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

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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]
  - By example diabetes [IDF]
    - **371 million** people have diabetes in 2012; by 2030 this will have risen to **552 million**
    - Diabetes caused **4.8 million deaths** in 2012
    - The number of people with diabetes is increasing in every country and it is estimated that **the worldwide diabetes prevalence will rise from 8.2% in 2012 to 9.9 in 2030**
    - Diabetes caused at least **USD 465 billion dollars** in healthcare expenditures in 2011; **11% of total healthcare expenditures** in adults (20-79 years)

⇒ the healthcare needs of patients have been shifting from predominantly acute care to care for chronic diseases

⇒ We must realise that each of us is the primary healthcare provider for ourselves

⇒ healthcare can be delivered more efficiently and with lower costs if patients are full partners in the process – towards a patient-centric care

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]

- There are different ways strengthening Patient Empowerment
  - e.g. ensuring participation of patients and citizen in decision-making processes, strengthening health literacy, providing self-management support, fostering patient-physician relationship

- An empowered activated patient can be described by several characteristics [ENOPE, 2012]:
  - He understands his health condition and its effect on his body.
  - He feels able to participate in decision-making with his healthcare professionals.
  - He actively seeks out, evaluates and makes use of information.
  - He feels able to make informed choices about treatment.
  - He is able to challenge and ask questions of the healthcare professionals providing their care.
  - He takes responsibility for his health and actively seeks care only when necessary.
  - He understands the need to make necessary changes to his lifestyle for managing their conditions.

=> information & decision making, self-control & self-management, behaviour changes

What does Self-Management mean?

- 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 extent, 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]

- **Self-management is what people do to manage their diabetes or other chronic condition and its effects on their physical health, daily activities, social relationships and emotions**. [Diabetes Initiative, 2009]
  - Deal with illness, such as medication, physical activity, doctor visits, changing diet
  - Continue the normal daily activities, such as housework, employment, social life, etc.
  - Manage the changing emotions about by dealing with a chronic condition, such as stress, uncertainty about the future, worry, anxiety, resentment, changed goals and expectations, depression, etc.

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- **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
- **Budget**: 4.277.000 Euro

- **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

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

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

⇨ **and how can that be supported by ICT?**

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Objectives in EMPOWER

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

- by including treatment goals and recommendations from physicians
- Adapted to the patients skills, requirements and needs
- Including disease-relevant information material and hints (EMPOWER Tips) as an intergrated part of the EMPOWER features

(2) Supporting behaviour changes with personalised action plans

- by including services for personalised, long-term self-management goals realised by short-term activities

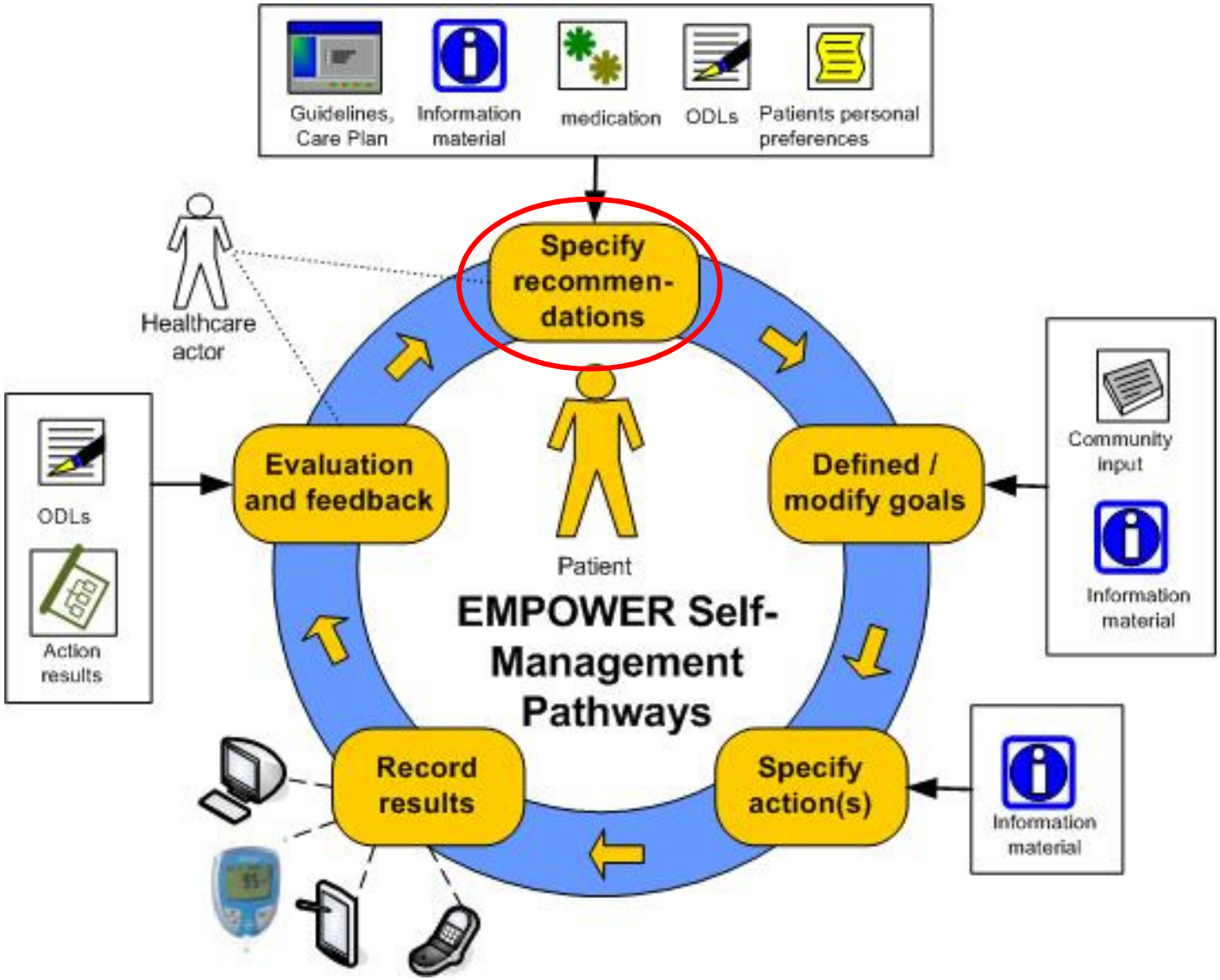
(3) Facilitating self-control by collecting patterns of daily living

