Norwegian Centre for
E-health Research

Person Centered Care and its Principles

Gro Rosvold Berntsen – Professor

Norwegian centre for e-health research

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On behalf of an ISQUA working group on Person-Centered Care: S Yaron, M Chetty, C Canfield, L Ako-Egbe, P Phan, C Curran, and I Castro

ISQua
International Society for Quality in Health Care

ISQUA PCC group

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Louis Ako-Egbe

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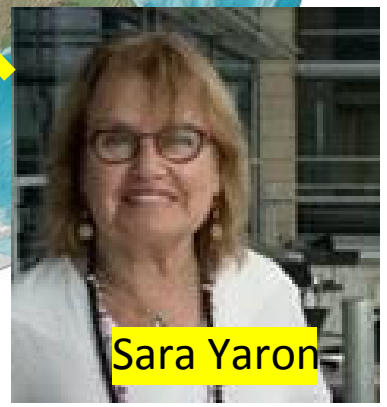


Sara Yaron

Our mission

- Draft of a white paper on PCC for ISQUA => up for review

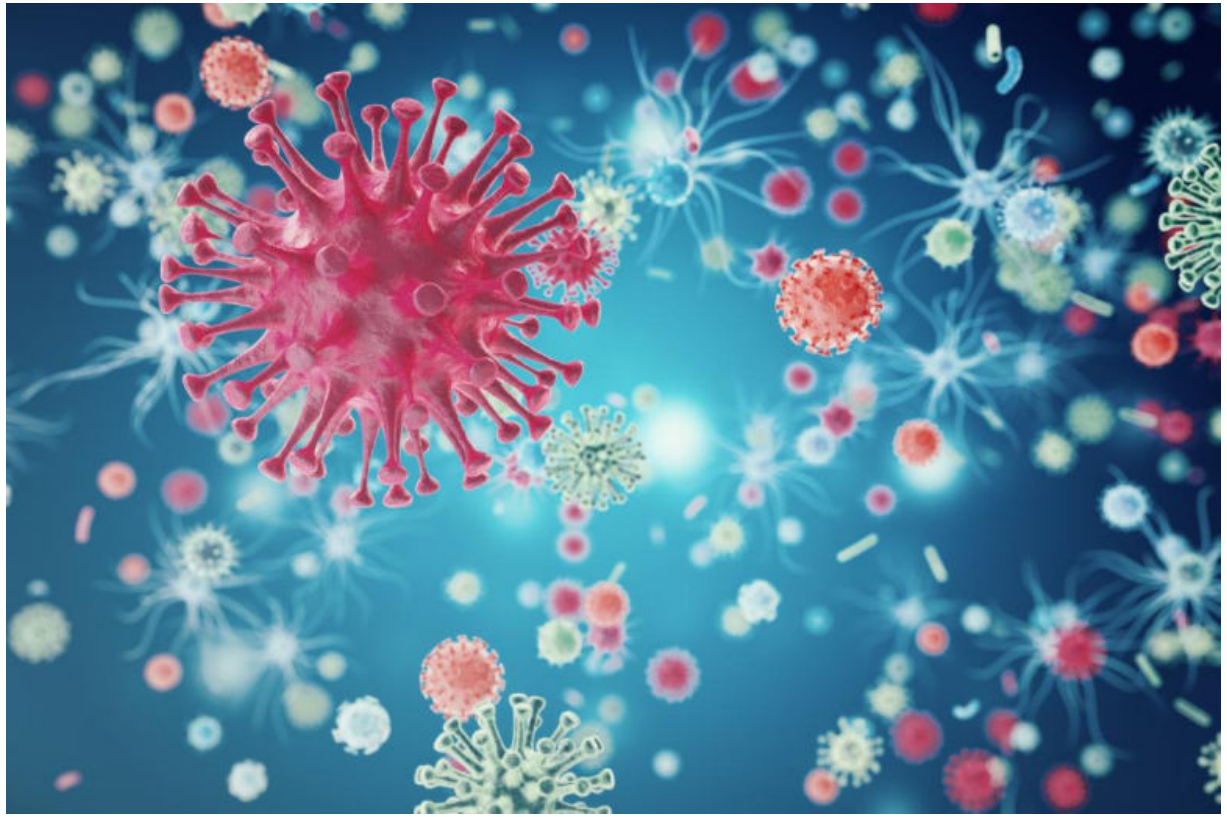
- Building awareness, knowledge and reflection:
  - Why is PCC important
  - What is PCC ?
  - How PCC can become a design feature of our care systems ?

