

# Evivo – supporting health literacy and chronic illness self-management

Program principles, early experiences and preliminary findings on the  
Stanford self-management program CDSMP in Austria and Switzerland

Dr. Jörg Haslbeck, Careum Foundation, Copenhagen April 13th 2012 and Zurich November 12th 2012

# Agenda

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- Reminder self-management support
- Stanford model – supporting health literacy in chronic illness
- Cross-border adaptation/adoption for Switzerland and German-speaking countries
- Early insights and first experiences
- Closing thoughts

# «Self-management context»

# What is self-management? And why important?

In a nutshell... – a summary from Kate Lorig

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**EVIVO**  
Clips

[www.evivo.ch](http://www.evivo.ch)

# How should we define health?

Last year's debate in public health

Some authors are asking for a new perspective of our understanding of health:

**«... health, as the ability to adapt and to self-manage»**

Huber et al. *BMJ* (2011), 343:d4163



# Empowering citizens, clients and health care users

## Co-producing health and co-designing systems

**„When we want your opinion we'll give it to you“**



**„I'm sorry doctor, but again I have to disagree“**



# Providing information and supporting skills

No 'one-size-fits-all' – a variety of approaches needed

«Self-management works ... proactive strategies work best»



# «Adaptation and implementation»

Cross-border adaptation and adoption of the Stanford model for / in Switzerland, Germany, and Austria



# Stanford model

## Chronic Disease Self-Management Program (CDSMP)

The screenshot displays the Stanford Patient Education website. At the top, the Stanford School of Medicine logo is on the left, and a search bar with the text "Search This Site" and a "SEARCH" button is on the right. Below the search bar, there are radio buttons for "This Site Only" (selected) and "Stanford Medical Sites". A breadcrumb trail reads: "Stanford Medicine » School of Medicine » Department of Medicine » Patient Education » Organizations Offering Our Programs".

The main content area is titled "Stanford Self-Management Programs". It features a paragraph: "In the past 20 years or so, the Stanford Patient Education Research Center (formerly the Stanford Arthritis Center Education Office) has developed, tested, and evaluated self-management programs for people with chronic health problems. Our first program was the Arthritis Self-Management Course (also known as the Arthritis Self-Help Workshop), which became the prototype for all our self-management programs. All of our programs are designed to help people gain self-confidence in their ability to control their symptoms and how their health problems affect their lives. Our small-group workshops are generally 6 weeks long, meeting once a week for about 2 hours, which are led by a pair of lay leaders with health problems of their own. The meetings are highly interactive, focusing on building skills, sharing..."

On the left side, there is a sidebar with the "STANFORD PATIENT EDUCATION RESEARCH CENTER" logo and a "PATIENT EDUCATION" menu. The menu items are: Home, Meet Our Staff, Training, Licensing, Materials, Organizations Offering Our Programs, and Self-Management Programs (English). Under "Self-Management Programs (English)", there is a link for "Chronic Disease".

On the right side, under the heading "Available programs", there is a list of links: "Chronic Disease Self-Management Program (CDSMP)", "Tomando Control de su Salud (Spanish CDSMP)", "Diabetes Self-Management Program (DSMP)", "Tomando Control de su Diabetes (Spanish Diabetes)", and "Arthritis Self-Management".

# What is the CDSMP

Community course for people with various diseases & significant others

- 6 weeks long
- Each week's session about 2,5 hrs
- Led by two peer leaders
- Based on manual and supplementary book
- Evidence-based and disseminated to various countries



# International examples

## «CDSMP» in Europe

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### **UK – e. g. Expert Patients Programme CIC**

- About 80'000 participants in EPP courses between 2007 and 2010



### **DK – Danish Committee on health education**

- About 2'500 participants annually in courses run by municipalities



### **CH, A – Careum and partner organizations**

- 11 courses with roughly more than 100 participants since «go live» in January 2012

Studies and pilots also in Australia, the Netherlands, China and Kanada

# Improving health literacy in chronic illness

«e» for empowerment – «vivo» for living a healthy and active life

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An evidence-based Stanford self-management program