- Services for Observations of Daily Living (ODLs) about vital, physical and mental parameters and about physical and lifestyle activities based on openEHR archetypes

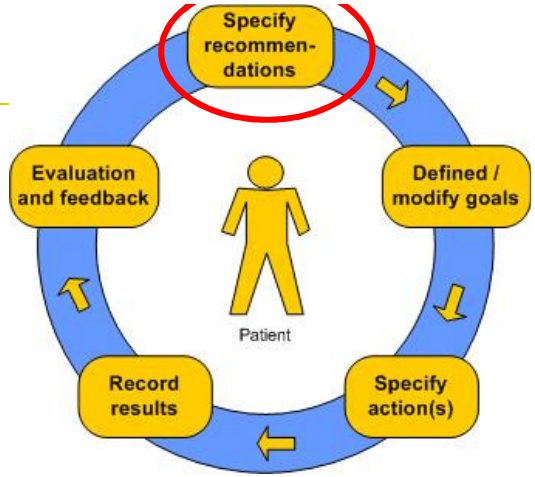
(4) Semantic interoperability with existing Personal Health Applications

- by supporting semantic interoperability based on established standards such as HL7 IHE profiles (XPHR), ISO/CEN13606 information models

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



Specify recommendations



Diagnose Typ-2-Diabetes

Diabetes-Training, Nutrition, Activity and Medication: Metformin

HbA1c < 7,5 %

OAD combination therapy or OAD / exenatide combination therapy

- metformin / acarbose
- metformin / DPP-4 inhibitor
- metformin / Exenatide
- metformin / SH
- metformin / SHA

Intensification of insulin th
- MDI (basal/bolus
- Premixed insulin
- Combination witt contraindication/in