Why is PCC important?
Case stories

The story of «Robert»

- Lives in a Sub-saharan country
- He is HIV positive
- He has dropped out of his Anti-Retroviral Therapy (ART) program
- ART is a life long treatement

- Up to 1/3 of HIV patients are lost to follow-up
- Why did Robert drop out?



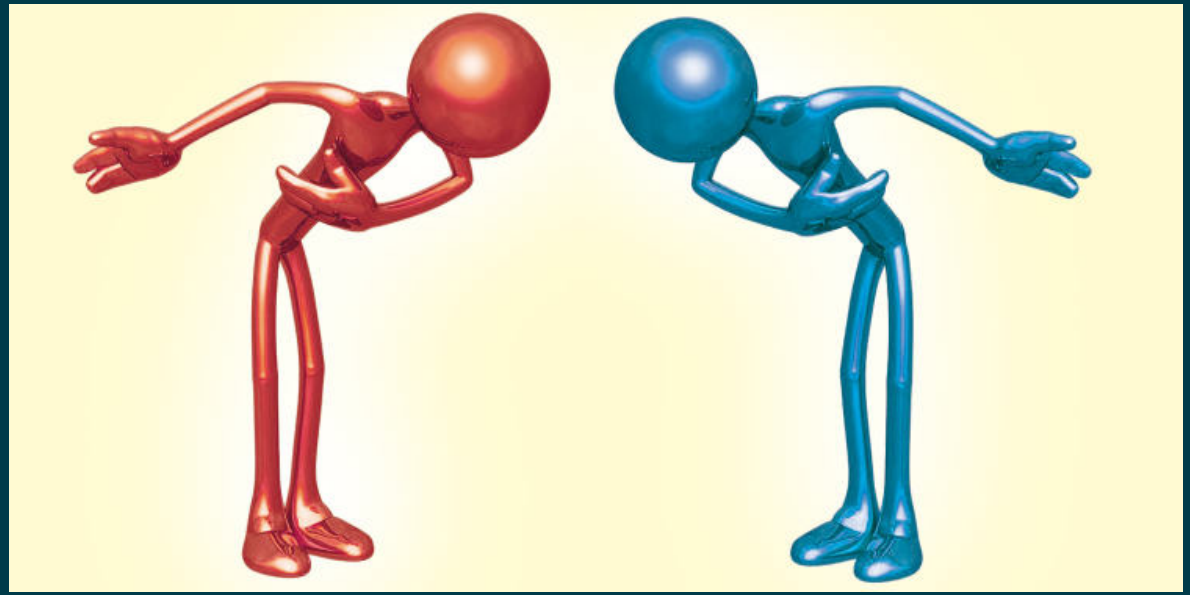
Chi BH, Yiannoutsos CT, Westfall AO, Newman JE, Zhou J, Cesar C, et al. Universal definition of loss to follow-up in HIV treatment programs: a statistical analysis of 111 facilities in Africa, Asia, and Latin America. 2011;8(10):e1001111.

- *We fail to get vehicles sometimes. And when you go to look for money for [a motorcycle taxi] you find you do not have it.*
- *So when you miss your appointment and go to clinic on another day, [the provider] starts quarreling with you about not having come on the appointed day.*
- *And when you tell that person you got problems, he tells you, "You should spend the night on the road."*
- *How can I spend the night on the road? Here I am, having failed to get money for taking me to the hospital and then I'm supposed to get money to spend the night somewhere and feed myself? These are some of the problems I have in going to the clinic.*

Ware NC, Wyatt MA, Geng EH, Kaaya SF, Agbaji OO, Muyindike WR, et al. Toward an understanding of disengagement from HIV treatment and care in sub-Saharan Africa: a qualitative study. 2013;10(1):e1001369.

Respect

- *…"Why did you stop coming to the clinic…despite what happened, you should have come back to the clinic and met other people."*
- *I told her no, I didn't want to show up because what happened to me [at the clinic] was still in my heart.*
- *If I was treated nicely the situation would have been different; since I was treated badly I saw the treatment was meaningless.*



Ware NC, Wyatt MA, Geng EH, Kaaya SF, Agbaji OO, Muyindike WR, et al. Toward an understanding of disengagement from HIV treatment and care in sub-Saharan Africa: a qualitative study. 2013;10(1):e1001369.

