Support of Patient Empowerment by an intelligent self-management pathway for patients

Pre-Study: Empowering Patients for Self-Management

SRA Europe Conference 2012 in Zürich, 18 - 20 June

19.06.2012

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1. Rationale

2. EMPOWER
   2.1 Objectives
   2.2 Work Plan

3. Frameworks
   3.1 The EMPOWER Framework
   3.2 Health Literacy and Psychological Empowerment

4. Focus Group Study

5. Need Analysis
1. Rationale

Diabetes Mellitus

- is one of the most common non-communicable diseases worldwide
- 4th or 5th leading cause of death in most high-income countries
- caused 4.6 millions deaths in 2011
- 366 million people have diabetes (2011)
- By 2030 the number will have reached 552 million
2. EMPOWER
Support of Patient Empowerment by an intelligent self-management pathway for patients

Project Identifier: FP7-ICT-2011-288209
Project Type: Small or medium-scale focused research project (STREP)

Project Budget: 4,28 Million Euro
EC Contribution: 3,02 Million Euro
Funded By: EU 7th Framework Programme, Theme ICT

Start Date: 2012-02-01
End Date: 2015-01-31
Duration: 36 months

Partners: 7 (2 research institutes, 1 university, 3 companies, 1 public body)
Nations involved: Austria, Germany, Greece, Switzerland, Turkey
Website: http://www.empower-fp7.eu/
2. EMPOWER
2.1 Objectives

What do patients need to cope better with their chronic diseases as part of their daily life?

Objectives

1. Fostering self-management with adaptive and secure patient pathways
2. Supporting behavior changes with personalized action plans
3. Collecting patterns of daily living
4. Semantic interoperability with existing personal health applications
2. EMPOWER

2.2 Work Plan

- **Objective 1 - fostering self-management with adaptive and secure patient pathways**
  - Task 1.1 Pre-Study - Empowering Patients for Self-management
  - Task 1.2 Knowledge Models for Diabetes Self-Management Pathways and Components
  - Task 1.3 Knowledge-based Pathway Engine
  - Task 1.4 Trends and Visualisation of Self-management Services
  - Task 1.5 Patient Consent Management and Security
  - Task 1.6 Learning Paths for Self-management Services
  - Task 1.7 Integration into an accompanying PHRS
  - Task 1.8 Quality Criteria for Self-management

- **Objective 2 - supporting behaviour changes with personalised action plans**
  - Task 2.1 Pre-Study - Empowering Patients for Self-management
  - Task 2.2 Knowledge Models for Diabetes Self-Management Pathways and Components
  - Task 2.3 Knowledge-based Pathway Engine
  - Task 2.4 Trends and Visualisation of Self-management Services
  - Task 2.5 Patient Consent Management and Security
  - Task 2.6 Learning Paths for Self-management Services
  - Task 2.7 Integration into an accompanying PHRS
  - Task 2.8 Quality Criteria for Self-management

- **Objective 3 - collecting patterns of daily living**
  - Task 3.1 Pre-Study - Empowering Patients for Self-management
  - Task 3.2 Knowledge Models for Diabetes Self-Management Pathways and Components
  - Task 3.3 Knowledge-based Pathway Engine
  - Task 3.4 Trends and Visualisation of Self-management Services
  - Task 3.5 Patient Consent Management and Security
  - Task 3.6 Learning Paths for Self-management Services
  - Task 3.7 Integration into an accompanying PHRS
  - Task 3.8 Quality Criteria for Self-management

- **Objective 4 - semantic interoperability with existing Personal Health Applications**
  - Task 4.1 Pre-Study - Empowering Patients for Self-management
  - Task 4.2 Knowledge Models for Diabetes Self-Management Pathways and Components
  - Task 4.3 Knowledge-based Pathway Engine
  - Task 4.4 Trends and Visualisation of Self-management Services
  - Task 4.5 Patient Consent Management and Security
  - Task 4.6 Learning Paths for Self-management Services
  - Task 4.7 Integration into an accompanying PHRS
  - Task 4.8 Quality Criteria for Self-management
2. EMPOWER
2.2 Work Plan