➢ **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

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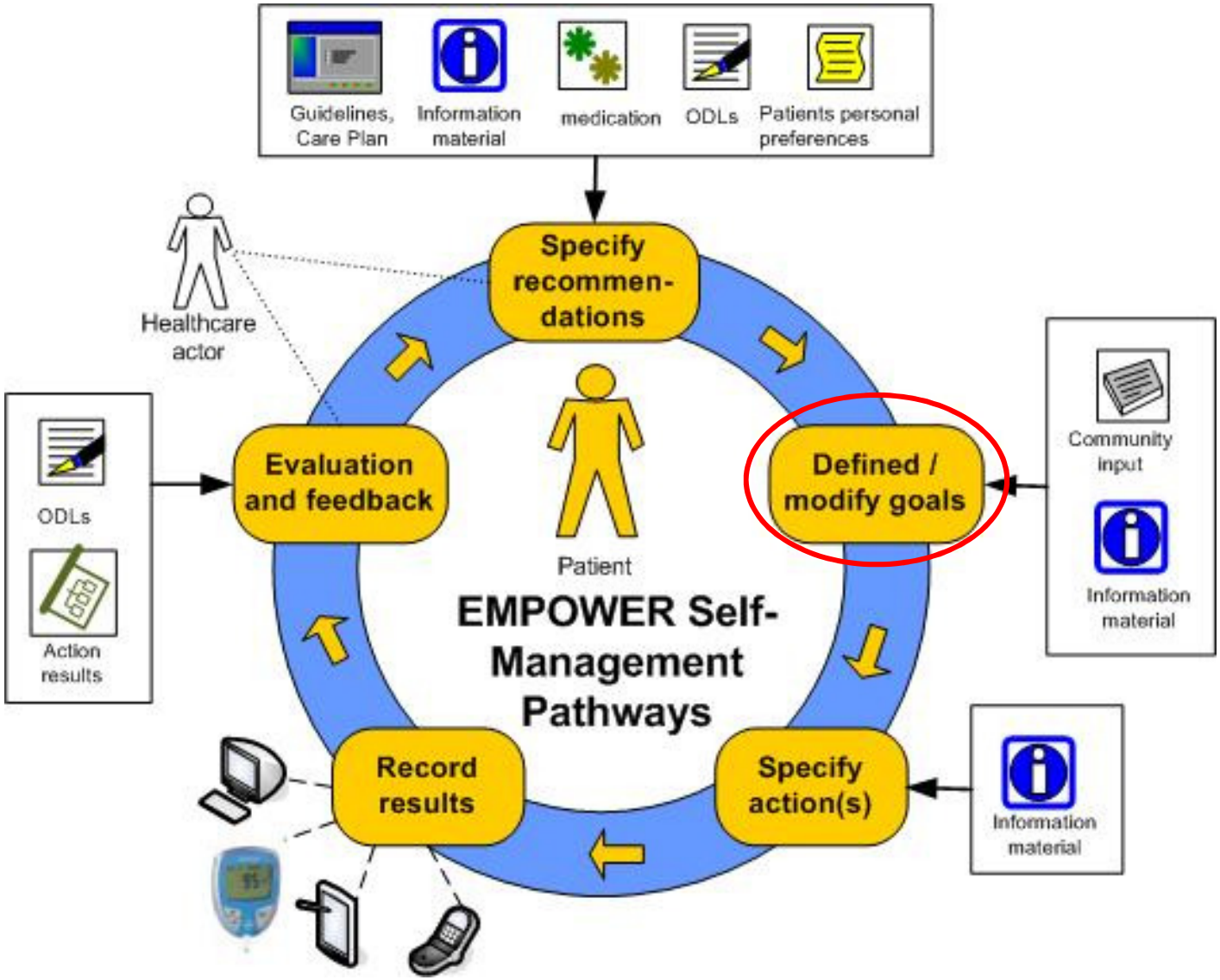
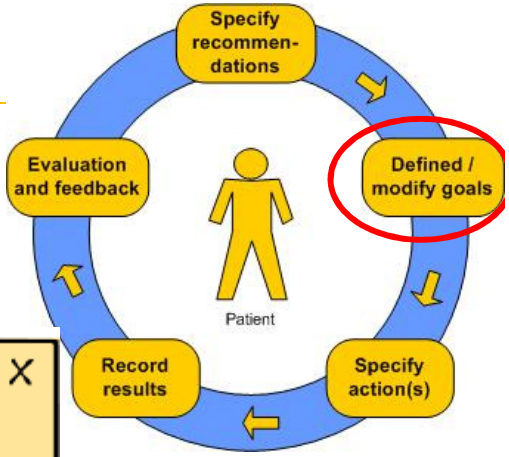


Define / modify long-term goals



Specify a Self-Management Goal - Step #1

Step #1 Step #2

Choose a treatment goal for specifying your own, m

Date	Doctor	Treatment Goal
2012-02-08	Dr. Paul Schmid	Take Metformin - D 1 week 2 x 500 mg
2012-02-08	Dr. Paul Schmid	Reduce 5 kg in the
2012-02-08	Dr. Paul Schmid	Measure and recor
2012-02-08	Dr. Paul Schmid	Check weight once
2012-02-08	Dr. Paul Schmid	Do some moderate
2012-02-08	Dr. Paul Schmid	Check and change

For defining your own self-management goal you mig to look at additional information. For opening Help c

EMPOWER Tip

Ad the beginning select a treatment goal you can eas You can select none, one or more treatment goals

Specify a Self-Management Goal - Step #2

Step #1 Step #2

Specify a goal

Sport - 3 times a week

Description

Jogging, biking, stationary bike
30 min each time

Rewards

If I achieve this goal I will bye the new digital camera

Comment

EMPOWER Tip

If it is difficult for you, look for options or alternatives.
- you can share your goals with the family, friends, health professionals or use the Internet or
- you could break down a goal in smaller sub-goals with a higher likelihood to be achieved