Maternity Care – world wide


PLOS | MEDICINE

RESEARCH ARTICLE

The Mistreatment of Women during Childbirth in Health Facilities Globally: A Mixed-Methods Systematic Review

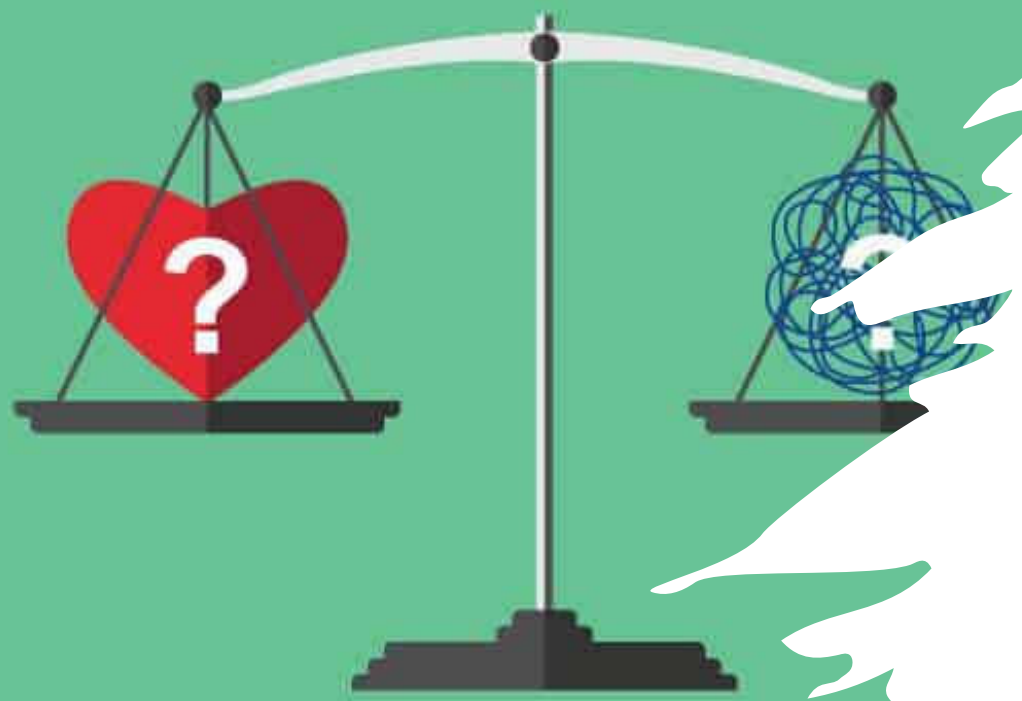
Meghan A. Bohren[1,2]*, Joshua P. Vogel[2], Erin C. Hunter[3], Olha Lutsiv[4], Suprita K. Makh[5], João Paulo Souza[6], Carolina Aguiar[1], Fernando Saraiva Coneglian[6], Alex Luíz Araújo Diniz[6], Özge Tunçalp[2], Dena Javadi[3], Olufemi T. Oladapo[2], Rajat Khosla[2], Michelle J. Hindin[1,2], A. Metin Gülmezoglu[2]

- …evidence on the mistreatment of women during childbirth in health facilities
- 65 studies - from 34 countries.
- Seven domains of abuse:
- 1) physical abuse
- 2) sexual abuse
- 3) verbal abuse
- 4) stigma and discrimination,
- 5) failure to meet professional standards of care
- 6) poor rapport between women and providers
- 7) health system conditions and constraints.

Maternity Care in 3 LMIC countries

- … 90% of 3625 women => providers never introduced themselves,
- 73% of 1980 in India => providers never asked permission before performing medical procedures.

Afulani PA, Phillips B, Aborigo RA, Moyer CA. Person-centred maternity care in low-income and middle-income countries: analysis of data from Kenya, Ghana, and India. The Lancet Global Health. 2019;7(1):e96-e109.



The health care system – an adversary?

- *“Ellen, a cancer patient in her 50s, wrote in a letter to the oncology department: . . . I’ve worked as a nurse for many years—been part of the public healthcare system.*
- *Now I feel like I’m put on the side-line, having to fight in two ‘battlefields’ at the same time, against the system and the cancer . . .*
- *I’m afraid our next meeting will not allow the time or possibility for discussing anything but medical/technical themes.*
- *I’m afraid of being seen as difficult and making incessant complaints, afraid not to get a chance to express myself and have real inter-human contact.’”[2]*

The health care systems challenge

- **Health care is not paying sufficient respect to the individuality and human dignity <u>of persons</u> who seek help from care systems.**

What is PCC?