Kurs: «Gesund und aktiv mit Krankheit leben»

eVIVO



# From CDSMP to Evivo

Adapting course material and manuals 2010/2011

- Expert and patient review
- Pilot leaders training May 2011
- Integrating CDSMP experiences  
Suisse Romande 2011/2012
- Establishing pioneer partnerships
- Continuous dialogue with ENOPE  
members and Stanford



# Evivo Pioneer Partnerships

Joining efforts in course delivery and implementation

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## Helsana

# Setting examples of Evivo

## Integrating self-management support in various settings

### Community, independent counselling



# EVIVO

GESUND UND AKTIV MIT CHRONISCHER  
KRANKHEIT LEBEN



Leben Sie selbst, lebt ein Mitglied Ihrer Familie oder jemand aus Ihrem Bekannten- und Freundeskreis mit einer chronischen Krankheit wie Diabetes, Migräne, Allergien, einer Herz-Kreislauf-Erkrankung, Wirbelsäulenbeschwerden oder einer anderen, vielleicht seltenen Krankheit? Lernen Sie in einem Evivo Kurs neue Möglichkeiten kennen, den Alltag aktiv und gesundheitsbewusst zu gestalten.



Evivo – ein wissenschaftlich geprüftes Stanford Selbstmanagementprogramm

**EVIVO**

### Local services, home care



**leila**  
Leben mit Langzeiterkrankung

#### EVIVO – Gesund und aktiv mit Krankheit leben

Sind Sie von einer chronischen Krankheit betroffen? Oder kennen Sie jemand in Ihrer Familie oder aus Ihrem Bekanntenkreis mit Beschwerden wie z. B. Herz-, Lungen- und Kreislauferkrankungen, Diabetes, Osteoporose, rheumatische Erkrankungen oder anderen Beeinträchtigungen? Solche Langzeiterkrankungen können zwar nicht geheilt werden. Der Alltag lässt sich trotzdem besser bewältigen als Sie vielleicht denken. Gönnen Sie sich diesen Kurs.

In exklusiver Partnerschaft mit der Careum Stiftung und Spitex Zürich führen wir im Projekt Leila Evivo Gruppenkurse durch. Im sechsteiligen Evivo Kurs werden die Teilnehmenden ermutigt und befähigt, aktiv mit chronischen Gesundheitsbeschwerden umzugehen. Der Kurs richtet sich an Betroffene und Angehörige.

Evivo – ein wissenschaftlich geprüftes Stanford Selbstmanagement Programm

#### Informations- veranstaltung

Spitex Zürich Limmat  
Zentrum Rigiplatz  
Winterthurerstrasse 25  
8006 Zürich  
Anmeldung siehe Rückseite

Dienstagabend, 24. April 2012  
19.00 bis 20.00 Uhr

#### Evivo Abendkurs

Spitex Zürich Limmat  
Zentrum Rigiplatz  
Winterthurerstrasse 25  
8006 Zürich  
Anmeldung siehe Rückseite

#### Kursdaten

6 x jeweils am Dienstagabend  
19.00 bis 21.30 Uhr

08. Mai 2012  
15. Mai 2012  
22. Mai 2012  
29. Mai 2012  
05. Juni 2012  
12. Juni 2012





# Starting in 2013: Evivo in the Suisse Romandie

## Partnership with cantonal diabetes program Vaux

[ADMINISTRATION](#) [INTERNATIONAL](#) [TOURISME](#)



### Le diabète



**THÈMES** **AUTORITÉS**

[Annuaire](#) [Index A-Z](#)  [chercher](#)

**Santé, Social**  
**Prévention**  
**Le diabète**  
Qu'est-ce que le diabète ?  
Pour la population  
Pour les patients  
**Pour les professionnels de la santé**  
Education thérapeutique  
**Projet Stanford**  
Passeport Diabète  
Programme cantonal

[Accueil](#) > [Thèmes](#) > [Santé, Social](#) > [Prévention](#) > [Le diabète](#) > [Pour les ...](#) > [Projet Stanford](#)

## EVIVO - Vivre avec une maladie chronique -

Vivre avec une maladie chronique est un processus difficile qui exige énormément de temps, d'énergie, d'efforts et qui est souvent source de frustration.