Back Save

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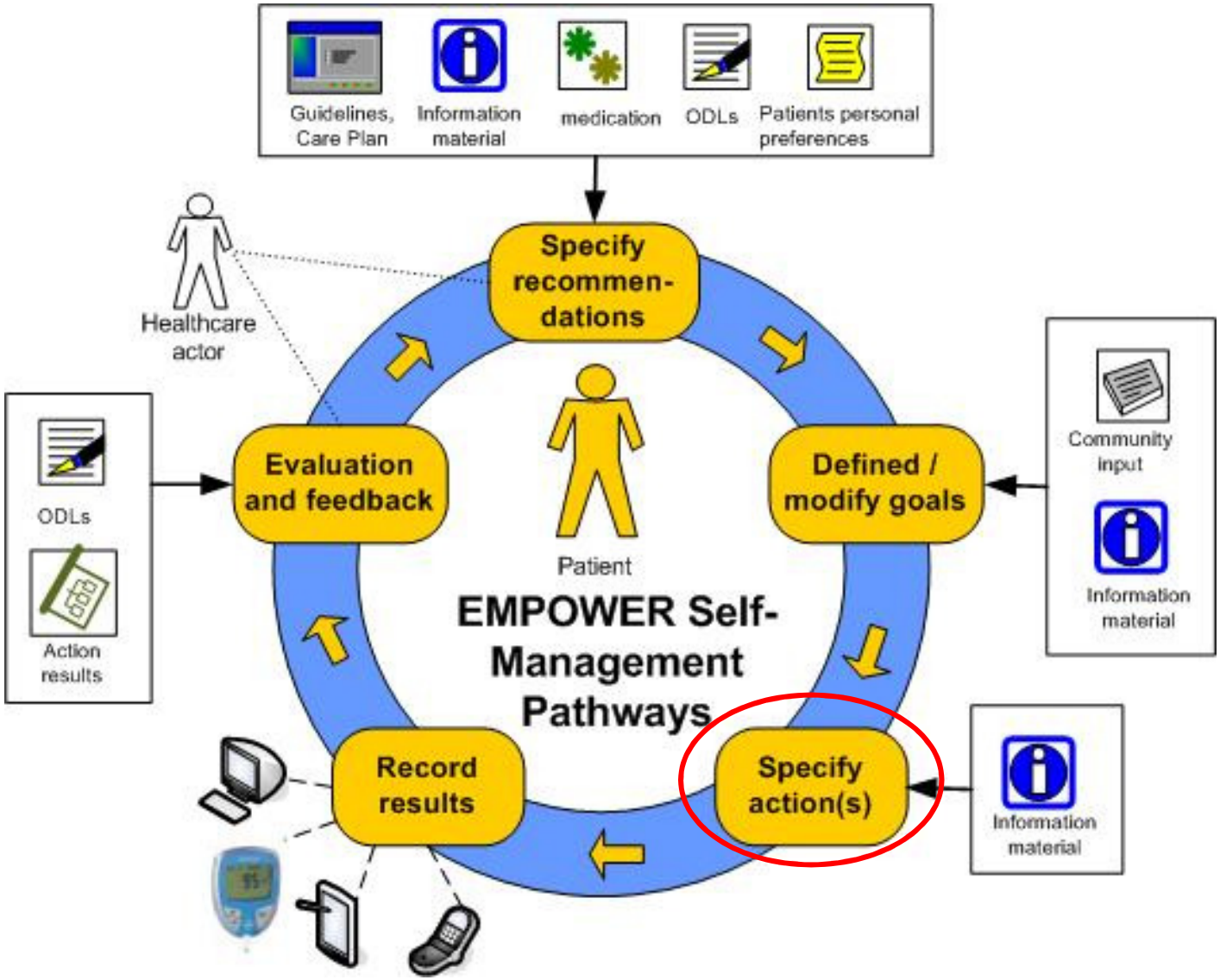
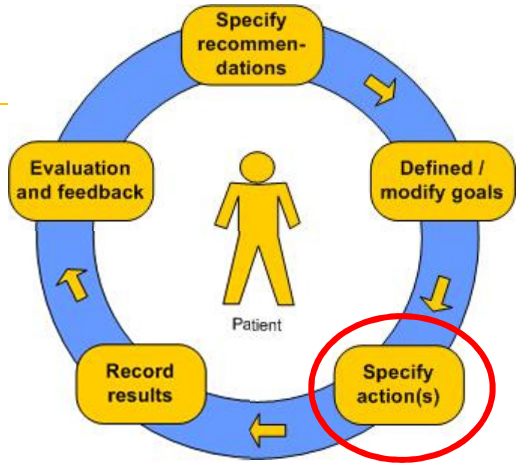


Specify short-term actions



Specify an Action - Step #1

Step #1 Step #2 Step #3 Step #4

Choose an activity

Measure blood sugar level

Select an activity category

Medication | Monitoring | Food

My personal goals

Date	My goals
2012-02-25	To take his medic
2012-02-25	To measure and
2012-02-25	To measure and
2012-02-25	To check his weig
2012-02-25	To change his eat
2012-02-25	Some sport - 3 ti

Description

before breakfast
don't forget to record results

EMPOWER Tip

Make a specific plan what you ar
- Exactly what I'm going to do?
- How much will I do?

Back

Specify an Action - Step #1

Step #1 Step #2

Choose an activity

Measure blood sugar le

Select an activity categ

Medication | Monitoring

For specifying activities
information materials. Fo

Configure Reminder

Step #1 Step #2 Step #3 Step #4 Step #5

Activity: Measure blood sugar level

From 2012-02-25 7:00 Repeat

To 2012-02-25 7:00

Reminder

Remind me in advance of

15 Minutes

Remind me via

- E-Mail
- SMS
- EMPOWER dashboard

Remind also

my wife

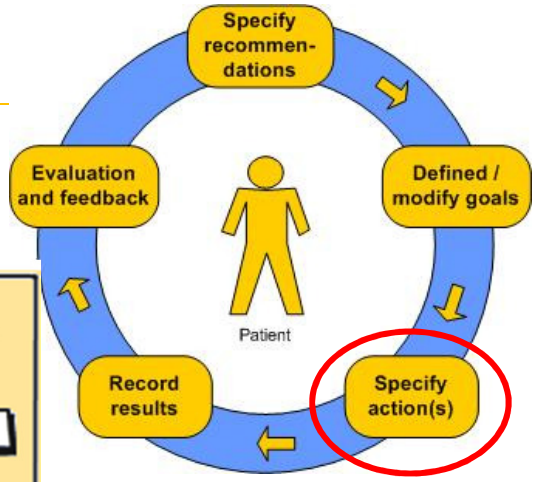
EMPOWER Tip

Make a specific plan what you are doing. Ask yourself:
- When will I do this?
- How often will I do the activity?

