

Declaration of interest

Financial

No relevant financial relationship exists for the presenters. The presenters do not receive any royalty payment in connection to the tools presented.

Non-financial

All presenters are affiliated to the University of Gothenburg Centre for Person-Centred Care (GPCC)

Disposition of workshop

- Introduction
- Presentation of four of our tools:
 - The European standard 'Patient involvement in healthcare – Minimum requirements for person-centred care'
 - The PCC game
 - Mutual meetings
 - The Generic Person-Centred Care Questionnaire (GPCCQ)
- Panel discussion



Menti.com
Code: 6259 2155

GPCC (Gothenburg Centre for Person-Centred Care)

- Established in 2010
- Government funding (90 mkr) for 5 years (2010-2014)
- Continued establishment (2015-2026)
- Interdisciplinary research centre
- Research mainly about personcentredness in chronic conditions
- Organises about 100 researchers och 20-30 PhD-students
- About 30 on-going research projects

What is a person?

- Someone who has capabilities
- Someone who has self-respect
- Someone who is interacting with others

Sen A. 1993, "Capability and Well-being," *The Quality of Life*, Oxford: Clarendon Press
Ricoeur Paul (1992). *Oneself as another*. Chicago: University of Chicago Press.;
Smith, S. (2010). *What is a person?* Chicago: University of Chicago Press.

Building partnership

Initiating the partnership –
patient (and relative) narrative

Working the partnership –
mutual understanding och creation of a
health plan

Safeguarding the partnership - documenting
the agreed goals and a health plan

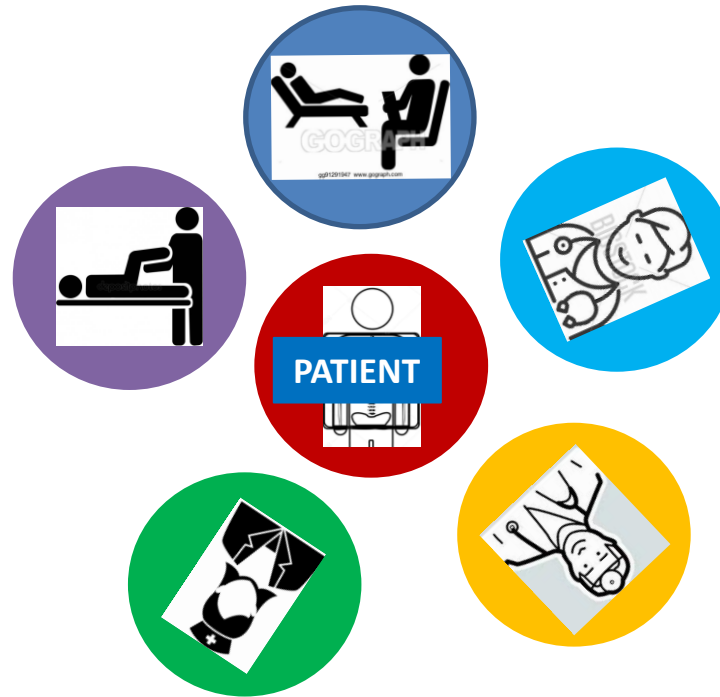


Ekman I, et al. Person-Centred Care – Ready for Prime Time. *Eur J Cardiovasc Nurs*. 2011;10(4):248-51.

Ekman I, et al. Person-centred care, - the Swedish initiative. *BMJ* 2015;350:h160