Objective 1 - fostering self-management with adaptive and secure patient pathways

Task 1.4 Ethical Management
Task 2.1 Pre-Study - Empowering Patients for Self-management
Task 2.4 Information and Education Material for Patients
Task 3.4 Knowledge Models for Diabetes Self-Management Pathways and Components
Task 4.1 Knowledge-based Pathway Engine
Task 4.2 Trends and Visualisation of Self-management Services
Task 4.3 Patient Consent Management and Security
Task 5.1 Learning Paths for Self-management Services
Task 5.4 Integration into an accompanying PHRS
Task 7.1 Quality Criteria for Self-management
3. Framework
3.1. The EMPOWER Framework
3. Framework
3.2 Health Literacy and Psychological Empowerment

Health Literacy
- Functional literacy
- Declarative knowledge
- Procedural knowledge
- Judgement skills

Psychological empowerment
- Meaningfulness
- Competence
- Impact
- Self-determination

Sources/Influencers
- Lay sources
- Mass media
- Government

Health Care Professionals

Decisions

Effects
- Constructive or destructive activities
- Health status
- Quality of life

Health Literacy and Psychological Empowerment Model (Schulz and Nakamoto, 2012)
4. Focus Group Study

Three focus groups

**Two with diabetes type 2 patients**
1. FG: 8 participants (6 male, 2 female)
2. FG: 10 participants (6 female, 4 male)
   Age: from 60 to 79

**One with doctors** 7 doctors (including 6 GPs and 1 ophthalmologists)

**Duration:** Each group lasted 90 Minutes

**Location:** GOIN (Gesundheitsorganisation Ingolstadt), Germany
**Dates:** 27./28.03.2012
4. Focus Group
Results in light of proposed theoretical framework

<table>
<thead>
<tr>
<th>Psychological Empowerment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Meaningfulness</strong></td>
</tr>
<tr>
<td>Nutrition</td>
</tr>
<tr>
<td><em>To follow dietary guidelines is meaningful to me.</em></td>
</tr>
<tr>
<td>Hypoglycemia</td>
</tr>
<tr>
<td><em>In order to guarantee immediate quality-of-life, I have to avoid hypoglycemia.</em></td>
</tr>
<tr>
<td>Physical Activity</td>
</tr>
<tr>
<td><em>I wish I could see how physical activity affects me in the long run.</em></td>
</tr>
</tbody>
</table>
## 4. Focus Group

*Results in light of proposed theoretical framework*

<table>
<thead>
<tr>
<th>Psychological Empowerment</th>
<th>Impact</th>
<th>Self-Determination</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Monitoring Blood Glucose</td>
<td></td>
</tr>
<tr>
<td>Women: “Keeping track has an impact.” Vs. “Men: “Keeping track does not make a difference”</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Physical Activity</td>
<td></td>
</tr>
<tr>
<td>Physical activity is a means to help me to manage my weight but how could I better manage it?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Quality of Life</td>
<td></td>
</tr>
</tbody>
</table>

“This (measurement result) can’t be right! What did I do wrong?”
(Female Participant – FG 1)
### 4. Focus Group

*Results in light of proposed theoretical framework*

<table>
<thead>
<tr>
<th>Health Literacy &amp; Sources/Influencers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Declarative Knowledge</strong></td>
</tr>
<tr>
<td>Nutrition</td>
</tr>
<tr>
<td><em>What is the right choice of food?</em></td>
</tr>
<tr>
<td>Monitoring Blood Glucose</td>
</tr>
<tr>
<td><em>I understand the meaning of the results.</em></td>
</tr>
</tbody>
</table>

“*I always hear measuring but no one tells you how to measure and when to measure.*”

(Male Participant – FG 1)
### 4. Focus Group

*Results in light of proposed theoretical framework*

<table>
<thead>
<tr>
<th>Health Literacy &amp; Sources/Influencers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Judgment Skills</strong></td>
</tr>
<tr>
<td>Listening to oneself</td>
</tr>
</tbody>
</table>

*With time, I have learned what is best for me.*

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

(Female Participant - FG 2)
5. Need Analysis

*Sense-Making in diabetes care*

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

Thank you for your attention.