Back

Next

Specify short-term actions



Weekly Planning

EMPOWER

search | Home | Settings | Help | Logout

Action Plan

Goals | Action Plan | Diaries | Charts | Diabetes Passport | Community | Health Record | Contacts

< February 27 - March 5, 2012 >

Status Weekly Planning: completed / work in progress

	MON 27.2.	TUE 28.2.	WED 29.2.	THU 1.3.	FRI 2.3.	SAT 4.3.	SON 5.3.
7:00	bloodsugar blood pressu medication						bloodsugar blood pressure medication check weight
8:00							
9:00							
10:00							
11:00							
12:00							
13:00							
14:00							
15:00							
16:00							
17:00							
18:00	jogging						

You have specified all your activities for this week.
You did a great Job!
Now have a final look how certain you are to complete all these acticities in this week.

- ☐ strongly certain
- ☐ certain
- ☑ neutral
- ☐ uncertain
- ☐ strongly uncertain

EMPOWER Tip

You don't know whether you will be able to fullfill all planned activities in this week.
Maybe this is not a yet a realistic plan.
Have again a look at your activities and ask yourself why you are not yet certain.

Finish

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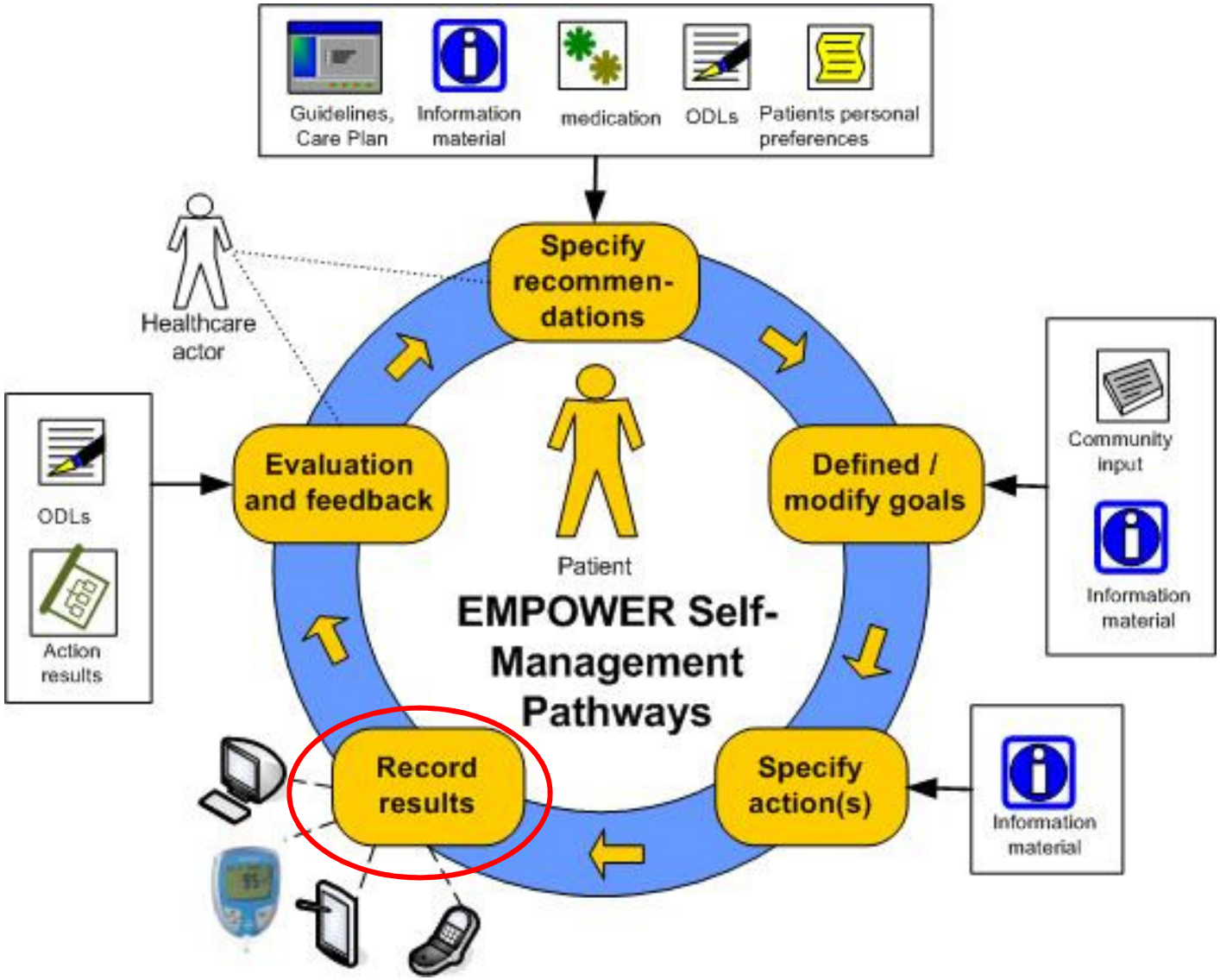
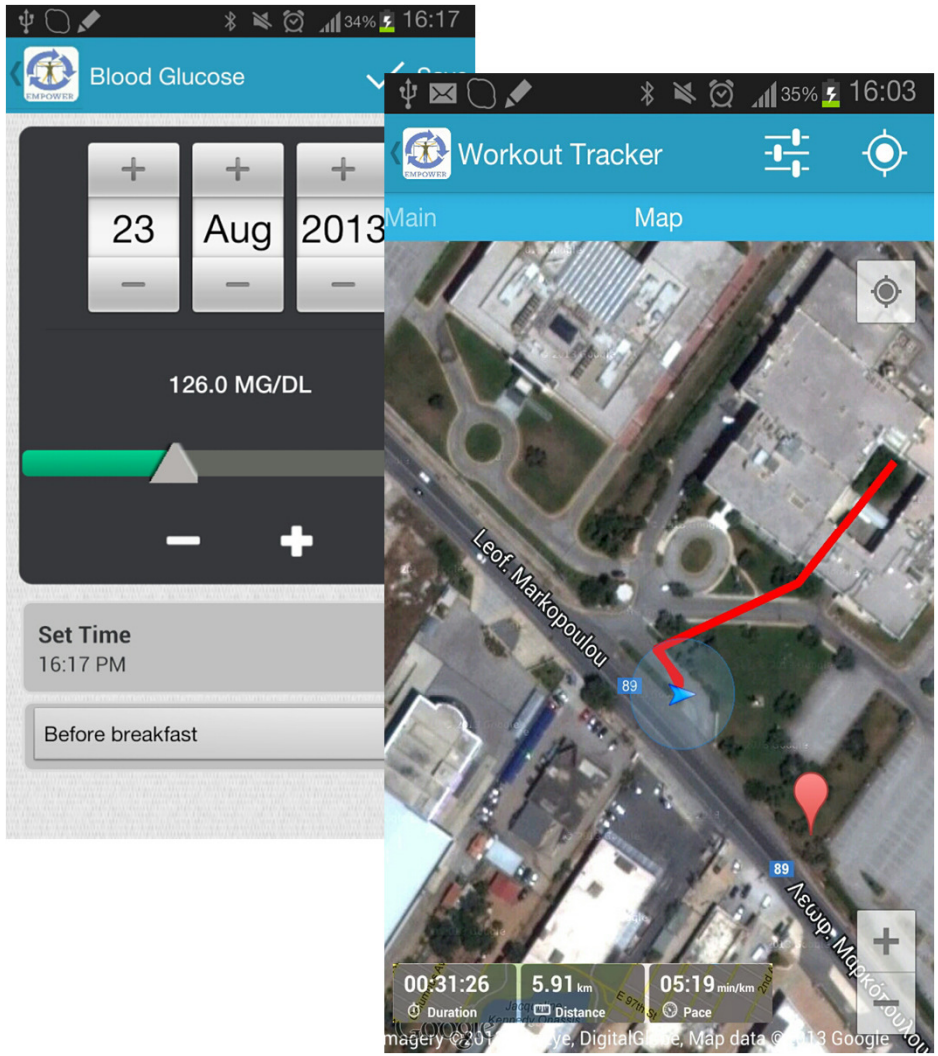
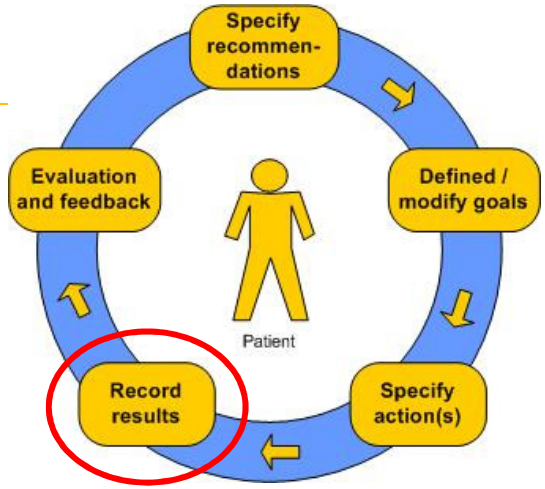