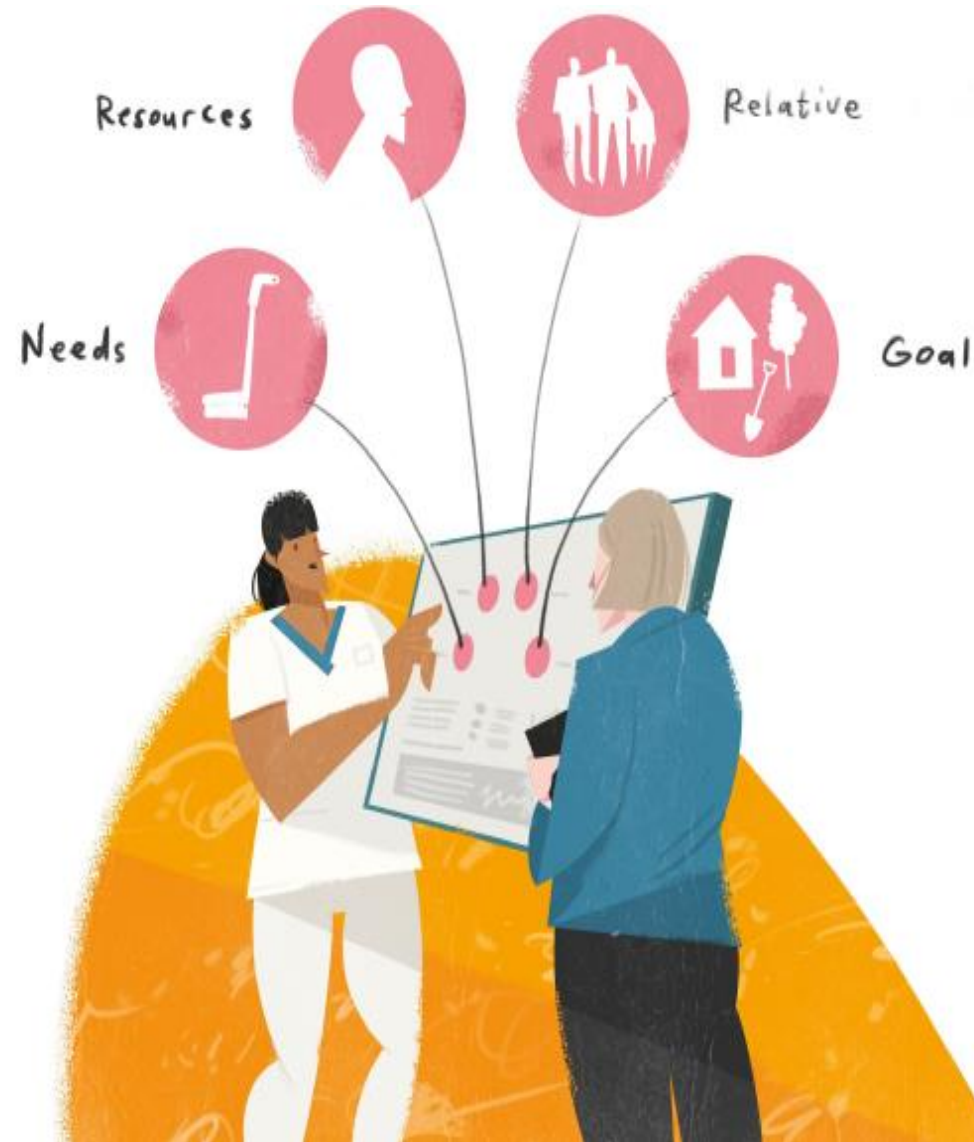
www.gu.se/gpec

Patient-Centred Care vs. Person-Centred Care



Co-created Health Plan

- Dialogue about health state, resources and needs
- Automated journal summary that presents what's important for each specific meeting
- Together updating the Health Plan with goals and healthcare strategies



Patient perspective

Håkan Hedman

SC member GPCC

President Swedish Kidney
Association

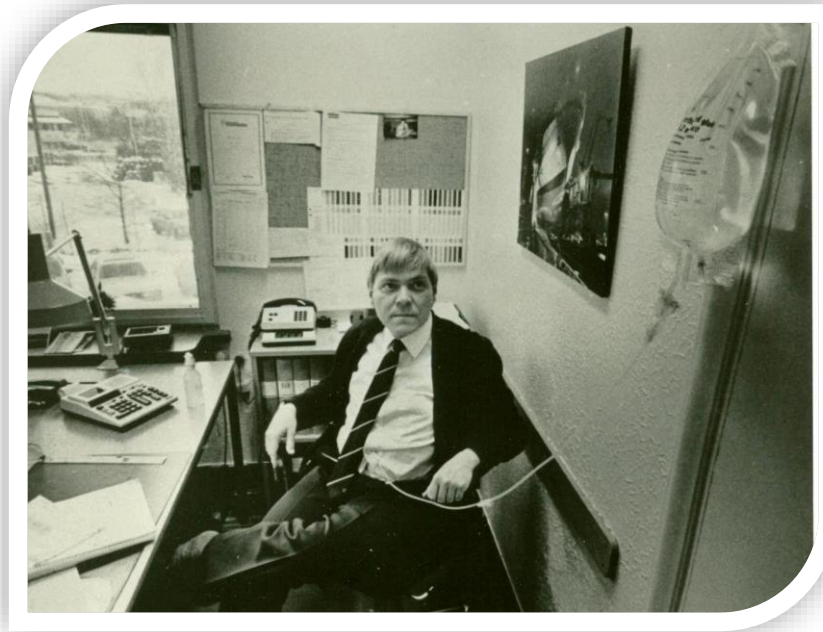
Honoray Doctor of Medicine
(MD h.c)



My background as an independent patient:



Home Hemodialysis
(HHD)
1976 – 1980



CAPD
1980 - 1985



Since 1985
kidney recipient

Person-Centered Care - in my opinion

- I am as a patient a person, not an object
- I am a partner in my care and involved in decisions and actions
- Mutual respect that I know best about my own situation while respecting the caregiver's medical knowledge.

What needs to be developed?

- Research based on patient benefit and with patient participation
- Gaps in knowledge among the public and decision-makers about what PCC means
- PCC must be implemented at all levels in healthcare, including transport of patients
- Co-influence of patient representatives in the hospital's management groups.

Summary:

With partnerships are:

- The patient participates in the development of health care
- Involved in research
- The patient is less lost in care (*vilse i vården*).
- Prerequisite for a good mutual treatment.
- Prerequisite for a good treatment result and less risk of medical injuries.
- The patient is seen and the care listens to the patient.