Le projet « Vivre mieux avec une maladie chronique » est une méthode qui vise à améliorer l'autogestion de la maladie et ses implications sur la vie quotidienne. Il s'agit d'un processus permettant d'augmenter l'estime de soi, le sentiment d'efficacité personnelle (mener à terme une action prédéfinie par soi-même) et la confiance d'être capable d'atteindre un but donné.

Ce programme est l'application du « Chronic Disease Self-Management Program <sup>[1]</sup> » développé par l'Université de Stanford. Il consiste en des ateliers hebdomadaires, animés selon des directives très structurées par un bénévole atteint d'une maladie chronique et un professionnel de la santé, tous deux formés et certifiés.



**Ecrire au service**  
Service de la santé publique  
**PROGRAMME CANTONAL**  
  
Programme cantonal  
**FLASH DIABÈTE**  
[S'inscrire à la lettre d'information du Programme cantonal Diabète](#)  
**DOCUMENTS UTILES**  
[Etude IUMSP des besoins des professionnels de la santé et des patients](#)  
[Campagne de dépistage 2011 - résultats \(en anglais\)](#)



# «Stanford model – content and principles»

Key elements of Stanford self-management programs

# Content of Evivo / Stanford programs

Structured and systematic sharing of experiences | supporting skills



«The course supports patients to live an active life and to be engaged in decisions about their care. It empowers them to take-up responsibility..»

An Evivo participant

## Providing information...

- Symptom- / medication management
- Fatigue
- Relaxation / exercise activities
- Healthy eating
- Communicating with family, friends, and/or health professionals

## ... and supporting skills

- Problem solving
- Action planning and goal setting
- Decision making
- Using resources

# «Activity – Stanford live»

# Key elements and principles

## Systematic 'peer approach' – manuals – goal setting & action planning

- Structured manuals
- «role modeling» of peers as course leaders living with chronic illness
- Systematic exchange of experiences
- Techniques: brainstorming, problem solving
- Making an action plan each week, individual goal setting
- Self-tailoring of tools and strategies

careum Die Gesundheitswelt der Zukunft denken

**E.VIVO** «Gesund und aktiv mit Krankheit leben»

**Manual Training**

**Mein Handlungsplan**

Wenn Sie Ihren Handlungsplan aufschreiben, legen Sie fest,

1. was Sie tun werden,
2. wie viel oder wie lange Sie es tun werden,
3. wann Sie es tun werden und
4. wie oft pro Woche Sie es tun werden.

Beispiel: Diese Woche werde ich dreimal (wie oft) jeweils nach dem Mittagessen (wann) 20 Minuten (wie lange) im Wald spazieren gehen (was).

Diese Woche werde ich \_\_\_\_\_ (was)  
\_\_\_\_\_ (wie lange/wie viel)  
\_\_\_\_\_ (wann)  
\_\_\_\_\_ (wie oft)

Wie zuversichtlich sind Sie, dass Sie es wirklich tun?  
(0 = nicht zuversichtlich; 10 = ganz zuversichtlich) \_\_\_\_\_

	Überprüfung	Notizen
Montag		
Dienstag		
Mittwoch		
Donnerstag		
Freitag		
Samstag		
Sonntag		

# «health information»

Lorig's book on "Living a healthy life with chronic conditions"  
Dialogue health's "WIE? SO!"

# Supplemental book in German and French

Lorig's book – based on research, developed/adapted with patients



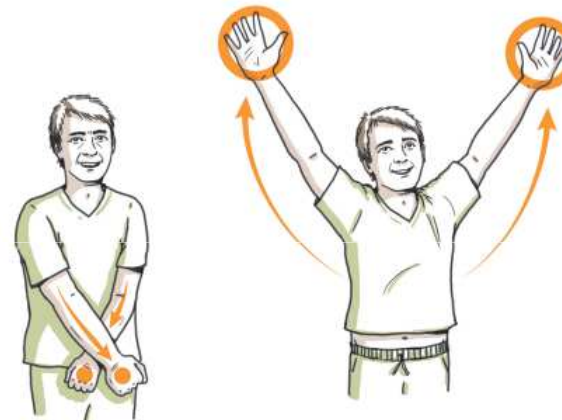
## Relevant health information on i.e.:

- Active self-management
- Understanding and managing symptoms
- Exercise
- Relaxation
- Fatigue
- Difficult emotions, depression
- Communication
- Healthy eating
- Medication management
- Advanced directive
- And many others