Health foundation 2014

…there is no single agreed definition of the concept.

…still an emerging and evolving area.

The Health Foundation
Inspiring Improvement

Person-centred care made simple

What everyone should know about person-centred care

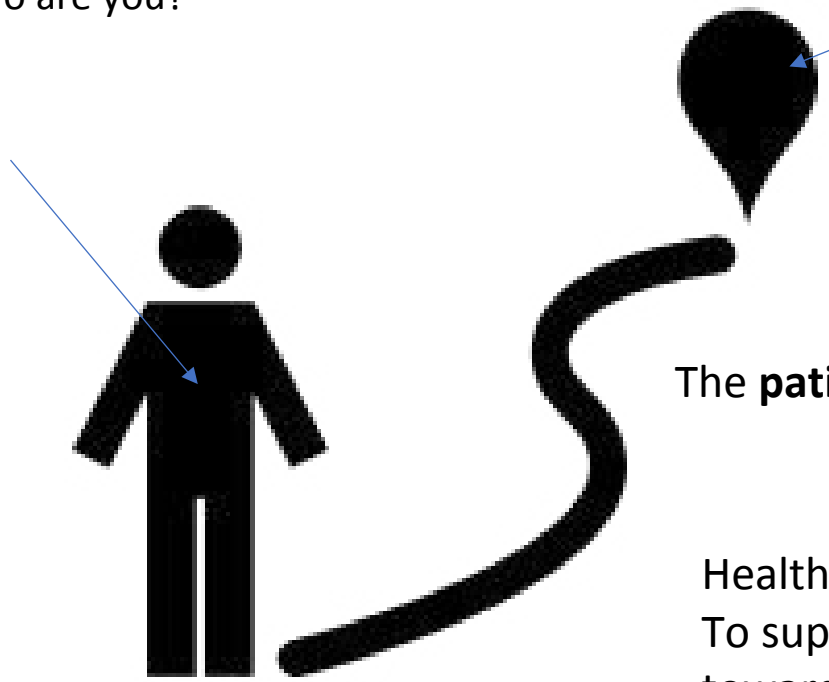
Patient value, goals and relationship

- ’Person-centred care means that **individuals’ values and preferences are elicited** and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals.
- Person-centred care is **achieved** through a dynamic relationship among individuals, others who are important to them, and all relevant providers. This collaboration informs decision-making to the extent that the individual desires”.

American Geriatrics Society Expert Panel on Person-Centered C, Brummel-Smith K, Butler D, Frieder M, Gibbs N, Henry M, et al. Person-centered care: A definition and essential elements. J Am Geriatr Soc. 2016;64(1):15-8.

The **goal**: What matters to you?

The **person:** Who are you?



The **patient journey**: How do we get to the goal?

Health care :
To support the person on their patient journey,
towards goals that are meaningful to the person

Person Centred Care

*PCC care is a sharing of power, so that the answer to: "**What matters to you**?" drives care decisions.*

*Patients and professionals co-create the **patient journey**,*

within the constraints set by the care system,

*to reach **goals** that are meaningful to the patient.*

ISQUA workinggroup on PCC

Why is PCC so difficult?

- If we do not understand the WHY PCC is not the norm
- We will not succeed in strengthening PCC

We tend to behave in line with the system goal

What we say the goal is ?
What our behaviour says the goal is ?

Vision

The goal of health care systems is to improve the health of the population it serves.

Veillard JHM, Brown AD, Barış E, Permanand G, Klazinga NS. Health system stewardship of National Health Ministries in the WHO European region: concepts, functions and assessment framework. Health Policy. 2011;103(2-3):191-9.

What is health?

- WHO -1947 :

- *"Health is a state of complete physical, mental and social well -being and not merely the absence of disease or infirmity"*

- WHO -1986 addition:
- *"Health is, therefore, seen **as a resource for everyday life**, not the objective of living.*
- *Health is a positive concept emphasizing social and personal resources, as well as physical capacities."*

How do care systems improve health?

