



EMPOWER – Support of patient empowerment by an intelligent self-management pathway for patients

Best Practise Beispiele
eHealth und Telemedizin – Herausforderungen
und Potenziale

July 1, 2014

Robert „Bob“ Mulrenin, Salzburg Research
robert.mulrenin@salzburgresearch.at
<http://www.empower-fp7.eu>



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

Background – Health Themes

- | Salzburg Research
 - | IOT - Internet of Things and eHealth
 - | Software development, eHealth and IOT R&D
- | Tufts New England Medical Center (Boston, MA)
 - | Endocrinology and Molecular genetics Department (Researcher - Diabetes)
 - | Diabetes – Basic research using alternative animal model: Zebrafish model
 - | Gene therapy
 - | Clinical Research Department (System manager)
- | Center for Cancer Researcher at MIT (Cambridge,MA)

EMPOWER – Support of patient empowerment by a self-management pathway (SMP)



- | **Call & Work Programm:** FP7-ICT-2011-7,
Objective ICT-2011.5.3a Patient Guidance Services (PGS),
Safety and Healthcare record information reuse (STREP)

- | **Duration:** 36 months, February 2012 – January 2015

- | **Partners:**
 - | Salzburg Research Forschungsgesellschaft m.b.H. (Austria) - Coordinator
 - | Helmholtz Zentrum München (Germany)
 - | GO IN Integrationsmanagement- und Beteiligungs-GmbH (Germany)
 - | Università della Svizzera italiana (Switzerland)
 - | Software Research and Development and Consultancy Ltd. (Turkey)
 - | Intracom Telecom (Greece)
 - | Ministry of Health (Turkey)

- | **2 Pilot Applications**
 - | 1 pilot in Ingolstadt, Germany with a network of GPs and diabetes specialists
 - | 1 pilot in Ankara, Turkey with family doctors and clinicians

Keep in this mind for the discussion panel

- | Telemedicine and Patient Empowerment – benefits, to whom?
- | Managing chronic diseases - supported by appropriate software tools
 - | Telemonitoring and patient self-management
 - | Patient shares data securely with particular healthcare providers
 - | Periodic consultations between patient and healthcare provider(s)
- | Cross border health care

The need for Patient Empowerment



- | Up to the 20th century, the primary cause of illness were acute diseases and patients were mainly inexperienced and passive recipients of medical care.
- | **Chronic diseases** are now the biggest cause of death and disability worldwide and account for an estimated 86% of deaths and 77% of the disease burden in the European Region [ENOPE, 2012]
 - | For example: diabetes [IDF]
 - | **382 million** people have diabetes in 2013; by 2035 this will have risen to **592 million**
 - | Diabetes caused **5.1 million deaths** in 2013
 - | The number of people with diabetes is increasing in every country and it is estimated that **the worldwide diabetes prevalence will rise from 8.3% in 2013 to 10.1 in 2035**
 - | Diabetes caused at least **USD 548 billion dollars** in healthcare expenditures in 2013; **11% of total healthcare expenditures** in adults (20-79 years)
- ⇒ We must realise that each of us is responsible for our health and can manage it.
- ⇒ Healthcare can be delivered more efficiently and with lower costs if patients are full partners in the process – towards a patient-centric care – active rather than passive.

What is Patient Empowerment?



- | “a philosophy of health care that proceeds from the perspective that optimal outcomes of health care interventions are achieved when **patients become active participants in the health care process.**” [Monteagudo & Moreno, 2007]
- | An empowered activated patient can be described by several characteristics [ENOPE, 2012]:
 - | She understands her health problems(s) and the effects on her body.
 - | She is able to participate in decision-making with her healthcare professionals.
 - | She actively seeks out, evaluates and makes use of health related information.
 - | She is able to make informed choices about treatment.
 - | She is able to challenge and ask questions of her healthcare providers.
 - | She takes responsibility for her health and actively seeks care when necessary.
 - | She understands the need to make necessary changes to her lifestyle for managing health conditions.
- | Focus of the patient
 - => information & decision making, self-control & self-management, behaviour changes



What does Self-Management mean?

- | **Self-management is what people do to manage their diabetes or other chronic condition and the effects on their physical health, daily activities, social relationships and emotions.** [Diabetes Initiative, 2009]
- | Patient must:
 - | Deal with illness, such as medication, physical activity, doctor visits, changing diet
 - | Continue normal daily activities, such as housework, employment, social life, etc.
 - | Manage their emotional changes about managing their chronic condition, such as stress, uncertainty about the future, worry, anxiety, resentment, changed goals and expectations, depression, etc.
- | Self-management is seen as a **key competence** for Patient Empowerment and emphasises that persons with chronic diseases has the central role in managing their health.
- | All people with chronic conditions self-manage to some degree,
 - | although **the ability and resources vary** across their lifespan
 - | and at **different stages** of the condition.
 - | Patients provide 98% of their own diabetes care. [Anderson & Funnell, 2010]

Patient Empowerment as the driving vision for EMPOWER

- | Patient empowerment is seen as an essential aspect of patient-centric care and is identified as a main element of change for improved quality and safety in healthcare.
- | **Patient Empowerment engages patients to a greater extent in their healthcare process** so that disease management becomes an integrated part of their daily life
- | There are different ways to strengthen Patient Empowerment
 - | Support patient's decision-making processes,
 - | Strengthen health literacy,
 - | Support self-management,
 - | Foster patient-physician relationship and communication

©_Fotolia_YuriArcurs

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



Objectives in EMPOWER



(1) Foster self-management with adaptive and secure patient pathways

- | Utilize the Stanford model for self-management of chronic diseases (Patients follow the Self-management pathway)
- | Enable Physicians to generate treatment goals based on diabetes guidelines and EHR data
- | Enable Physician to share itemized recommendations with the patient electronically.
- | Provide Disease-relevant information material and hints (EMPOWER Tips)
- | Support Patient consent management– the patient should be enabled to share PHR data with particular healthcare providers