# Collaboration and ‚patient‘ engagement

Adapting Lorig's book: structural aids, clarity, «warm language»

<b>„Das also ist des Pudels Kern.“</b>	Der erste und wichtigste Schritt, um ein Problem solches zu erkennen. Gleichzeitig ist das oft am man sogar, dass das Treppensteigen ein Problem herauszufinden, warum – etwa die Angst zu stür
<b>Ideen sammeln</b>	Sobald Sie das Problem erkannt haben, sammel die zu seiner Lösung beitragen. Stellen Sie selbst sammeln, aber fragen Sie auch andere um Rat Fachpersonen, Beratungsangebote usw.). Ein Tip schreiben Sie Ihre Probleme so genau wie mög besten helfen. Es macht beispielsweise einen gro



Marginal text – useful for  
«skimming», loosening up,  
‚Eye-Catcher‘ for important  
messages

Adapted and optimized  
figures

# Website evivo.ch

For course participants, leaders, stakeholder

Evivo Aktuelles Neues rund um Evivo	Evivo Veranstaltungen Alle Termine auf einen Blick	Evivo Angebote Evivo Kurse und Bücher	Evivo Kompetenzzentrum Fachinformationen und Netzwerk
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## Herzlich Willkommen bei Evivo!

Viele Menschen haben eine oder mehrere chronische Krankheiten und nicht wenige leben mit Behinderungen. Evivo ist für diese Menschen und ihre Angehörigen. Evivo unterstützt Sie, mit chronischen Krankheiten und Behinderungen gesund und aktiv zu leben.

-  In diesem Portal finden Sie alles rund um das Evivo Programm der [Careum Stiftung](#) und ihrer [Partnerinnen und Partner](#).
-  Sie interessieren sich für einen Evivo Kurs? Unter «Angebote» finden Sie alle Kurszeiten, wo die Kurse stattfinden, wer sie anbietet und von wem sie geleitet werden.
-  Sie brauchen Informationen, wie man Selbstmanagement bei chronischer Krankheit fördert? Im Kompetenzzentrum werden Sie fündig.
-  Für Ideen und Fragen haben wir jederzeit ein offenes Ohr. Schreiben Sie uns unter [patientenbildung@careum.ch](mailto:patientenbildung@careum.ch), rufen Sie uns an: +41 43 222 64 00 oder einfach per Skype: careum\_patientenbildung.





# Swiss Wellness-Guide „Wie? So?“

A ‚bottom-up‘ community project

**Health information based on needs of community members especially being better informed along “life and life-events”**

- Printed booklet
- Education on health and life-long learning
- Based on wellness-guide licence of Health Research for Action University, Berkeley CA



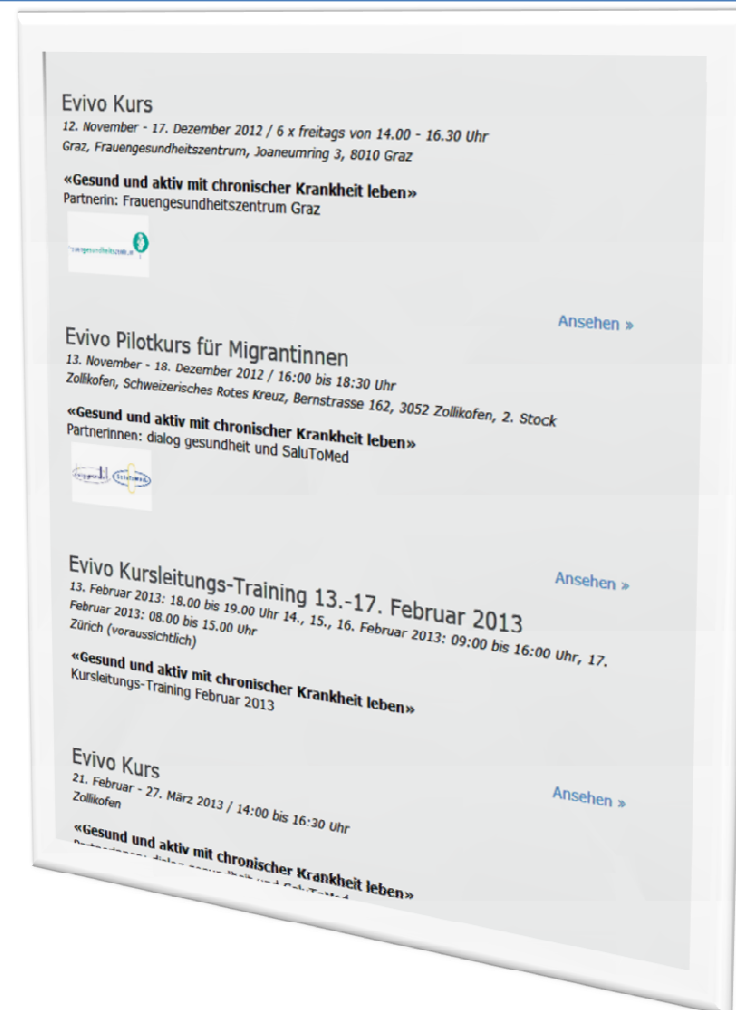
# «Early insights, first experiences»