- The consultation – this is where the person meets the professional

a professional a patient

The three roles in every patient journey

Patient,
professional

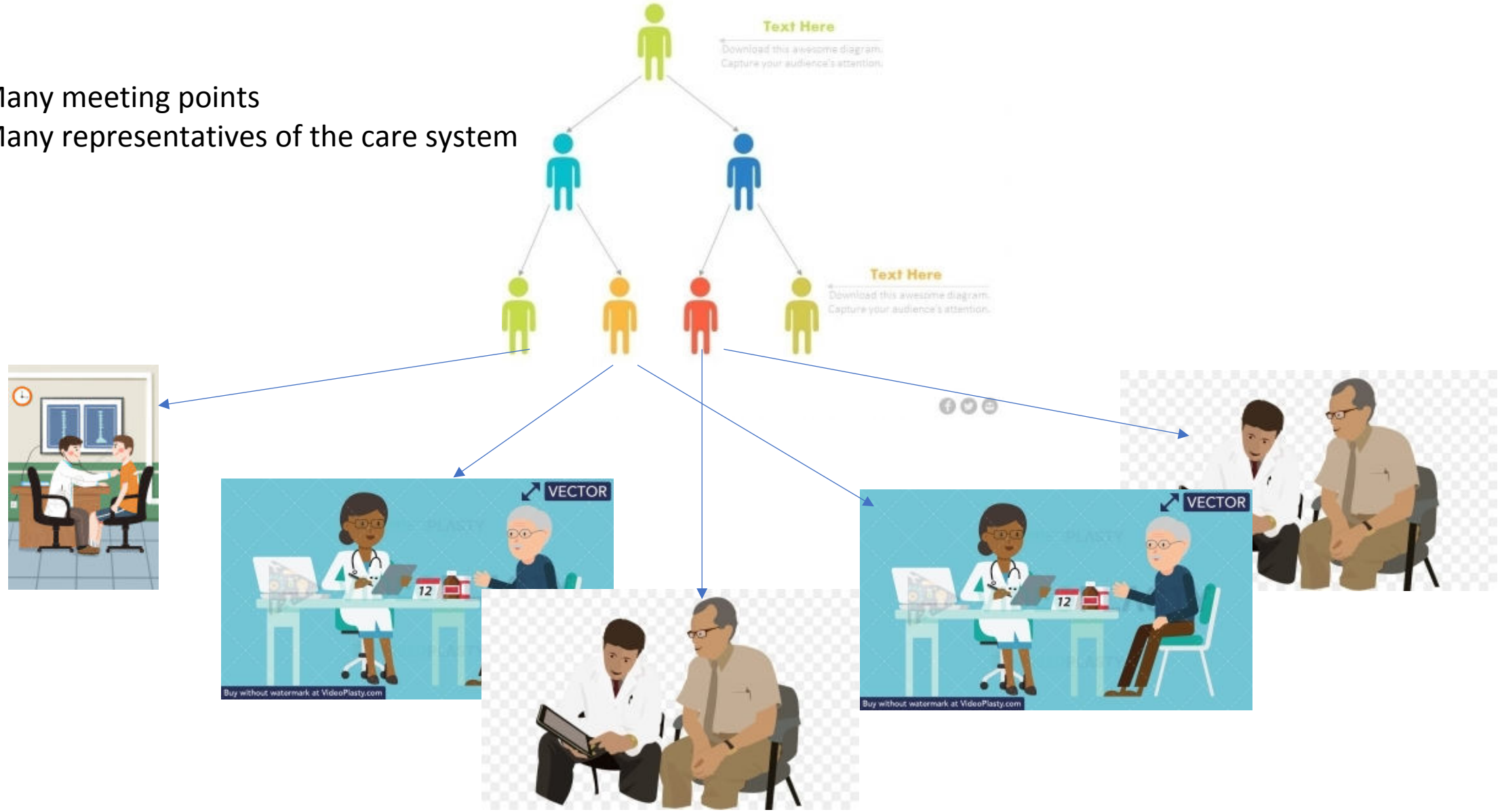
+ System

Top level
National Governance

Mid level
Organization

Front line
professionals

Many meeting points
Many representatives of the care system



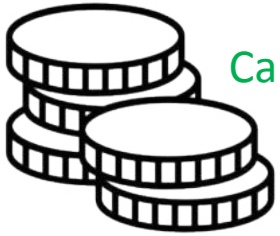
Roles and structures

Process

Desired Outcomes – Quadruple Aim

Person with a health challenge

Patient experience + health and function