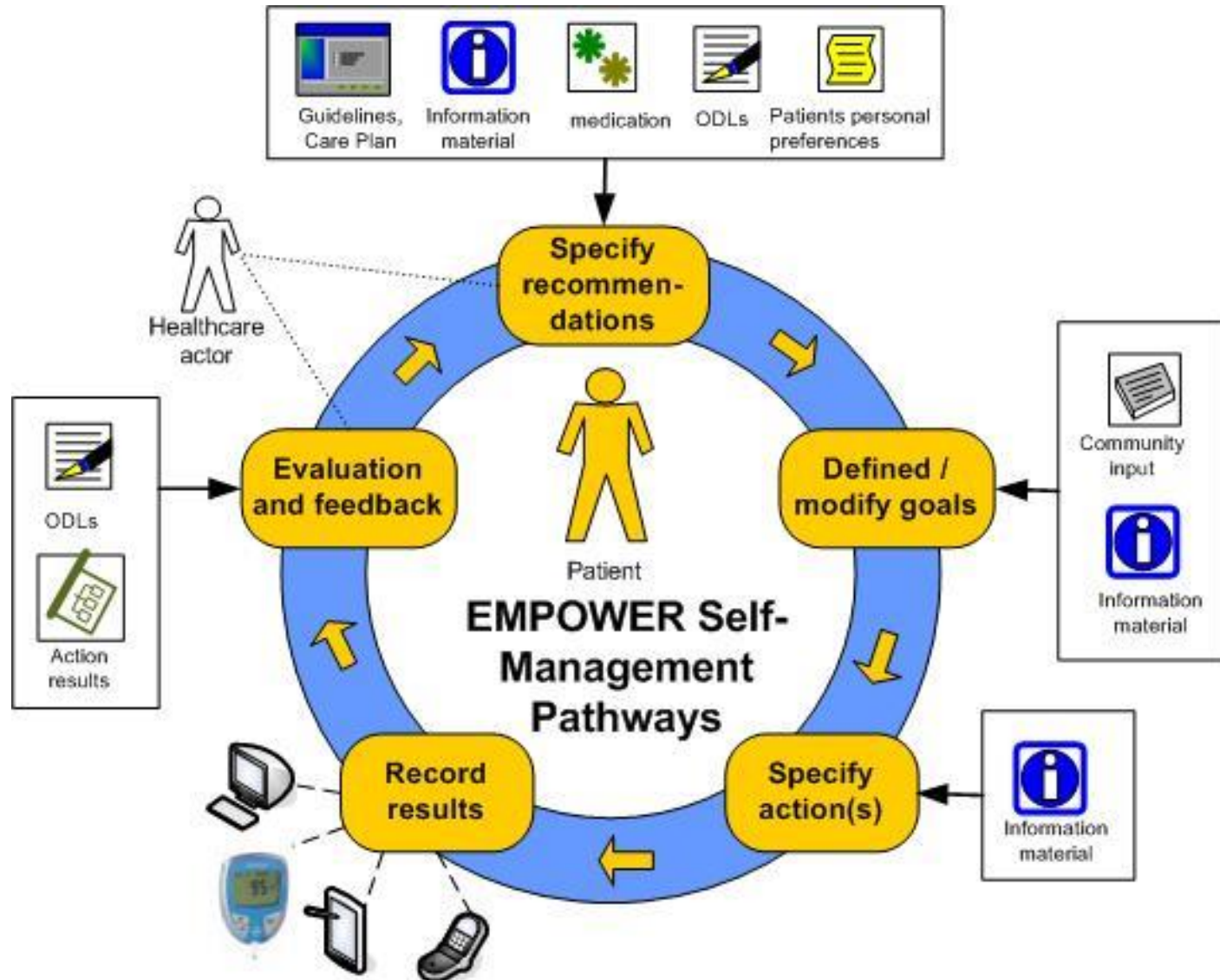
(2) Support behaviour changes with personalised action plans

- | Enable the patient to use the physician's recommendations to create smaller achievable goals
- | Self-management goals are realised by short-term activities planned by the patient in a calendar
- | Provide feedback to the patient to motivate and help the patient towards their goals. Patient use tools to visualize their performance (charts, tables) and to perform WEEKLY reviews of their progress.

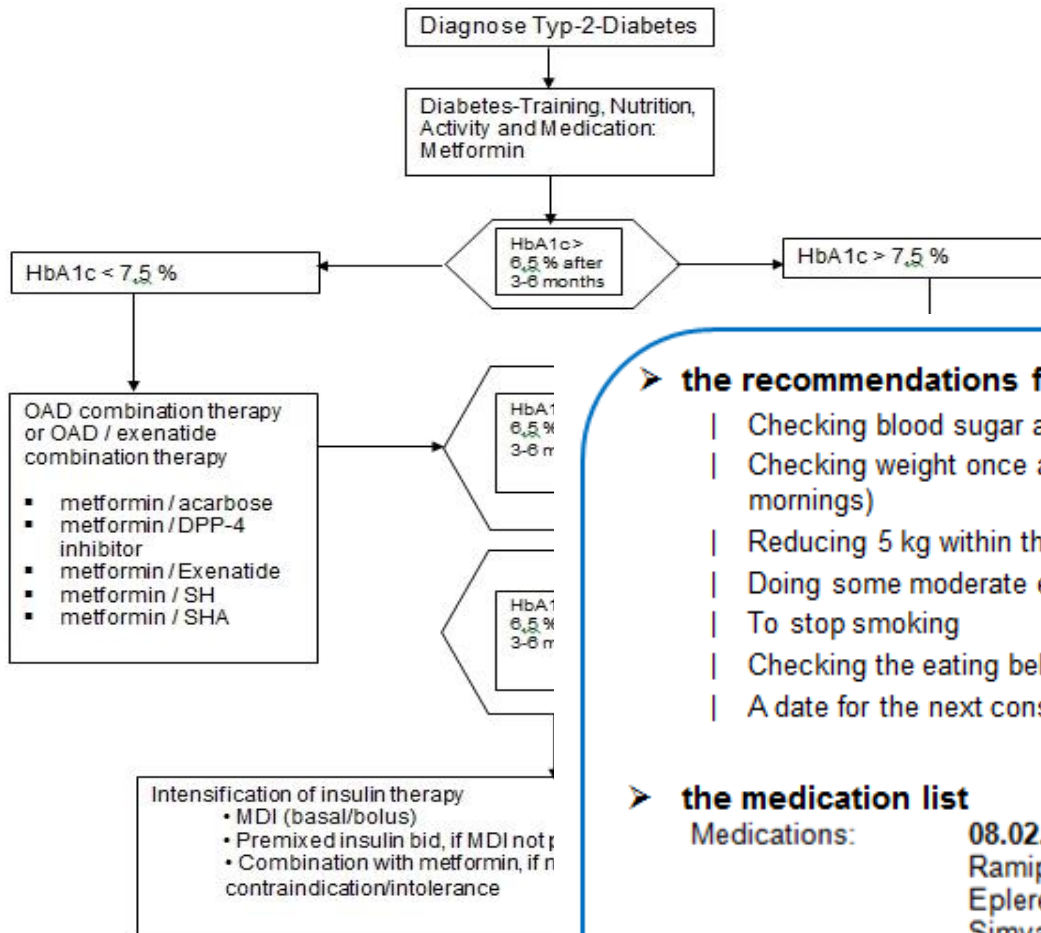
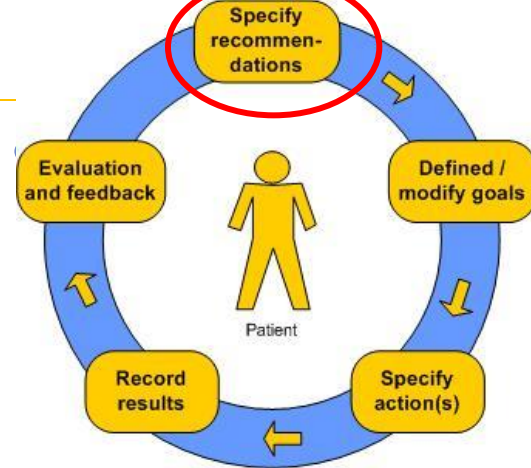
(3) Facilitate self-control by collecting patterns of daily living