Examples and preliminary findings from Switzerland and Austria

# Evivo – How many courses? Who participates?

## Courses and trainings since January 2012

- Currently 11 courses in CH/A (in 2012)
- Currently about 100 participants, mainly (90%), 1-2 family members per course
- Age range 20 up to 80 years
- Broad range of chronic conditions:
  - diseases related to musculoskeletal system
  - neurological disease
  - respiratory diseases
  - psychological diseases
  - cancer
  - gastro-intestinal diseases
- 3 trainings of leaders A/CH/D (n=36)



# What did Swiss and Austrian participants say?

Early findings from focus groups (spring and summer 2012)

## Patient-provider-communication

«We have been encouraged to speak with the physician and to ask questions. If you do not ask questions how can he know what our problems are and why we feel bad?»

## Group experience

«The group has encouraged me to turn my plans and wishes into a reality.»

«Terrific when patients and family members can participate in the same course. Helps a lot!»

## Motivation and «role modelling»

«It was helpful and motivating that the leaders also had a chronic condition.»

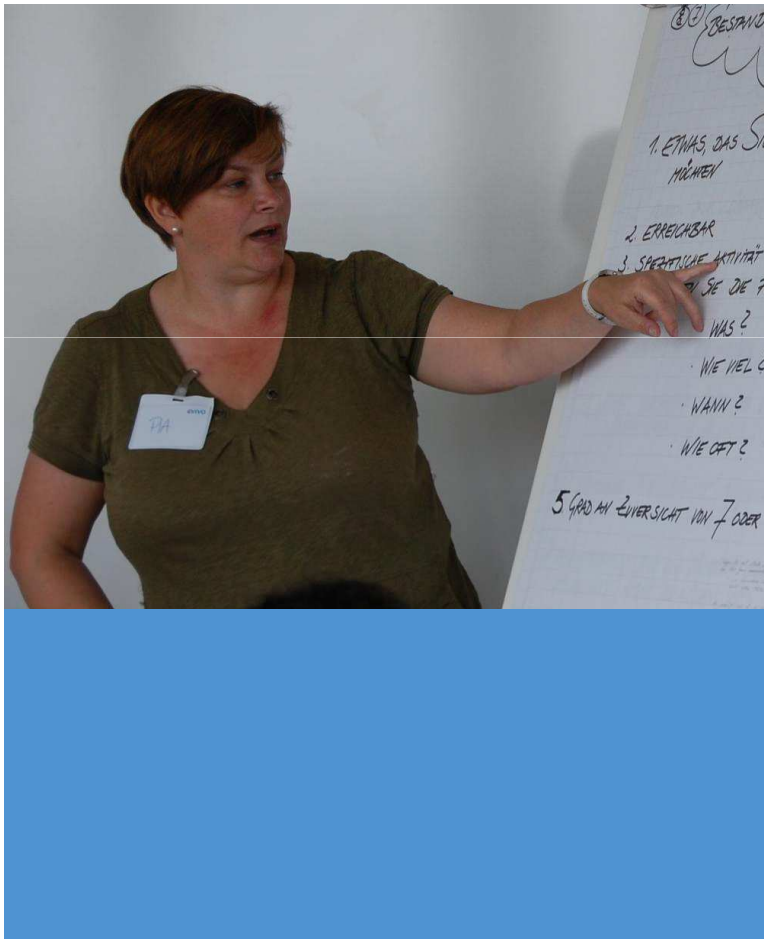
«When I saw the announcement I was thinking “Great, this is it!” and in the course you noticed “Everybody has something»



«Since the course I do my action plans consistently. And if I don't do them, I am actually missing something.»