European Standard for Person-centred Care

Karl Swedberg

Senior Professor in Cardiology and Care Science

Sahlgrenska Academy and GPCC

[CEN COMMUNITY](#)[TECHNICAL BODIES](#)[STANDARDS EVOLUTION AND FORECAST](#)[SEARCH STANDARDS](#)[Technical Bodies](#) > **CEN/TC 450**

CEN/TC 450 - Patient involvement in person-centred care

[General](#)[Work programme](#)[Published Standards](#)[EN](#)[FR](#)[DE](#)

CEN/TC 450 Published Standards

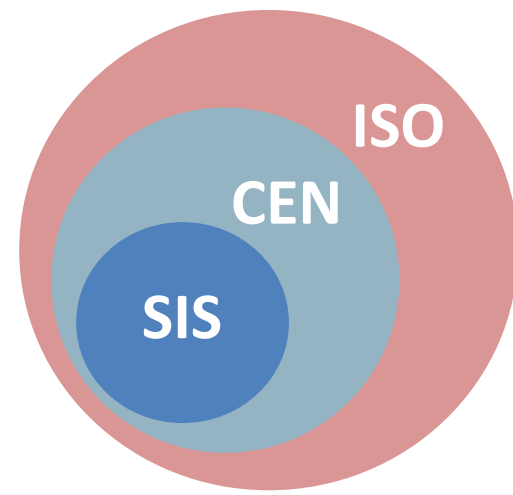
**Reference, Title****Publication date****Sales Points****EN 17398:2020** (WI=00450001)

Patient involvement in health care - Minimum requirements for person-centred care

2020-06-10



Why a Standard?



- To standardise care within and between hospitals
- To standardise care between countries
- To define research methodology within and between countries

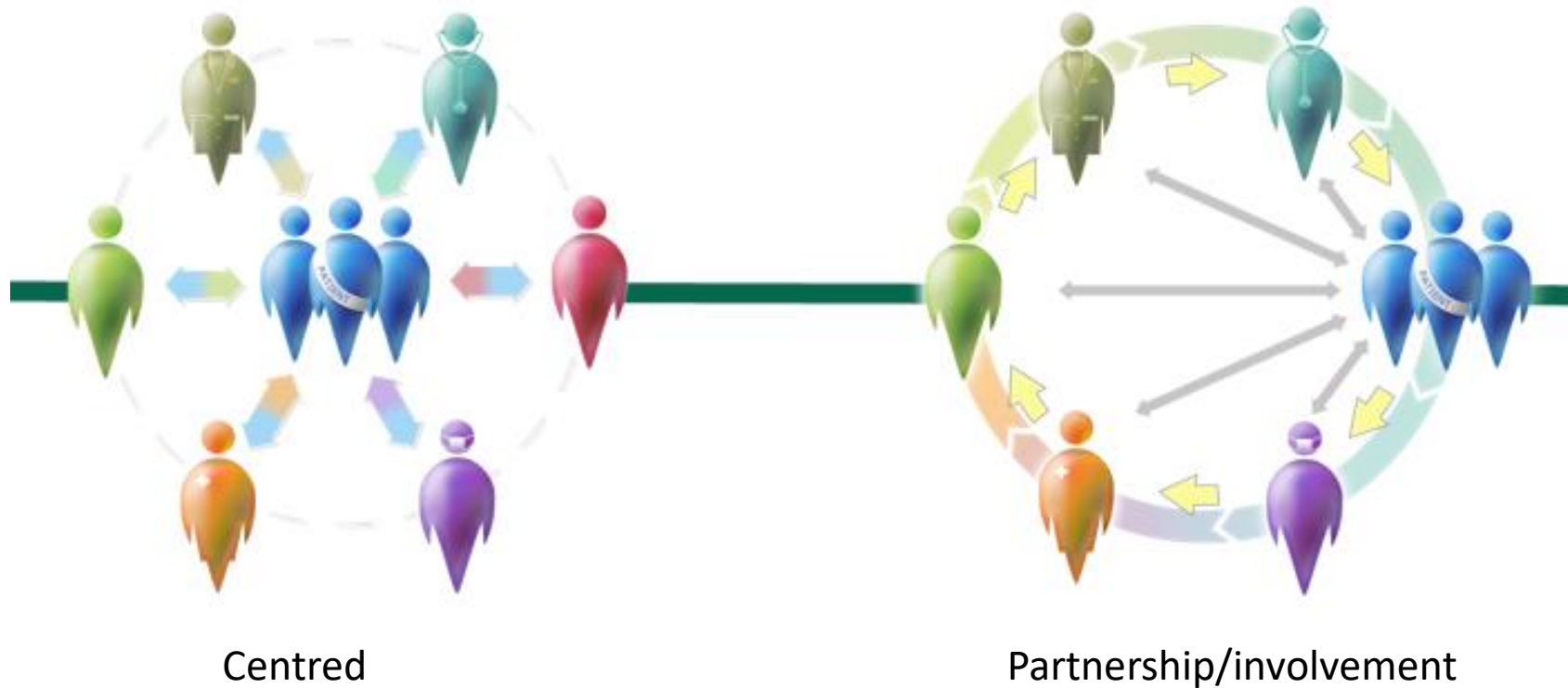
Background

- Initiative from GPCC, centre for person-centred care at the University of Gothenburg
- After contact with Swedish Institute for Standards (SIS) a Swedish Technical Committee was created Chair: Karl Swedberg

Goal and Challenges

- Goal: To create a European platform for person-centred care
 - First standard - European standard that ensures minimum requirements for patient participation in person-centered care
- CEN / TC 450 Patient involvement in person-centred care started November 2016
 - Chair: Axel Wolf, GPCC
- Controversial area - professionally controlled
- Purpose: to influence structures and processes
 - for the benefit of patients and the health care services,
 - for increased societal benefit and profit,
 - not to standardize or restrict the practice of medicine
- Different countries have different distances, different views of the patient in care and legal requirements varies.