- | Provide services to collect Observations of Daily Living (ODLs) about vital, physical and mental parameters and about physical and lifestyle activities.
- | Enable ODL collection via web or mobile apps and collect EHR data from the doctor.

EMPOWER approach - supporting (self-)management of diabetes patients



EMPOWER - Physician specifies treatment goals self-management recommendations



➤ the recommendations for self-management goals

- | Checking blood sugar and blood pressure daily
- | Checking weight once a week (preferably always at the same time, e.g. in the mornings)
- | Reducing 5 kg within the next three months
- | Doing some moderate exercises on a regular basis
- | To stop smoking
- | Checking the eating behaviour and changing it to a diabetes-compliant nutrition.
- | A date for the next consultation in 3 months

➤ the medication list

Medications:

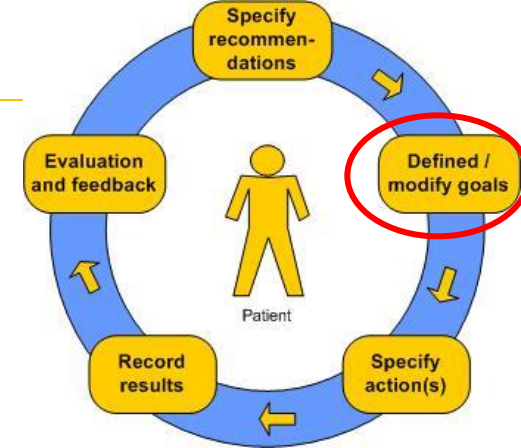
08.02.2012

Ramipril 2.5 mg 1 x 1, at morning
 Eplerenon 25 mg 1 x 1, at morning
 Simvastatin 40 mg 1 x 1, at evening
 ASS 100 1 x 1, at lunchtime
 Carvedilol 12.5 mg 1 x 1, at morning
 Metformin 500 : 1 x 500 mg at night, 1 week 2 x 500 mg at night, after 7 days 2 x 1000 mg

Aspects supporting goal creation by patients and self motivation (Milios, 2011)

- **Start with the right attitude** – be mindful, pay attention what you are doing when you are doing it
 - ⇒ Become aware of your unhealthy habits, e.g. with the help of a diary
- **Set realistic goals and break your goals into smaller steps** – it is more motivating to set smaller goals/actions and achieve them than to set unrealistic goals and fall short
 - ⇒ Hints and supported messages for guiding through the goal setting process
- **Use small successes to get to larger ones** – success breeds more success
 - ⇒ Report, graphs and trends can give continuous positive feedback
- **Focus on what you want** – instead of focusing on what you don't want
- **Reinforce the habit of discipline** – discipline are the key to habits, because they lead to results
 - ⇒ Becoming an active self-manager by Weekly Planning of actions (Lorig et al, 2006)
 - ⇒ Reminders for ODLs or weekly planning
- **Remain flexible** – if you can't reach a goal focus on which part of the goal you can achieve
 - ⇒ Have a look at goal and recommendations (the purpose behind)
- **Reward and reinforce** – reward your hard work and discipline and be pride in your positive results

EMPOWER - Define goals



Please specify your personal self-management goals:

1. Select Recommendations 2. My Goal

Tips

At the beginning, select a treatment goal you can easily start with.
You can select none, or one or more treatment goals.

Choose a treatment goal for specifying your own, more detailed self-management goals

My recommendations for self-management from

<input type="checkbox"/> Date	Care Provider	Recommendation
<input type="checkbox"/> Wed Feb 08 09:36:00 CET 2012	Hans Schmidt	Take the medication
<input checked="" type="checkbox"/> Wed Feb 08 09:36:00 CET 2012	Hans Schmidt	Measure and record blood sugar
<input type="checkbox"/> Wed Feb 08 09:36:00 CET 2012	Hans Schmidt	Check your weight
<input type="checkbox"/> Wed Feb 08 09:36:00 CET 2012	Hans Schmidt	Change your exercise routine
<input type="checkbox"/> Wed Feb 08 09:36:00 CET 2012	Hans Schmidt	Do some sports

Next Step →

Please specify your personal self-management goals:

1. Select Recommendations 2. My Goal

Tips

If it is difficult for you make goals, experiment with strategies that might help you.
You might share your goals with family or friends, health professionals, or use the Internet.
You might divide your goals into smaller goals that are more achievable for you.

Specify a goal Blood sugar

Goal Description Get regular with measuring my blood sugar before October

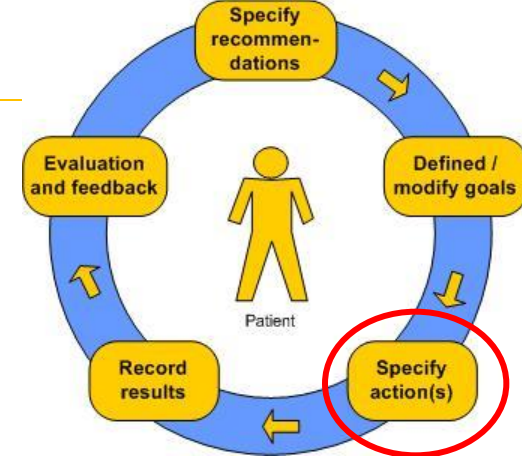
Describe any rewards or motivations that might help you achieve your goal:
Make a city-trip to Budapest for Christmas!

Comments

← Previous Step

Save Goal

EMPOWER – specify actions on a weekly basis



1. Activity

2. Associate Goals

3. Plan it

4. Save

Tips

Make a specific plan about w

Ask yourself:

Exactly what I'm going to

Name of the activity

Select an activity category

Please describe your activity

Blood sugar

1. Activity

2. Associate Goals

3. Plan it

4. Save

My activity:

For specifying activities you might find it helpful to k

Which personal goals are relevant to your activity?