Record results (web + mobile)





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

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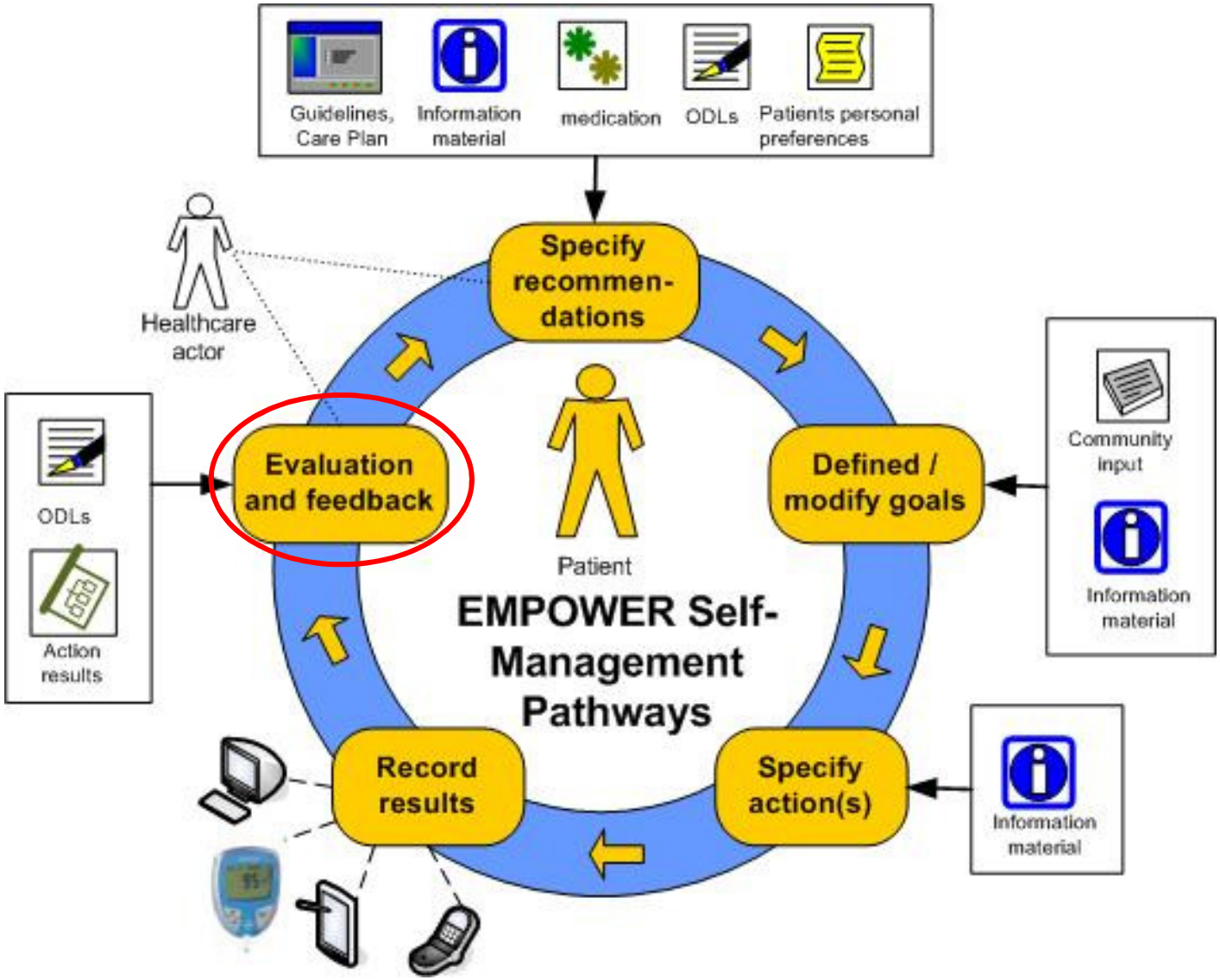
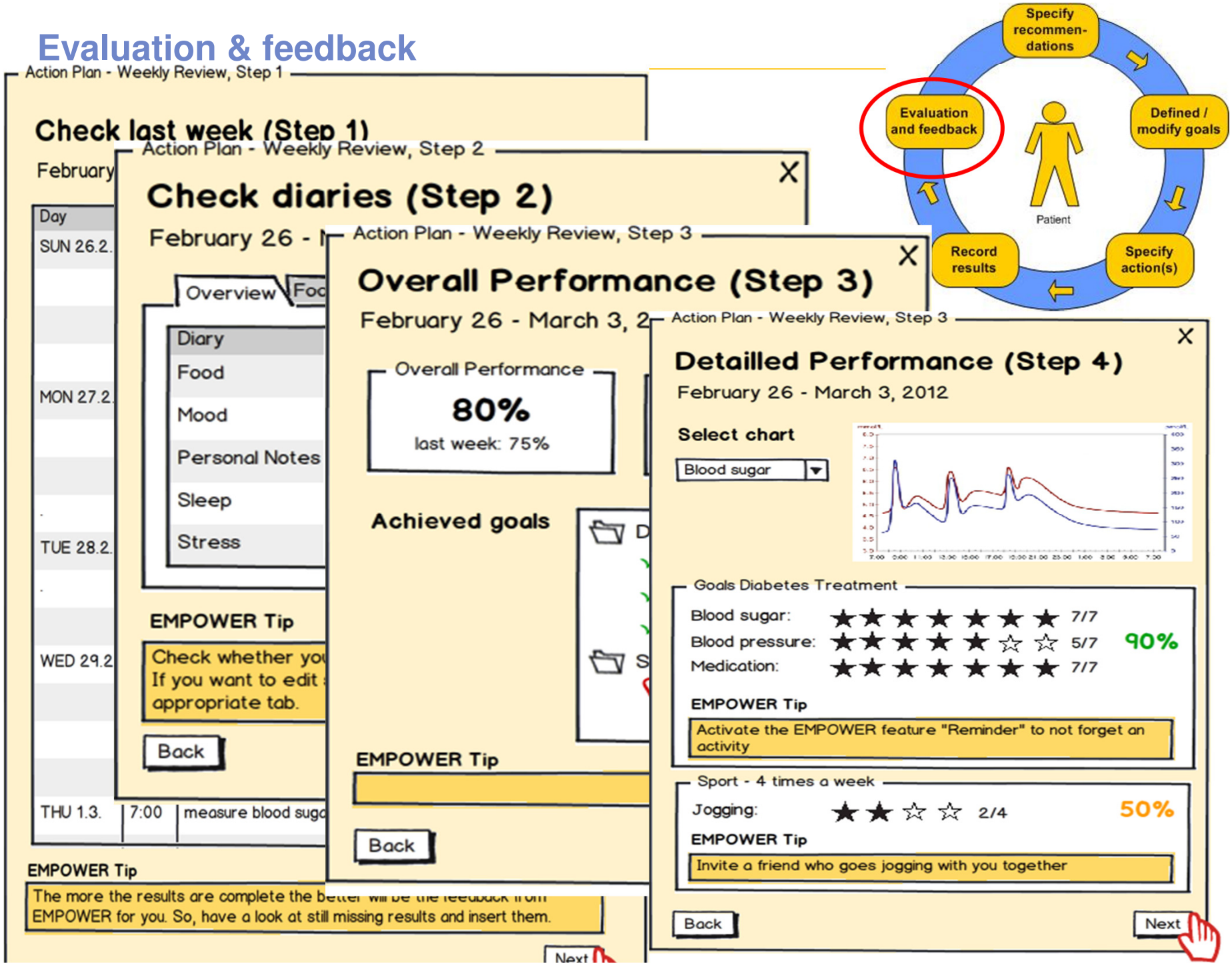