“Patient involvement in health care – Minimum requirements for person-centred care”



European standardisation - CEN

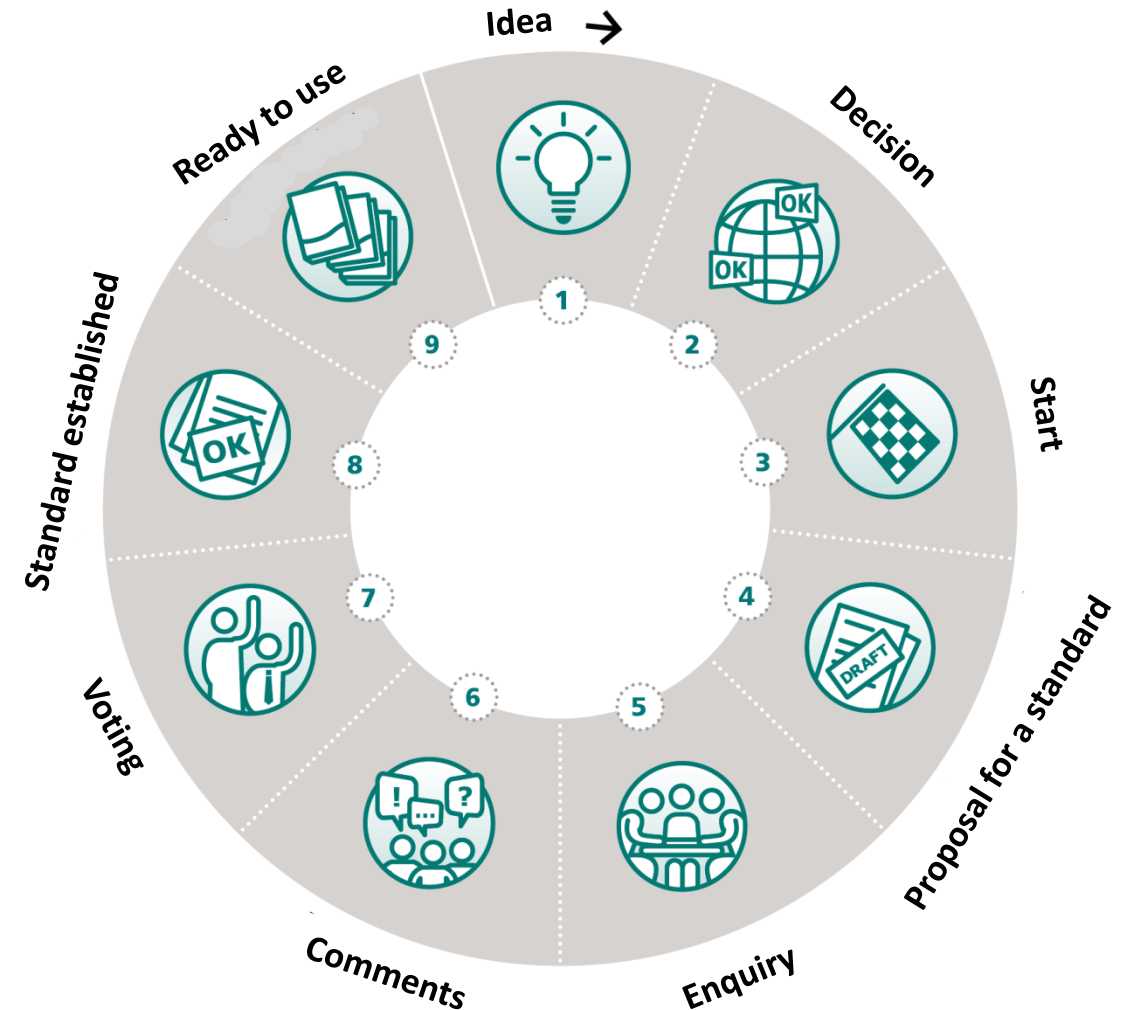
34 national members – participation, commenting, voting

Partner Organizations – eg. ANEC (no voting)

Weighted votes based on countries population sizes

Actively involved countries: Austria, Belgium, Czech Republic, Finland, Ireland, Norway, Sweden, Portugal

Actively involved organisations: European Trade Union Confederation (ETUC) and ANEC (the European consumer voice in standardisation)



Scope

- This document specifies the **minimum requirements enabling patient involvement in health care services** with the aim to create favourable structural conditions for person-centred care.
- It aims to facilitate by initiating **patient empowerment** and developing a **partnership** between the patients and their relatives
- To health care professionals that originates from the patient's resources, capacities and needs.
- It is also intended to be used on a **strategic** level for quality assurance and improvement.

Content and Struct

Four main parts:

- The patient's narrative and experience of illness

- Partnership

- Care plan

- Patient and Public Involvement in Management, Organization and Policy

Requirements in two subcategories:

- Organizational level

- Point-of-care level

Appendix with case descriptions - examples of how the standard can be used

The content is presented in the hand-out you have



How to get hold of the standard?