SRA Europe Conference 2012 in Zürich, 19.06.2012

Presenter: Sarah Mantwill
## 5. Need Analysis

*Behavior change in diabetes care*

<table>
<thead>
<tr>
<th>Need</th>
<th>Health Literacy and Psychological Empowerment Model</th>
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<th>Keywords</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding behaviour changes</td>
<td>Meaningfulness</td>
<td>Recomm. and Goals</td>
<td>Information Material</td>
</tr>
<tr>
<td></td>
<td>Impact</td>
<td>Information Material</td>
<td>Information Interaction</td>
</tr>
<tr>
<td>Repetition</td>
<td>Declarative Knowledge</td>
<td>Reminder</td>
<td>Information Active Involvement</td>
</tr>
<tr>
<td></td>
<td>Procedural Knowledge</td>
<td>Action Plan</td>
<td></td>
</tr>
<tr>
<td>Reminding</td>
<td>Declarative Knowledge</td>
<td>Reminders</td>
<td>Information Reminder</td>
</tr>
<tr>
<td></td>
<td>Procedural Knowledge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personalized Behaviour Changes</td>
<td>Meaningfulness</td>
<td>Recommendations and Goals</td>
<td>Personalization</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Personalized Personalized</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Information Information</td>
</tr>
</tbody>
</table>
## 5. Need Analysis

*Social interaction in diabetes care*

<table>
<thead>
<tr>
<th>Need</th>
<th>Health Literacy and Psychological Empowerment Model</th>
<th>EMPOWER</th>
<th>Keywords</th>
</tr>
</thead>
<tbody>
<tr>
<td>The partner, my support.</td>
<td>Sources/Influencers</td>
<td>Patient Consent Information Material</td>
<td>Interaction</td>
</tr>
<tr>
<td>The doctor, my support.</td>
<td>Sources/Influencers Declarative Knowledge</td>
<td>Health Actor Services Personalized Recommendations</td>
<td>Interaction</td>
</tr>
<tr>
<td>Telling friends.</td>
<td>Self-Determination</td>
<td>Online Community Self-help group</td>
<td>Facebook, Twitter, etc.</td>
</tr>
<tr>
<td>Share Experiences</td>
<td>Sources/Influencers</td>
<td>Self-help group Online Community Information Material</td>
<td>Connect with other diabetes patients.</td>
</tr>
</tbody>
</table>
## 5. Need Analysis

*Monitoring in diabetes care*

<table>
<thead>
<tr>
<th>Need</th>
<th>Health Literacy and Psychological Empowerment Model</th>
<th>EMPOWER Patient Empowerment Framework</th>
<th>Keywords</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding monitoring</td>
<td>Meaningfulness Impact</td>
<td>Recommendations and Goals</td>
<td>Monitoring</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Action Plan</td>
<td>Prompt Feedback</td>
</tr>
<tr>
<td></td>
<td></td>
<td>ODL</td>
<td>Personalized information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Evaluation</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Information</td>
<td></td>
</tr>
<tr>
<td>Affordable and easy to use devices</td>
<td>Self-Determination Declarative Knowledge</td>
<td>Information</td>
<td>Product information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Online Community</td>
<td></td>
</tr>
</tbody>
</table>
6. Example: Recommendation

**Recommendation: *Tell them why.***

Patients want to make sense out of what they are seeing. Make the act of e.g. measuring blood glucose meaningful to them. Provide patients with information on why it is necessary to monitor blood glucose levels. 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?”
6. Next steps

Leading Partner
Exploitation and Dissemination Plan (Month, 12, 24, 36)
Quality Criteria for Self-Mangement (Month 24)
Development of Information material for Patients (Month 26)

Involved Partners
Learning Paths for Self-Management Services