☐ Date

My Goals

☐

Half-Marathon

☒

Blood sugar

← Previous Step

Next Step →

Blood sugar

1. Activity

2. Associate Goals

3. Plan it

4. Save

My activity:

Reminder

today

<

>

Jan 27 — Feb 2 2014

Current Schedule:

Mo Tu We Th Fr 08:30 - 09:00

Mo Tu We Th Fr 17:00 - 17:30

Weekdays:



Mo Tu We Th Fr Sa Su

Begin: 17:00

End: 17:30

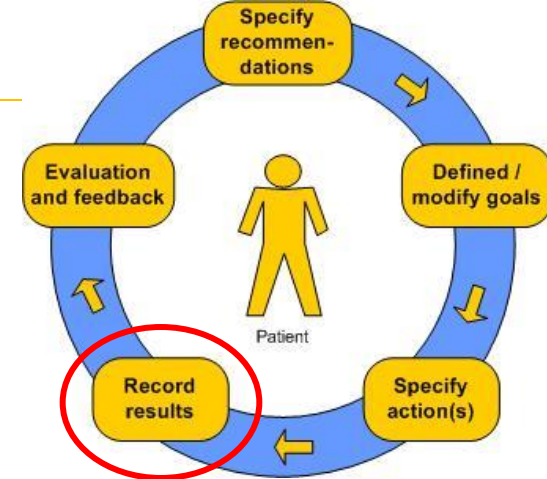
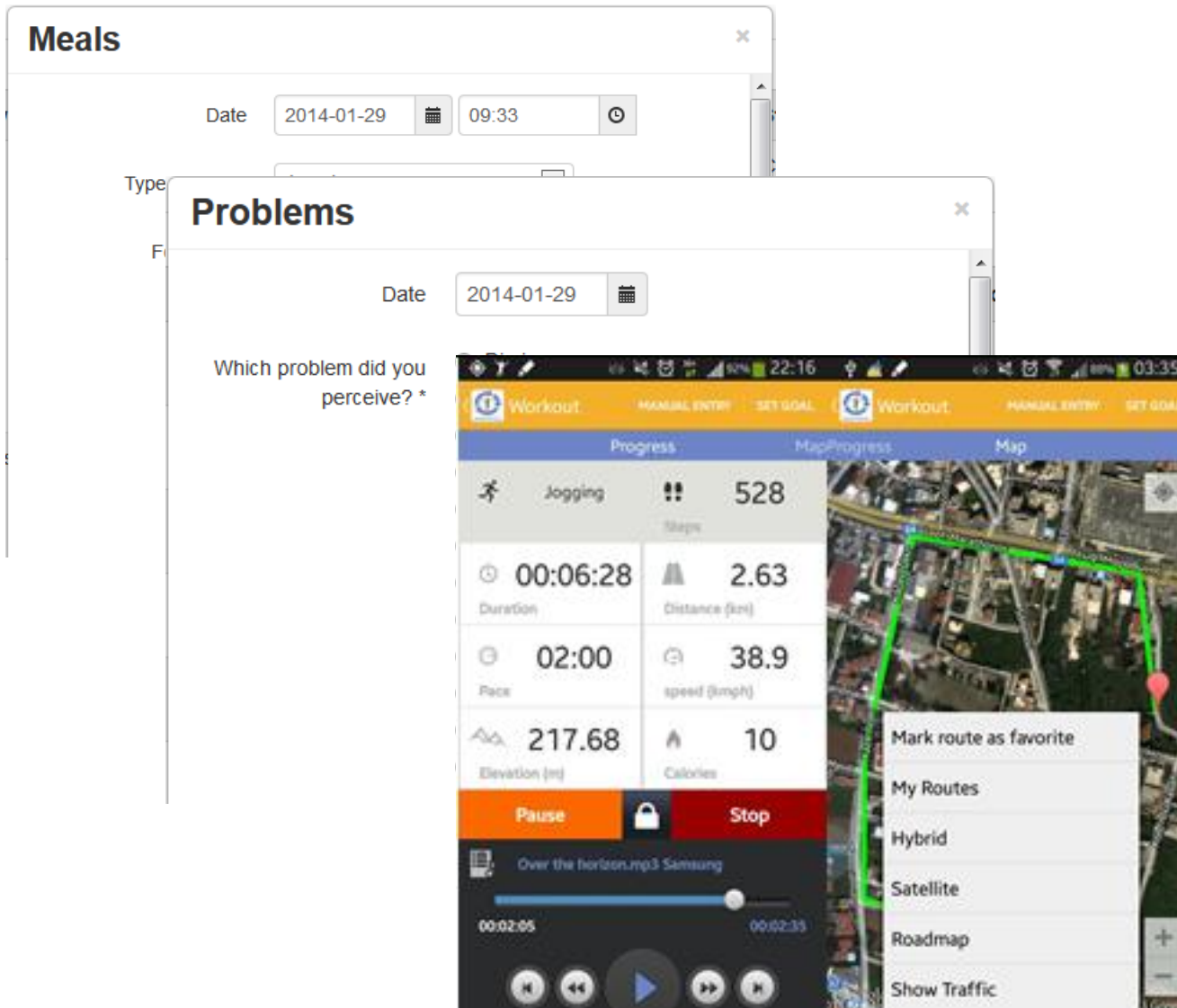
Carry on until:

Plan activity multi-time slots per day (unlike calendar apps)