A participating woman

## Evivo – early findings (cont.)



### Becoming aware of scope and limits

«[the] course, book, and exchange helped us to figure out what we can do by ourselves and where the limit is. The course helped us to use that scope and to start with our individual pathway.»

### Adherence and coping

One participant had stopped taking her medication; after more than 8 years she still could not believe she was ill. During the course her action plan becomes: «I will follow my regimen again!»

### Book as a resource and supplement

«I really did like the book! Everything you need to know is in there, isn't it? And it is so well written and easy to understand.»

# Closing thoughts

## About to start

Link to specific settings – vulnerable and hard-to-reach groups

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**Evivo course for migrant women**

**November/December 2012, Bern**

Partner: SaluToMed AG, dialog gesundheit

### **Kick-off in November 2012**

Evivo pilot for migrant women coming from different countries; course run in German

- Access to participants via gate keepers and champions in communities
- Engaging participants in program development

## Lots to be done – joining efforts

**Stanford model seems to work in German-speaking countries and Switzerland.**

**However, it appears to be useful to**

- join efforts and work with (inter-)national partners towards sustainability.
- be flexible within a fixed framework to bring in new perspectives.
- link it with existing approaches to create an attractive, pervious stream of programs .
- (re-)focus on diversity and hard-to-reach groups.