- Sweden:
 - GPCC has made possible to access reading the Swedish version for two years for everyone
<https://www.sis.se/standarder/kpenstandard/forkopta-standarder/personcentrerad-varld/>
 - Or if employed within an organisation connected to Swedish Association of Local Authorities and Region
- International
 - Via European Committee for Standardization (CEN): google: CEN/TC 450

[CEN COMMUNITY](#)[TECHNICAL BODIES](#)[STANDARDS EVOLUTION AND FORECAST](#)[SEARCH STANDARDS](#)[Technical Bodies](#) > **CEN/TC 450**

CEN/TC 450 - Patient involvement in person-centred care

[General](#)[Work programme](#)[Published Standards](#)[EN](#)[FR](#)[DE](#)

CEN/TC 450 Published Standards

**Reference, Title****Publication date****Sales Points****EN 17398:2020** (WI=00450001)

Patient involvement in health care - Minimum requirements for person-centred care

2020-06-10




Sales Points

Patient involvement in health care - Minimum requirements for person-centred care

Warning: CEN National Standardization Bodies have 6 months to implement European Standards from their publishing date.

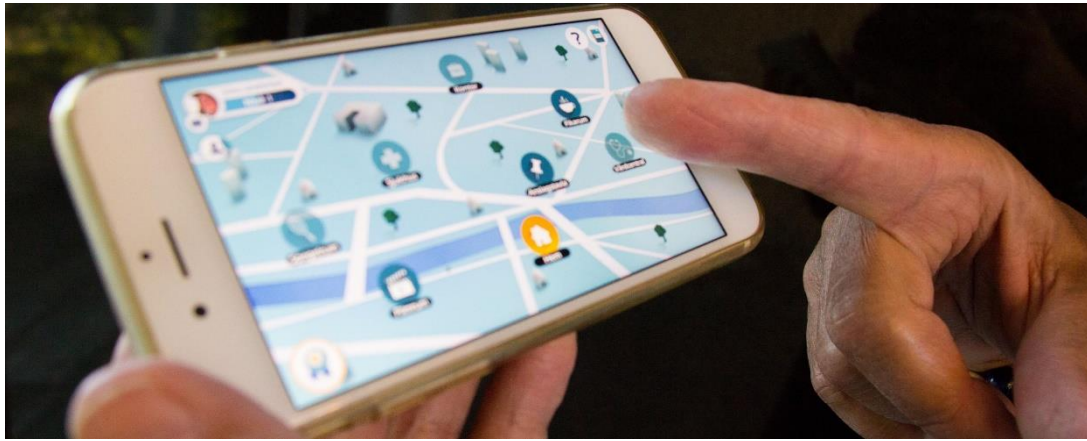
ENFRDE

Catalogue of Published Standards			
Country	National Organization	National Document Reference	
Austria	ASI	OENORM EN 17398	
Belgium	NBN	NBN EN 17398:2020	
Bulgaria	BDS	BDS EN 17398:2020	
Croatia	HZN	HRN EN 17398:2020	
Cyprus	CYS	CYS EN 17398:2020	
Denmark	DS	DS/EN 17398:2020	
Estonia	EVS	EVS-EN 17398:2020	
Finland	SFS	SFS-EN 17398:2020	
France	AFNOR	NF EN 17398	
Ireland	NSAI	I.S. EN 17398:2020	
Latvia	LVS	LVS EN 17398:2020	
Lithuania	LST	LST EN 17398:2020	
Malta	MCCAA	SM EN 17398:2020	

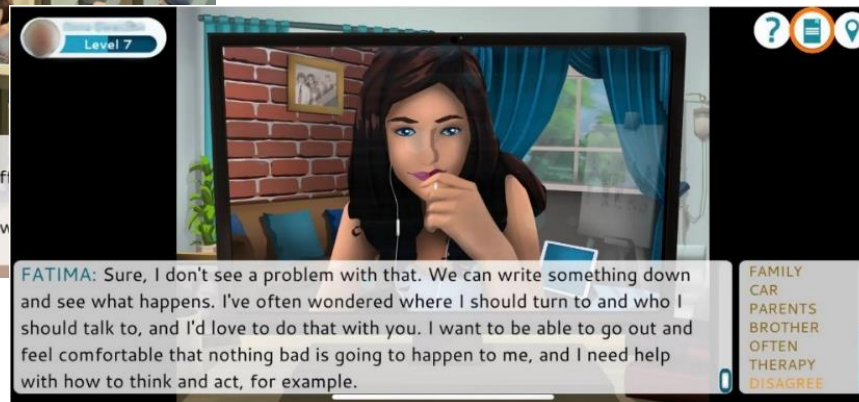
Summary

- Goal:
 - To create a European standard with minimal requirements for person-centred care (Achieved)
 - To support national guidelines for patient involvement
 - To support the process to increase patient involvement
- Applicable for different services in health care including self-care
- Consensus driven process by participation of 34 countries
- Consensus within the Swedish and CEN technical committees
- Approved 2020-06-16
- GPCC has made possible to access reading the Swedish version for two years