my BP
3/13

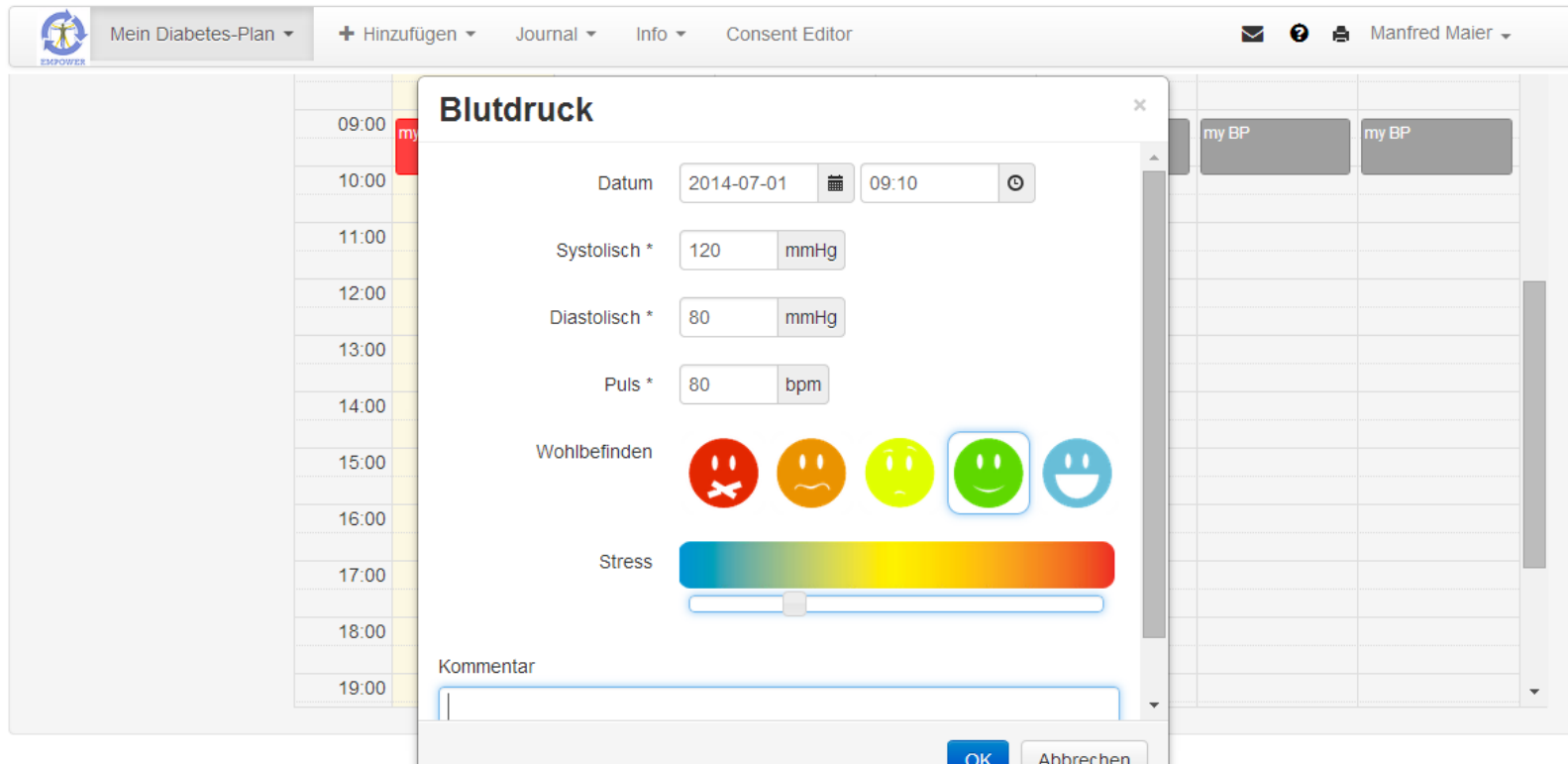
	Mo, Jun. 30	Di, Jul. 01	Mi, Jul. 02	Do, Jul. 03	Fr, Jul. 04	Sa, Jul. 05	So, Jul. 06
Ganztägig							
09:00	my BP	my BP	my BP	my BP	my BP	my BP	my BP
10:00							
11:00	my BP	my BP		my BP			
12:00							
13:00	my BP		my BP		my BP		
14:00							

EMPOWER – recording patient observations

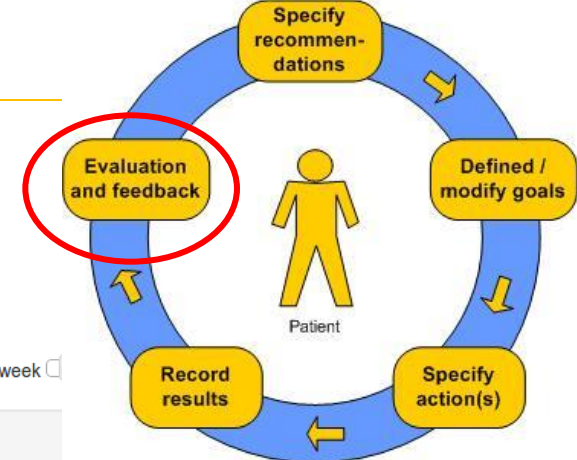


- | Blood Glucose
- | Blood Pressure
- | Body Weight
- | Meals
- | Physical Activities
- | Medication
- | Mood
- | Problems
- | Sleep
- | Stress

Alternative ways to enter observations manually. Is manual data entry better than automated? Build awareness....

The screenshot shows the EMPOWER software interface. At the top, there is a navigation bar with the EMPOWER logo, a dropdown menu "Mein Diabetes-Plan", and buttons for "+ Hinzufügen", "Journal", "Info", and "Consent Editor". On the right side of the navigation bar, there are icons for email, help, and a printer, followed by the user name "Manfred Maier". The main area of the interface is divided into three sections. On the left, there is a vertical timeline with time slots from 09:00 to 19:00. In the center, a modal window titled "Blutdruck" (Blood Pressure) is open. This window contains fields for "Datum" (Date) set to "2014-07-01" and "09:10", "Systolisch *" (Systolic) set to "120 mmHg", "Diastolisch *" (Diastolic) set to "80 mmHg", and "Puls *" (Pulse) set to "80 bpm". Below these fields, there are five smiley face icons representing different levels of well-being, with the green one (happy) selected. Below the smiley faces is a "Stress" slider with a color gradient from blue to red, currently positioned in the middle. At the bottom of the modal window is a "Kommentar" (Comment) text area and two buttons: "OK" and "Abbrechen" (Cancel). On the right side of the main interface, there is a table with two columns, each labeled "my BP".

EMPOWER – evaluation & feedback



Review Wed, Jan 22 - Tue, Jan 28, 2014

1 week

1-Check last week 2-Check Diaries 3-Activities Feedback 4-Charts 5-Goals Feedback 6-Update Action Plan for next week

Action Plan - Weekly Review, Step 1. Check your plan from last week.