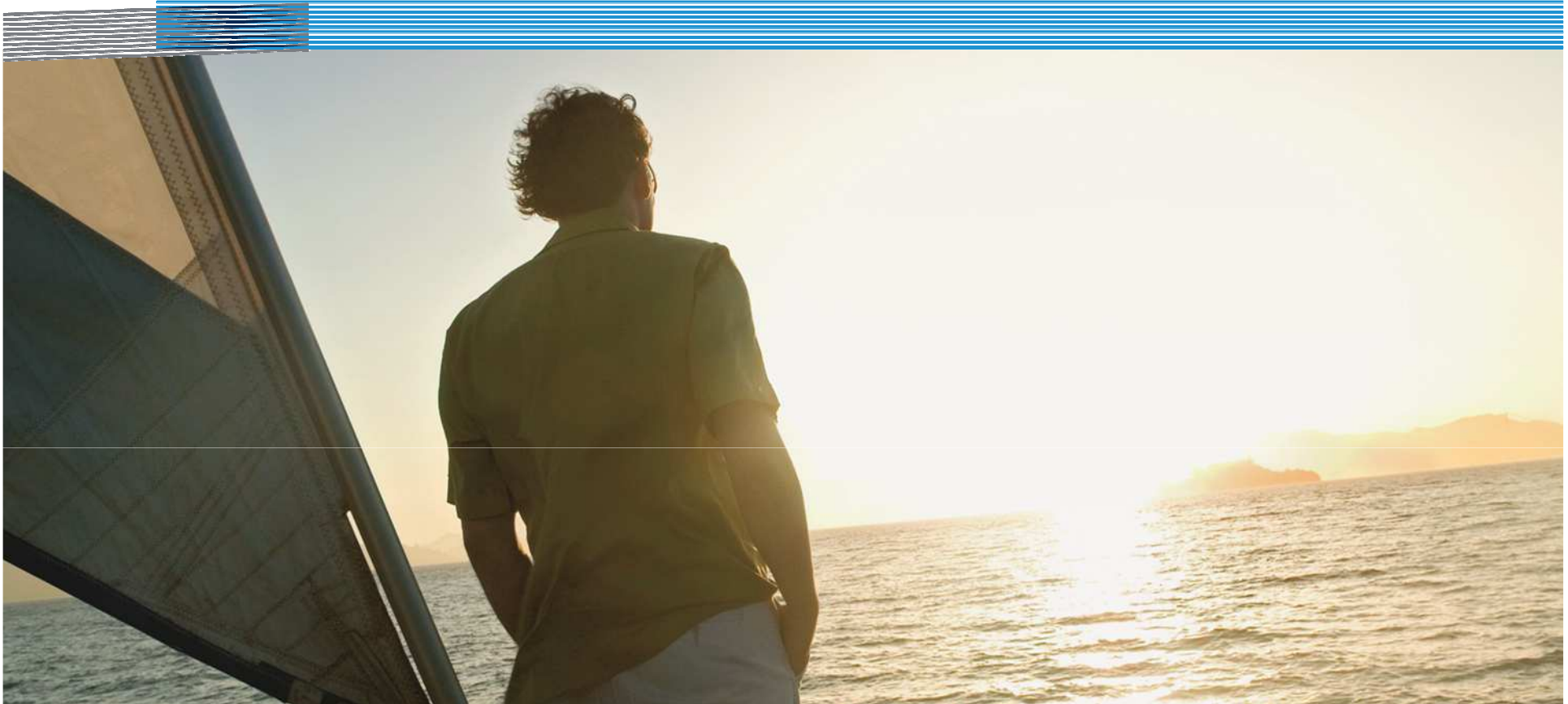




Thank you

careum

Die Gesundheitswelt der Zukunft denken



# Careum Foundation

Thinking about the future of health and care

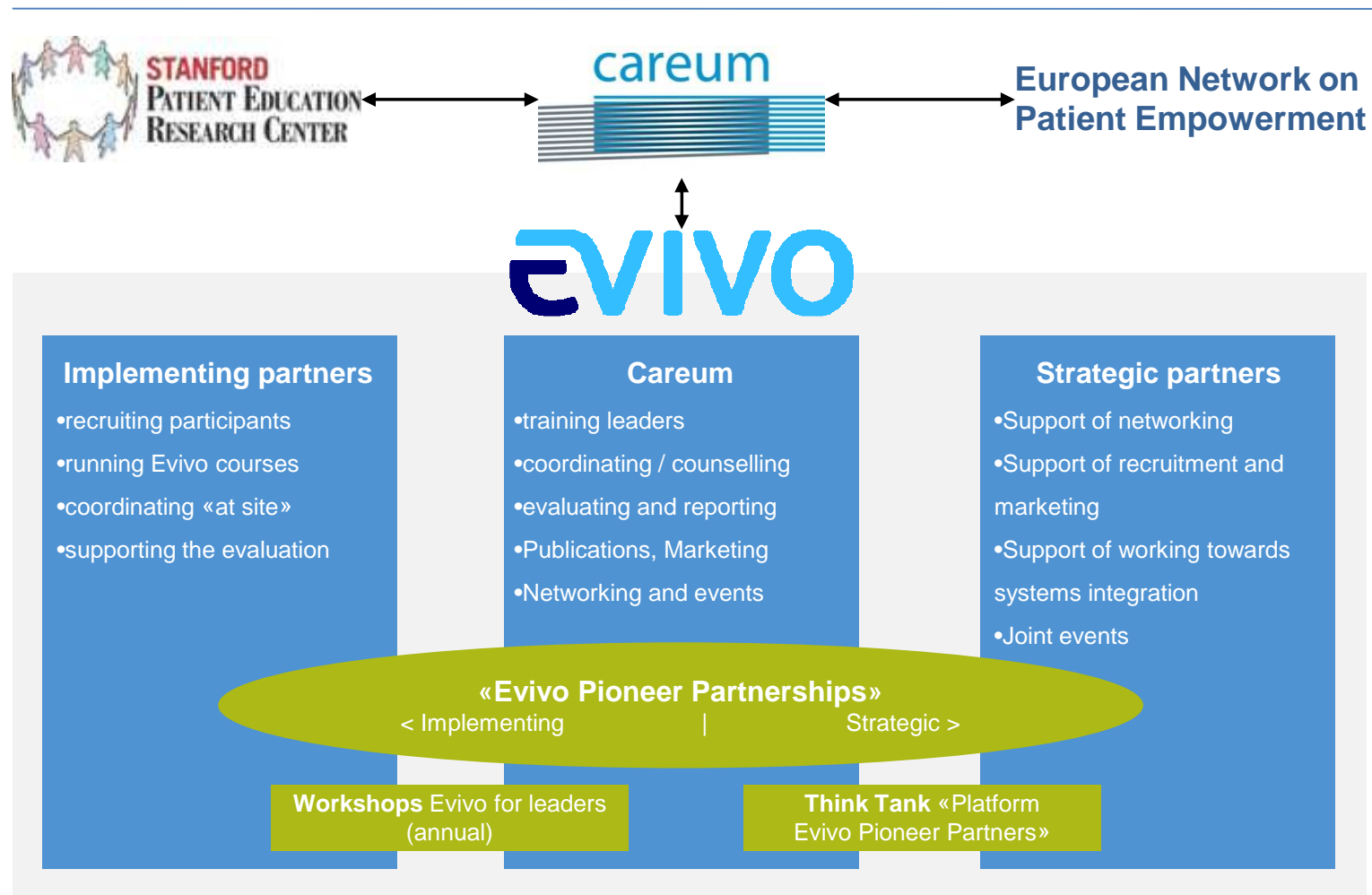
# Careum Foundation

As an independent non-profit-organization, one of Careum's principles is to improve patient skills and participation. The patient's view must be an integral part of all education and training in healthcare. Patient education as well as self-management support must be standard in healthcare education and training.