Evaluation & feedback



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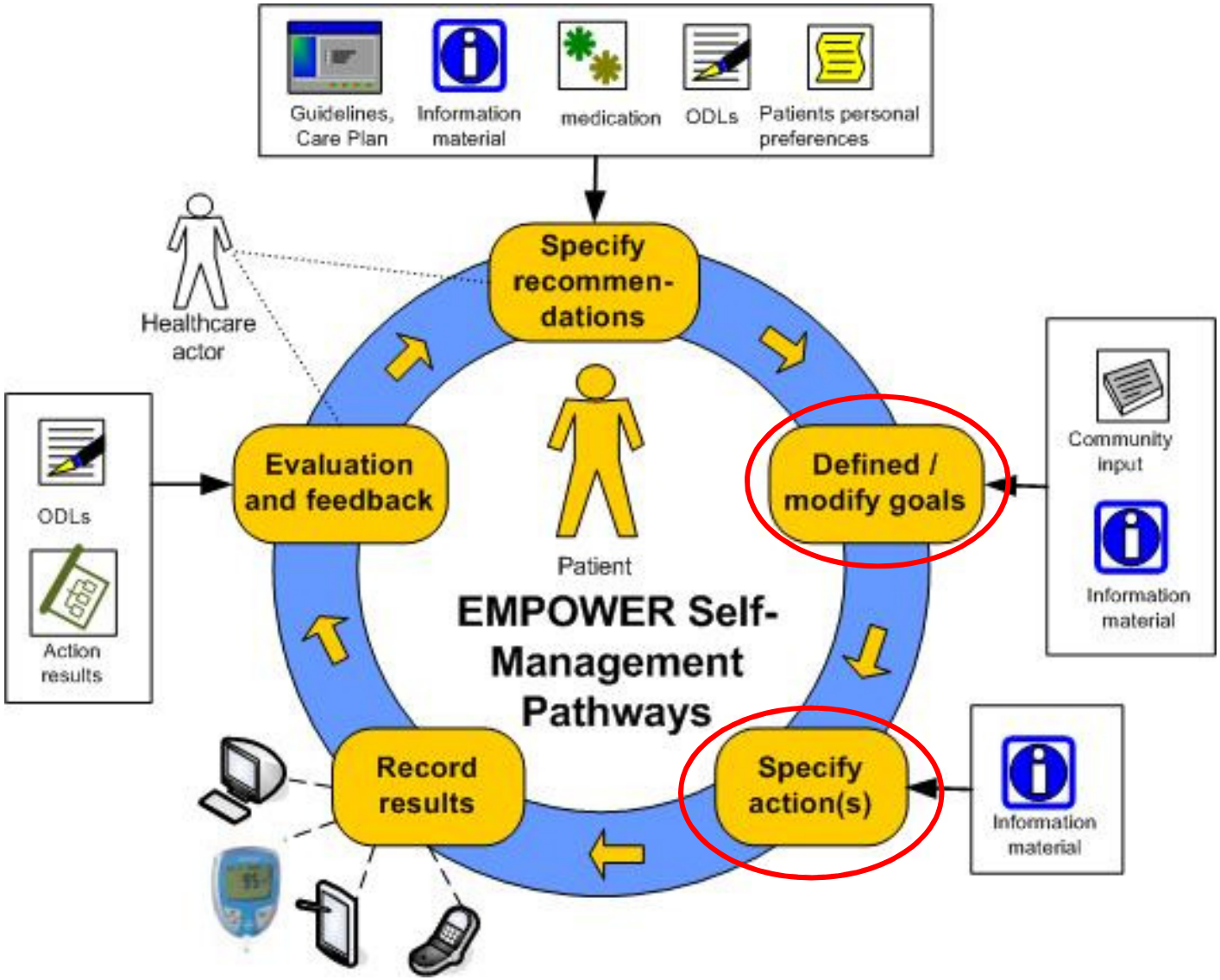

Some remarks and lessons learned

- **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

- **Incoporating 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 awarness
  - 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.

And finally…

We cannot empower patients!

We only can provide a framework (tools, services, etc.) that makes it easier for patients to empower themselves.

Contact

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