✓ Complete ✗ Incomplete 🔍 Observ

- 🔍 **Cycling** 30 min.
- ✓ **Biking** Riding the bike going to work 30 min.
- ✗ **Biking** Riding the bike going to work

Review Thu, Jan 23 - Wed, Jan 29, 2014

1 week

1-Check last week 2-Check Diaries 3-Activities Feedback 4-Charts 5-Goals Feedback 6-Update Action Plan for next week

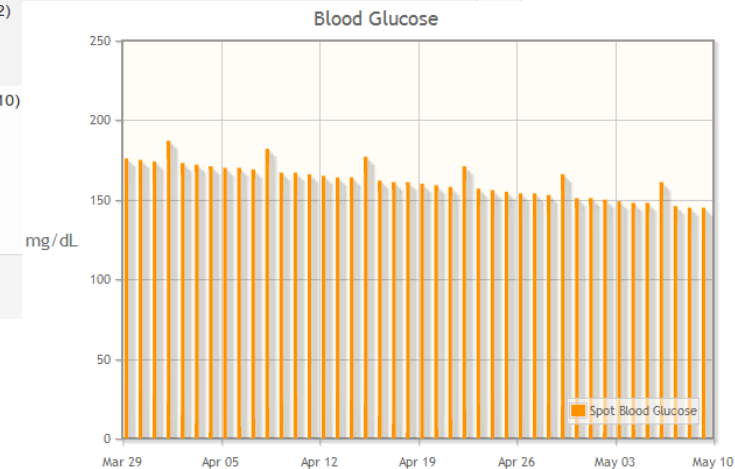
Action Plan - Weekly Review, Step 3. Activities Feedback.

Activity Feedback: 80% overall performance

Your overall performance trend ↗


Activity	Performance	Tips
Jogging	50% (1/2)	
Blood sugar	50% (5/10)	




← Previous Step Next Step →



Evaluation: Weekly review - Update missing data, check performance

Agenda view or Calender view


Mein Diabetes-Plan ▾
+ Hinzufügen ▾
Journal ▾
Info ▾
Consent Editor




Manfred Maier ▾

 Review Mo., Jun. 23 - So., Jun. 29, 2014

1 Woche

1-Letzte Woche prüfen 2-Journale prüfen 3-Feedback zu Aktivitäten 4-Diagramme 5-Feedback zu Zielen 6-Mein Diabetes-Plan für nächste Woche


Mein Diabetes-Plan - wöchentliches Review, Schritt 1. Überprüfen Sie den Plan der letzten Woche.

Filter: Fertig Unvollständig Extra



Blood glucose 142.0 mg/dL Di., 24. Jun. 2014 7:11 Uhr

Blood pressure 175.0/87.0 mmHg, 68.0 bpm Mi., 25. Jun. 2014 9:10 Uhr

 **my BP** *my activity description* So., 29. Jun. 2014 9:10 Uhr

Nächster Schritt →

Feedback:Charts (physician or patient) Blood sugar and Sport

Diagramme und Trends

Diagramm auswählen

Zeitbereich: 3 Monate

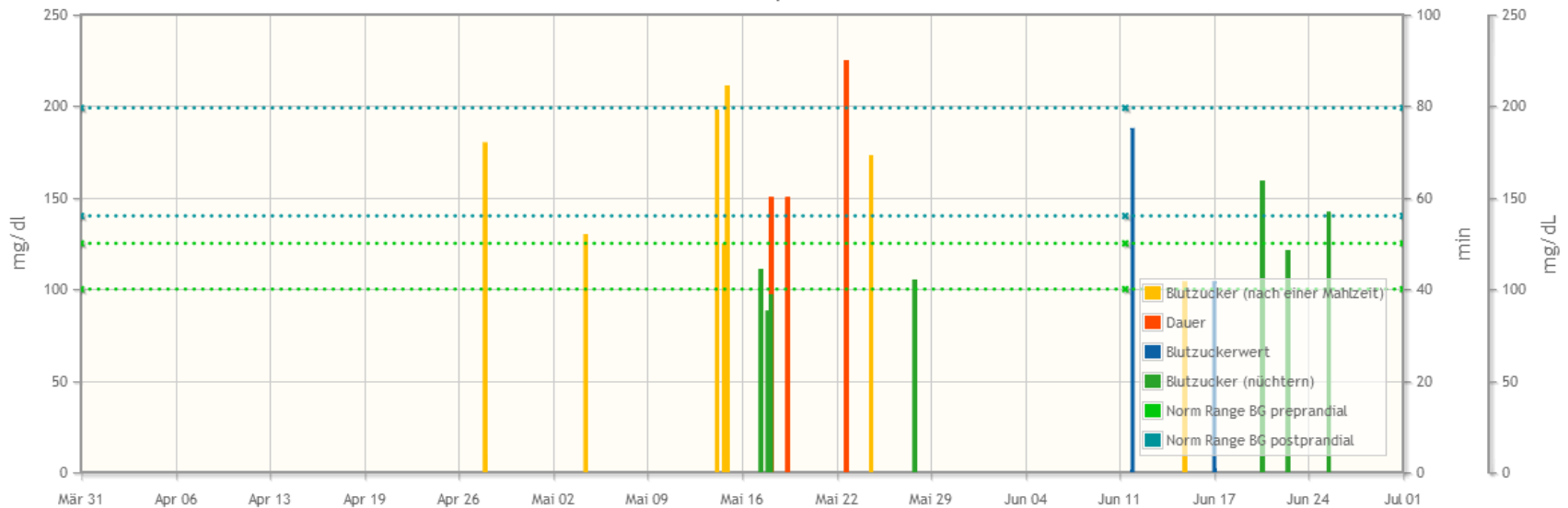
Bis Datum:

