwjf.org/pr/product.jsp?id=51248>

Observations of Daily Living (ODLs) <http://www.scribd.com/doc/14427729/Observations-of-Daily-Living-primer-from-Robert-Wood-Johnson-Foundation45> Observations of Daily Living
http://en.wikipedia.org/wiki/Observations_of_Daily_Living

World Health Organization, Adherence to Long-term Therapies: Evidence for Action, ed. E. Sabate 2003, Geneva, Switzerland: World Health Organization.

World Health Organization. Definition of Health. [cited 2011 Oct. 7]; Available from: <https://apps.who.int/aboutwho/en/definition.html>.

Table of Graphs

Graph 1: Prevalences of Diabetes and Impaired Glucos Tolerance in Turkey	30
Graph 2: Distribution of Top 20 Diseases Comprising Years of Life Lost (YLL/1000 persons) by Gender	30
Graph 3: Burden of non-fatal disease by main disease groups (YLD).....	31
Graph 4: Diabetes-Related Deaths Predicted for Years 2010, 2020 and 2030 in Men and Women.....	31
Graph 5: % households having access, via one of its members, to a computer.....	38
Graph 6: % households with internet access	39
Graph 7: % of households with access to the internet at home.....	39
Graph 8: % of households having a broadband connection	40
Graph 9: % of population accessing the internet through a mobile phone via UMTS (3G) Year 2011	41
Graph 10: % of households with access to the internet at home and % of population accessing the internet through a mobile phone via UMTS (3G) Year 2011	41
Graph 11: % of population who are regular internet users (at least once a weak).....	42
Graph 12: % of population who are frequent internet users (every day or almost every day).....	42
Graph 13: % individuals with internet skills (High, Medium and Low), 2010.....	43
Graph 14: % individuals with various internet skills, EU27.....	44
Graph 15: % of individuals with medium or high internet skills (3 or more of 6 internet activities)	44
Graph 16: % of internet users doing an online course (in any subject)	45
Graph 17: % of internet users seeking online information about health	46
Graph 18: Computer Use in Consultation with the Patient in Germany.....	48
Graph 19: % of disadvantaged people who are regular internet users (at least once a week)	55

Table of Figures

Figure 1: EMPOWER Management Pathways	9
Figure 2: Organogram of the Diabetes Control Program of Turkey	32
Figure 3: Miller Pyramid.....	34
Figure 4: Relation of the different concepts of digital competence, digital literacy, eSkills and media literacy.	36
Figure 5: Health Literacy and Psychological Empowerment	60
Figure 6: Direct and indirect pathways from communication to health outcomes	74
Figure 7: Integrated problem-solving model of chronic illness self-management	75
Figure 8: Self-Management Model with 5 A's	79
Figure 9: Using personas in continuous user requirements analysis and evaluation.....	93
Figure 10: Sketch of a possible set of personas (SRFG/vhp 2012).....	96

Table of Tables

Table 1: Diabetes Education Content	17
Table 2: DMP in Germany	27
Table 3: Electronic Patient Data Storage in Germany: Storage of Different Types of Individual Patient Data by GPs storing electronic medical patient data.....	47
Table 4: % of internet users in different age groups 2001, 2005 and 2010	49
Table 5: Social network sites and popular services ('know of' and 'regular use'). Gender differences in knowing about and using social media in Denmark. Gender Distribution. N=1710	50
Table 6: Health topics searched, differentiated by gender. N=3001	52
Table 7: Focus Group Results - Psychological Empowerment – Arrows indicate importance given to each of the topics in light of the construct used to analyze it.	65

Table 8: Focus Group Results – Health Literacy & Sources/Influencers – Arrows indicate importance given to each of the topics in light of the construct used to analyze it.....	69
Table 9: Types of doctor patient relationships	72
Table 10: Patients` needs relevant to empower.....	90