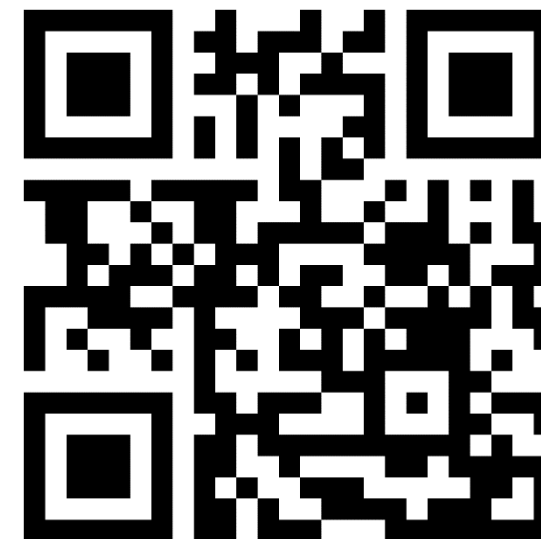
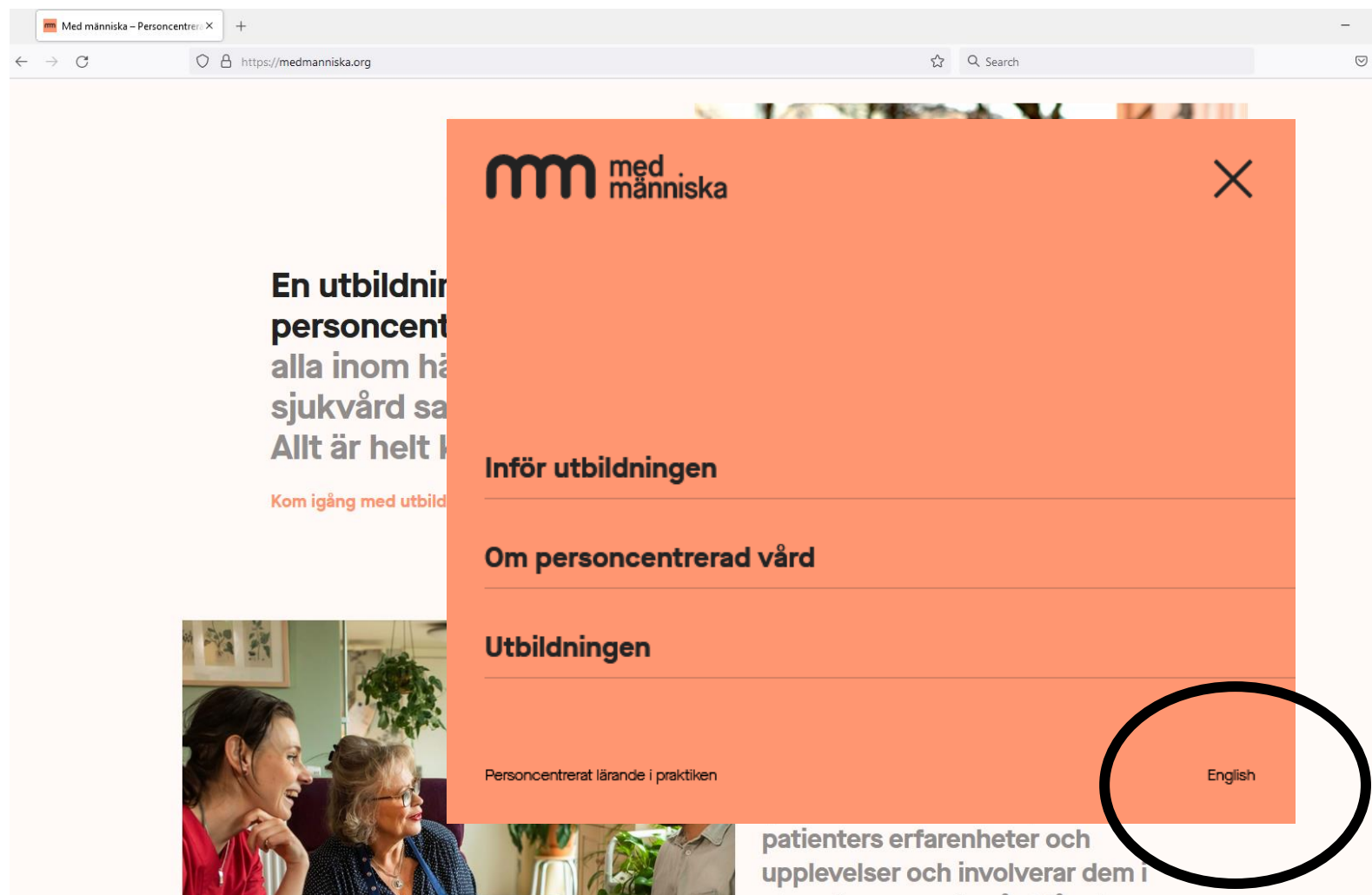
The Person-Centred Care game (PCC game)