Blutzucker & Körperliche Akt ▼

2014-06-30



Blutzucker & Körperliche Aktivitäten



nach oben

Feedback while inserting observations for planned events

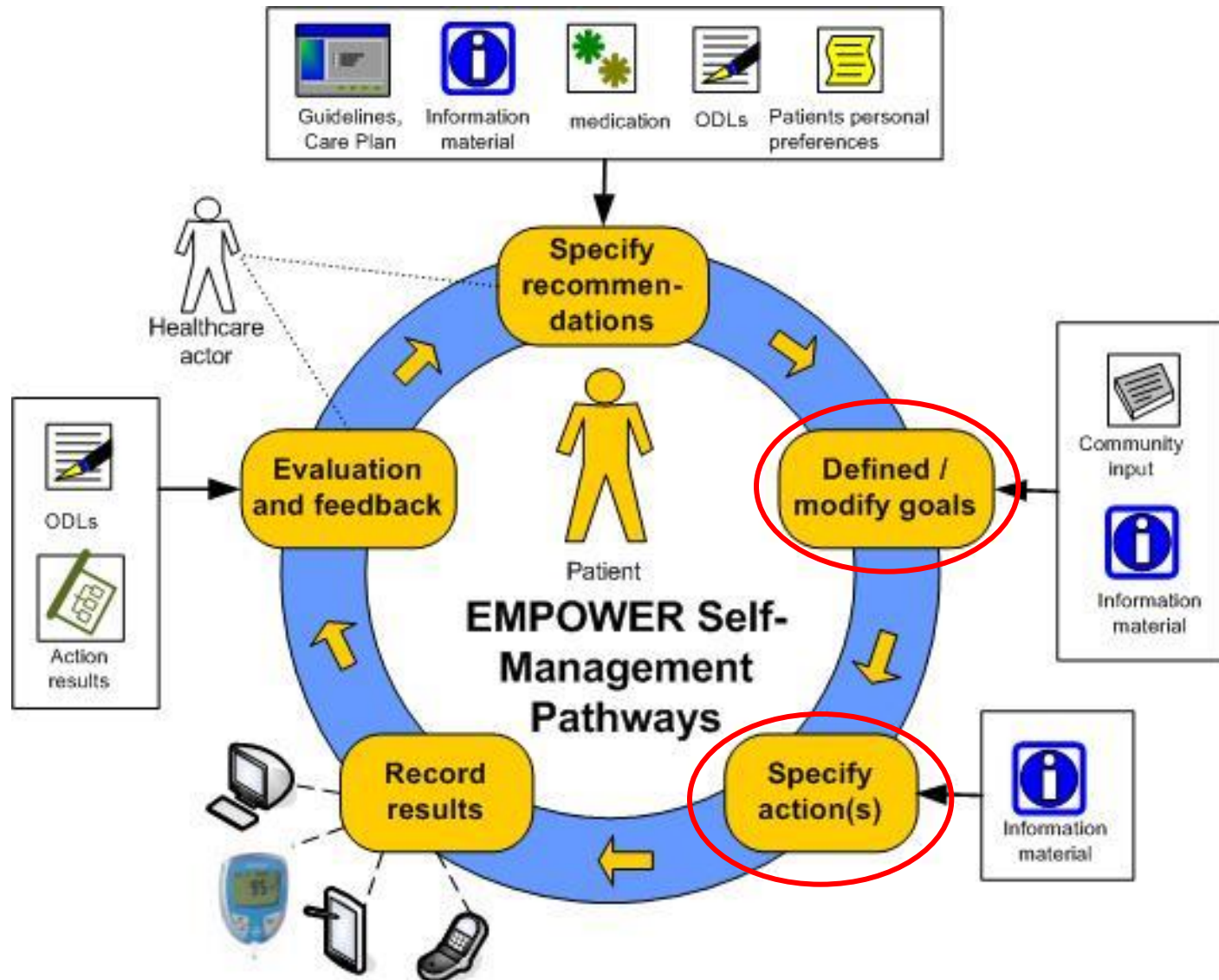


The screenshot displays the EMPOWER interface with a modal window titled "Details zur Aktivität" (Details of the Activity) open. The modal contains the following information:

- Status: **Nicht abgeschlossen** (Not completed)
- Ergebnisse eingeben (Enter results) with a plus icon
- Fertigstellung: 0/7 (0%)
- Aktivität bearbeiten (Edit activity) with a pencil icon
- ▼ Abhängigkeiten einblenden (Toggle dependencies)
- An OK button at the bottom right.

The background interface includes a sidebar with buttons: "+ Aktivität hinzufügen", "Feedback zu den Zielen", and a "my BP" button showing "0/7". The main area shows a calendar for "Sa, Jul. 05" with a time slot from 08:00 to 11:00. A "my BP" button is also visible in the bottom right of the calendar area.

EMPOWER approach – planning the next week



Self Management Pathway and Telemedicine

- | The SMP Self management pathway is a collaboration between both the patient and medical experts to support both patient self-management and the doctor patient relationship; especially to support consultations.
- | Hundreds of mobile health apps and monitoring devices are not integrated in patient treatment plan. However, some clinics do support ICT solutions for their patients.
- | Clinical PHR System - Telemonitoring issues
 - | With Personal Health Record systems (PHRS), patients do expect they are monitored 24 hours/day. There are legal and clinical policies to be clarified.
 - | Patient consent policies – the patient should be enabled to share PHR data with particular healthcare providers.

Final points – for discussion

- | Telemedicine and Patient Empowerment – benefits, to whom?
- | Managing chronic diseases - supported by appropriate software tools
 - | Telemonitoring and patient self-management
 - | Patient shares data securely with particular healthcare providers
 - | Periodic consultations between patient and healthcare provider(s)
- | The process of self-management must be defined and understood by the health care providers and patients as means to help the patient manage their disease.
- | Cross boarder care between TR and DE possible but not allowed by DE data ethics committee.
- | **Potentially**, a Patient consent manager component could enable Turkish patients to share data with doctors in DE or TR. Consequently, doctors could see results from both PHR and EHR sources of both countries.

Thank You!

Robert „Bob“ Mulrenin


Salzburg Research Forschungsgesellschaft m.b.H.
Jakob Haringer Straße 5/3 | 5020 Salzburg, Austria
robert.mulrenin@salzburgresearch.at
T +43.662.2288-403 | F +43.662.2288-222

Literature

- | [Anderson & Funnell, 2010] Anderson R. M., Funnell M. M.: Patient Empowerment: Myths and Misconceptions, Patient Educ Couns. 2010 June ; 79(3): 277–282. doi:10.1016/j.pec.2009.07.025
- | [Diabetes Initiative, 2009]
http://www.diabetesinitiative.org/documents/SelfManagement-5.12.09_000.pdf
- | [ENOPE, 2012] ENOPE European Network on Patient Empowerment: Patient Empowerment – Living with Chronic Disease, 2012
- | [IDF] <http://www.idf.org>
- | [Monteagudo & Moreno, 2007] Monteagudo J. L., Moreno, O.: Report on Priority Topic Cluster two and recommendations – Patient Empowerment. eHealth ERA, 2007