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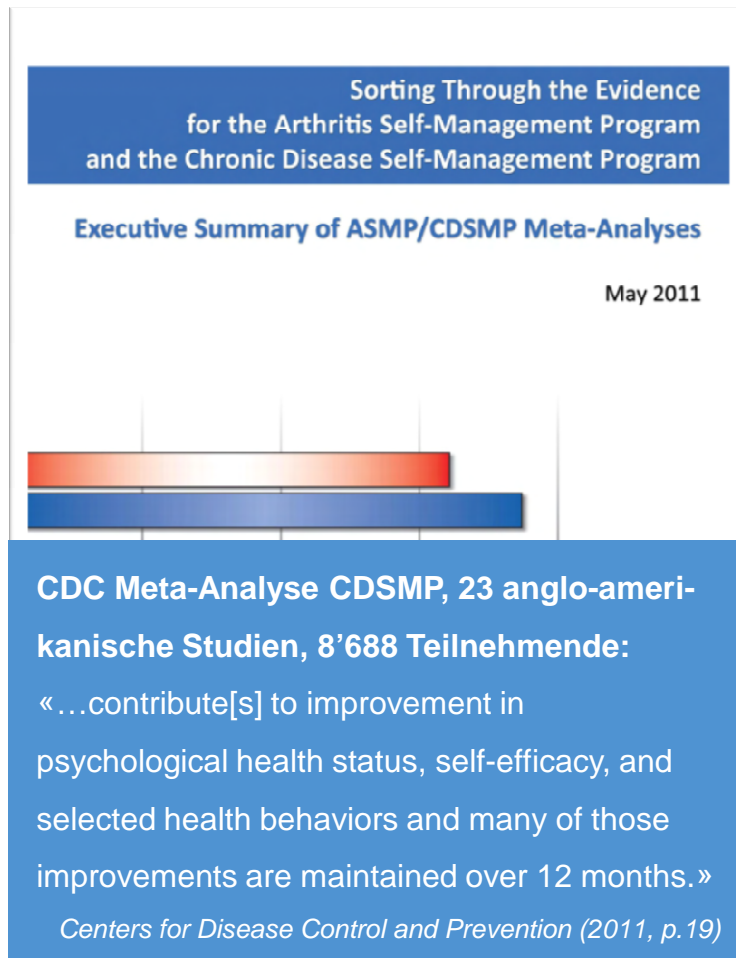
# Innovative partnering approach

Building a network and joining efforts for a sustainable implementation



# Evidenz zum Stanford Modell

«CDSMP – wesentlicher Beitrag zur Förderung von Public Health»



## Signifikant positiver Einfluss\*

- Selbstwirksamkeit
- Wohlbefinden (psych. health status)
- Erschöpfungszustand (Fatigue)
- Kognitives Symptommanagement
- Bewegung (Ausdauer, Dehnung)
- Kommunikation Fachpersonen (Arzt)
- Selbsteinschätzung Gesundheit (6 Mo.)
- Soziale Teilhabe