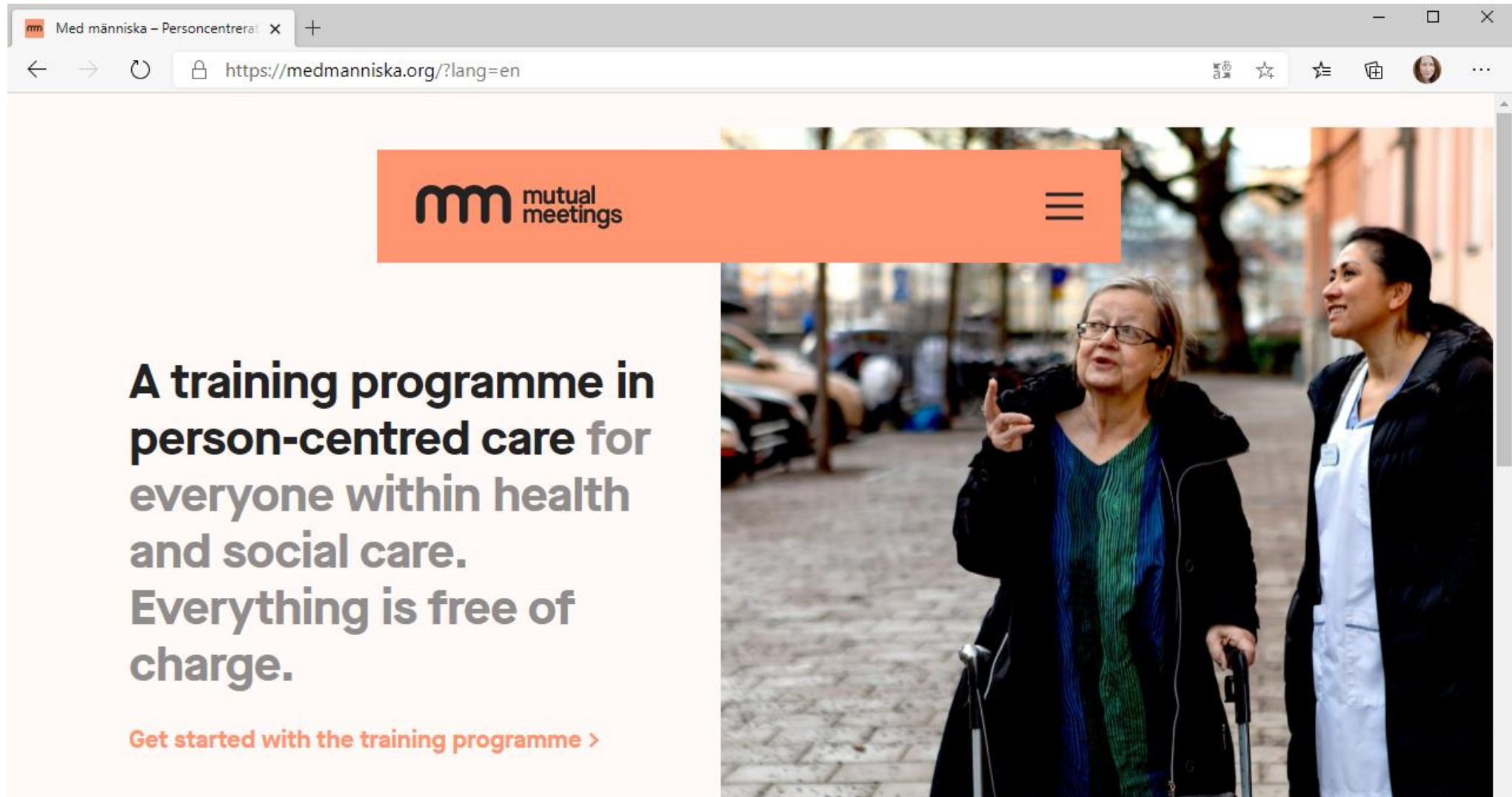
- A serious game app
- For everyone interested in person-centred care
- Learn more about person-centred care, practice and reflect in day-to-day work/life
- Freely available from App store and Google play



Mutual Meetings www.medmanniska.org



Mutual Meetings



The image is a screenshot of a web browser displaying the homepage of the Mutual Meetings website. The browser's address bar shows the URL <https://medmanniska.org/?lang=en>. The website has a light orange header with the logo 'mm mutual meetings' on the left and a hamburger menu icon on the right. The main content area features a large, bold text block on the left and a photograph on the right. The text block reads: 'A training programme in person-centred care for everyone within health and social care. Everything is free of charge.' Below this text is a link that says 'Get started with the training programme >'. The photograph on the right shows two women walking outdoors on a cobblestone street. One woman is older, wearing glasses and a black coat over a green and blue striped top, and is using a walking stick. The other woman is younger, wearing a white lab coat over a black jacket, and is looking towards the older woman.

mm mutual meetings

A training programme in person-centred care for everyone within health and social care. Everything is free of charge.

[Get started with the training programme >](#)

Mutual Meetings

- For all professions in all types of professional practice within health care
- Groups of approx. 4-6 participants – one group leader
- Initial meeting and three modules
 - **module 1 - the partnership**
 - **module 2 - the patient narrative**
 - **module 3 – documentation**
- Each module consists of three 50-minute meetings
- Each meeting is a combination of theory, discussion and exercises

Mutual Meetings

- Between each meeting, the members of the group will practice and reflect in their day-to-day work

Equipment and materials

- Any device to access the web page (Computer monitor, projector or mobile phone)
- “The situation map”
- Square Post-It notes in blue, green, yellow and pink
- Pens for everyone in the group

The Situation Map

<p>Significant situations in relation to you patients</p> <p><small>S.g. the welcome, admission or discharge, conversations, documentation in the medical records, follow-up etc.</small></p>					
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The Partnership