EXTRAS

Charts (physician or patient) : Blood sugar


Mein Diabetes-Plan ▾

+ Hinzufügen ▾
Journal ▾
Info ▾
Consent Editor







Manfred Maier ▾

Diagramme und Trends

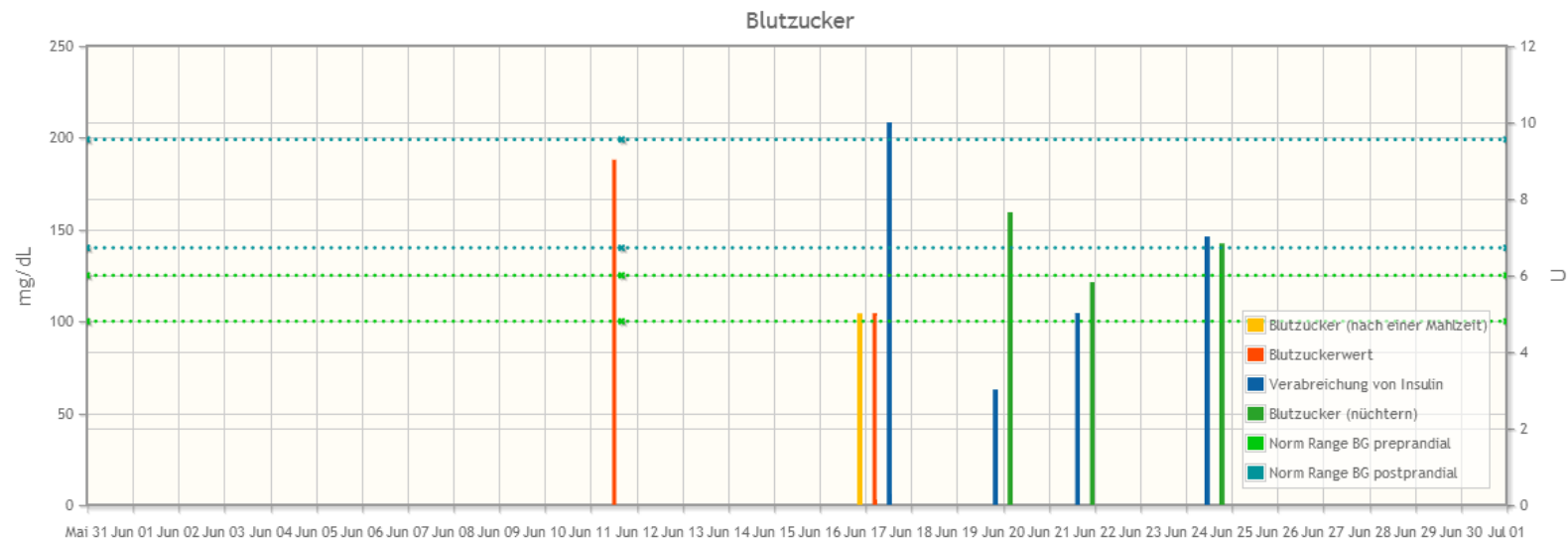
Diagramm auswählen

Zeitbereich: 1 Monat

Bis Datum:

Blutzucker ▾





[Zurück nach oben](#)

Willkommen auf Ihrem Dashboard, Manfred Maier

Sie finden hier eine Übersicht der wichtigsten Daten dieser Woche

Aktuelle Agenda

- + my BP Mo., 09:10 - 10:10
- + my BP Di., 09:10 - 10:10

Aktuelle Aktivitäten

▼ my BP 0/7

Empfehlungen ohne ein Ziel in dieser Woche

Sie haben noch keine Ziele für die folgenden Empfehlungen geplant:

- Take the medications every morning.
- Measure and record blood sugar and blood pressure daily.
- Check your weight on Sunday morning before breakfast.
- Change your eating behaviour within the next two months.
- Do some sports.
- Lose 5 kg.
- my_recommendation
- asdfasdf

[+ Persönliches Ziel erstellen](#)

[Zurück nach oben](#)

Ziele ohne eine Aktivität in dieser Woche

Sie haben noch keine Aktivitäten für die folgenden Ziele geplant:

- Jogging
- Eat less chocolate

[+ Aktivität erstellen](#)

Aktuelle Diagramme

Diagramm auswählen

Motivation – self-care coping strategies (Collins et al. 2008)

Information, hints, reminders,
decision aids, wizards, etc.

- | **Nonconformist** – is a patient who does not follow most of his/her prescribed self-care regimen
 - | They accepted minimal personal responsibility for their self-care
 - | They often deny the seriousness of their conditions
 - | They may believe that the burden of diabetes is overwhelming and that adopting positive lifestyle behaviours is too difficult.
- | **Passive Follower** – is a patient who follows his/her prescribed self-care regime, but does not react autonomously to changes in metabolic control.
 - | They prefer structure with no variation in medication or meal times. Most of the passive followers had type 2 diabetes and used diet or oral medications to control their diabetes.
 - | Passive followers tend to rely more on powerful others to help them make self-care decisions and appropriate lifestyle changes.
- | **Proactive Manager** – is a patient who independently monitors blood glucose and adjusts his/her self-care regime to maintain metabolic control
 - | They accept a high degree of responsibility for their health and believes there self-care actions will positively influence their metabolic control
- | **Survey**
 - | this sample was minimal biased in perceiving diabetes self-management competence (46% patients followed a DMP program; thus 66% regard themselves as active followers)
 - | Patients with high e-skills regarded themselves more likely as active followers

Aspects supporting motivation (Milios, 2011)

*Motivation is not like a mosquito.
It's not going to land on you, no matter how long you wait.
You must initiate it and create it by an act of will.
(Milios, 2011)*

- **Start with the right attitude** – be mindful, pay attention what you are doing when you are doing it
 - ⇒ Become aware of your unhealthy habits, e.g. with the help of a diary
- **Set realistic goals and break your goals into smaller steps** – it is more motivating to set smaller goals/actions and achieve them than to set unrealistic goals and fall short
 - ⇒ Hints and supported messages for guiding through the goal setting process
- **Use small successes to get to larger ones** – success breeds more success
 - ⇒ Report, graphs and trends can give continuous positive feedback
- **Focus on what you want** – instead of focusing on what you don't want
- **Reinforce the habit of discipline** – discipline are the key to habits, because they lead to results
 - ⇒ Becoming an active self-manager by Weekly Planning of actions (Lorig et al, 2006)
 - ⇒ Reminders for ODLs or weekly planning
- **Remain flexible** – if you can't reach a goal focus on which part of the goal you can achieve
 - ⇒ Have a look at goal and recommendations (the purpose behind)
- **Reward and reinforce** – reward your hard work and discipline and be pride in your positive results

Some remarks and lessons learned

- | **EMPOWER support behaviour changes until new, diabetes-compliant habits become second nature, e.g.**
 - | for newly diagnosed Type 1+2 diabetes patients
 - | for elderly diabetics who have to change their medication from pills to insulin

- | **Incorporating motivation in several ways is essential** because behaviour changes are often a huge challenge for diabetes patients, e.g.
 - | detailed feedback and hints as part of the Weekly Review
 - | diaries for raising awareness
 - | feedback and motivation from groups – e.g. self-help groups or forums for exchanging experiences with other patients sharing similar situations

- | **It is crucial to involve the end users** (diabetes patients, doctors, dieticians, etc.) **from the beginning into the project.**
 - | For requirement specifications, early feedback for the prototype

- | **The EMPOWER approach is not restricted to diabetes** because chronic diseases often needs self-control and behaviour changes.