<p>A</p> <p>Shared expertise</p> <p><small>We see the patient's health as the collective responsibility of the patient and the professionals and we utilize each other's expertise.</small></p>					
<p>B</p> <p>The Agreement</p> <p><small>Together with patients we arrive at decisions about goals for the patient's health and how health and social care will function.</small></p>					

The Patient Narrative

<p>C</p> <p>Experience and Perception</p> <p><small>We have an understanding of the patient's experience and perception of their symptoms and their condition.</small></p>					
<p>D</p> <p>See the person</p> <p><small>We understand the patient's abilities, the situation, and challenges.</small></p>					

Documentation

<p>E</p> <p>Shared documentation</p> <p><small>Our documentation shall capture the patient narrative, health goals and the medical information in a way that both patient and professionals understand.</small></p>					
<p>F</p> <p>Health Plan</p> <p><small>We clearly document the patient's agreed health goals and the steps/measurements get there. These are clearly and understandably documented in a health plan.</small></p>					

We who are in the group

--

Post-its - Colour code

- BLUE**
Significant situations in your relationship with patients
- GREEN**
Corresponds entirely to how we are currently working
- YELLOW**
Corresponds partially to how we are currently working
- PINK**
Does not correspond at all to how we are currently working

Post-Its - Colour code

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Significant situations in your relationship with patients
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Change Plan The Partnership

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Change Plan The Patient Narrative

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Change Plan Documentation

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The Situation Map

<div><div>Significant situations in relation to you patients</div><div>E.g. the welcome, admission or discharge, conversations, documentation in the medical records, follow-up etc.</div></div>	<div></div>	
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<div><div>B</div><div><div>The Agreement</div><div>Together with patients we arrive at decisions about goals for the patient's health and how health and social care will function.</div></div></div>		

Change Plan | The Partnership



Mutual Meetings workshop

- We will test the first minutes in **module 1 – the partnership** together
- Each round table will function as a group of "colleagues"
- I will be your group leader
- Before we begin, present yourself to your "colleagues"



How can we evaluate our implementation/QI efforts?

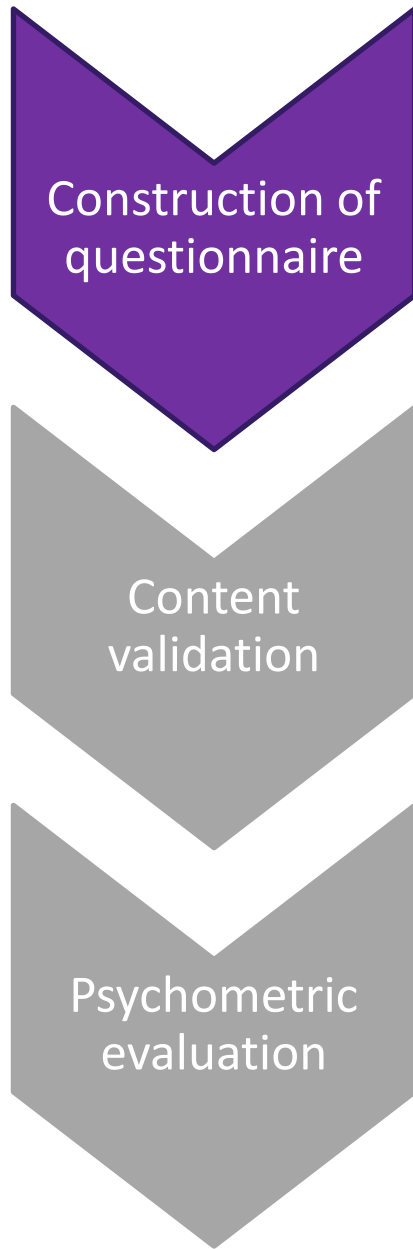
How can we measure to what degree health care is person-centred?

How can we measure change across time?

Development of a questionnaire to measure patient perceptions of person-centred care



- Operationalised to measure patients' perceptions of PCC in line with GPCC's concept
- Generic, not tied to setting, patient disease group or health care profession
- Relatively short, approx. 15 items
- Potential to be used for evaluation of PCC (before/after)



Review of literature

Key informants (3 researchers, 3 clinicians)

Review of existing questionnaires

Items from the National patient survey (n=19 items)

Version 1.0



Delphi study (2 rounds)
Content validity by CVI and expert comments
(3 patients, 3 researchers, 2 clinicians)
Questionnaire 2.0 (n=20 items)



Patients (n=553)

Rasch analyses

Cognitive interviews (n=10), freetext comments and fieldnotes analysed with deductive content analysis

Results

"I want the staff to understand that they are an important support for me. They are positive; they explain they don't just do things over my head because at other places they don't listen at all".

Results

Fridberg et al. *BMC Health Services Research* (2020) 20:960
<https://doi.org/10.1186/s12913-020-05770-w>


BMC Health Services Research

RESEARCH ARTICLE

Open Access

Development and evaluation of the measurement properties of a generic questionnaire measuring patient perceptions of person-centred care



Helena Fridberg^{1*} , Lars Wallin^{1,2}, Catarina Wallengren², Anders Kottorp³, Henrietta Forsman¹ and Malin Tistad^{1,4}

Continued work...

"There are a lot of things in health care that the staff members take for granted. I want to be a part of making decisions for myself. After all, it's about me and my body".



PLEASE SUBMIT YOUR FEEDBACK



Join at slido.com
#quality2022