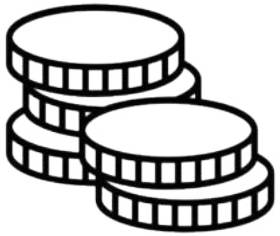


Care system/ payer

The patient Journey (PJ)
Patient - system events

Professional satisfaction

Health care team

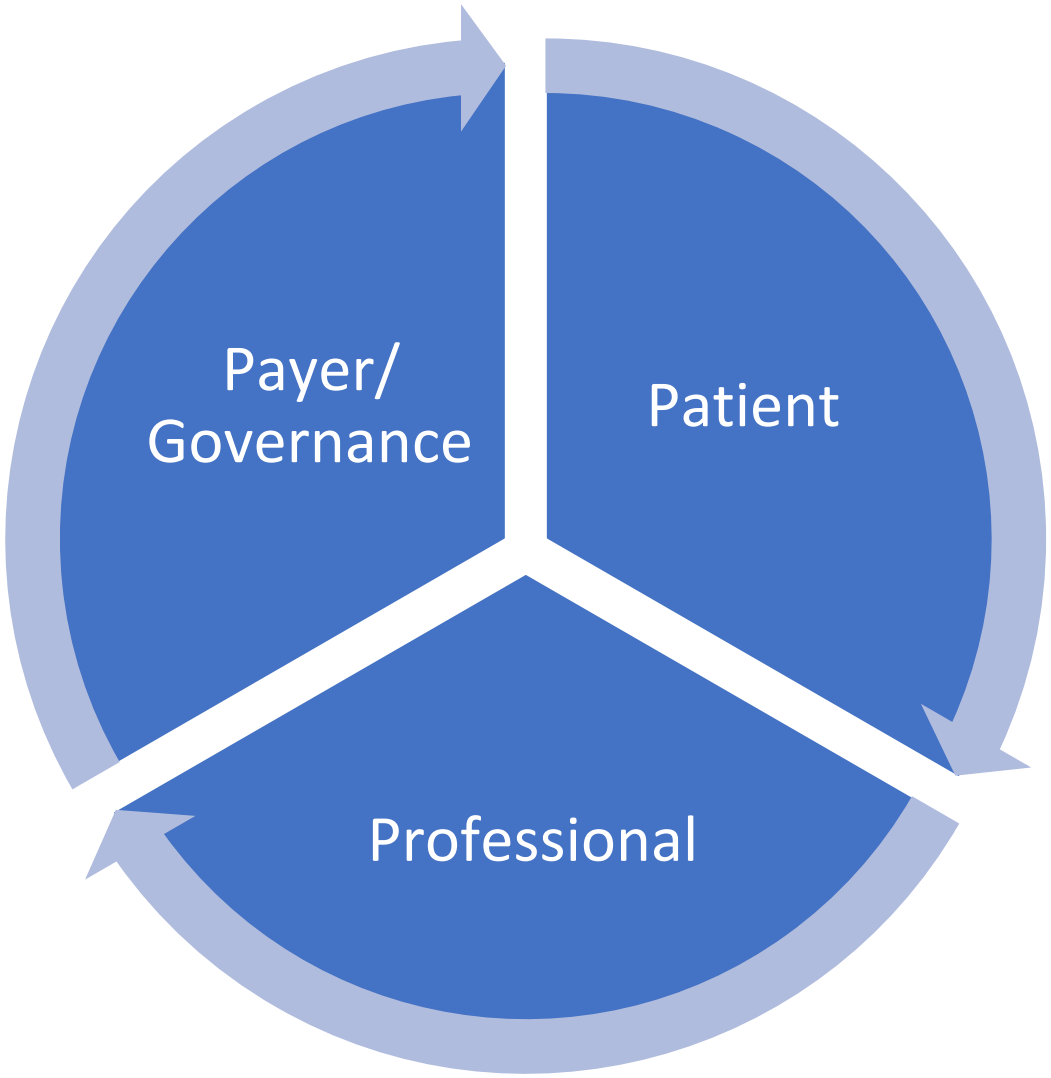


Cost-benefit ratio

Professional system-supported activities

The three goals

- The patient: My health is a resource in my life.
- Professionals: We serve to improve health and function of our patients
- Care system/ payer: We serve to maintain and improve health in the population



The clash of two lines of logic

The goals of persons:

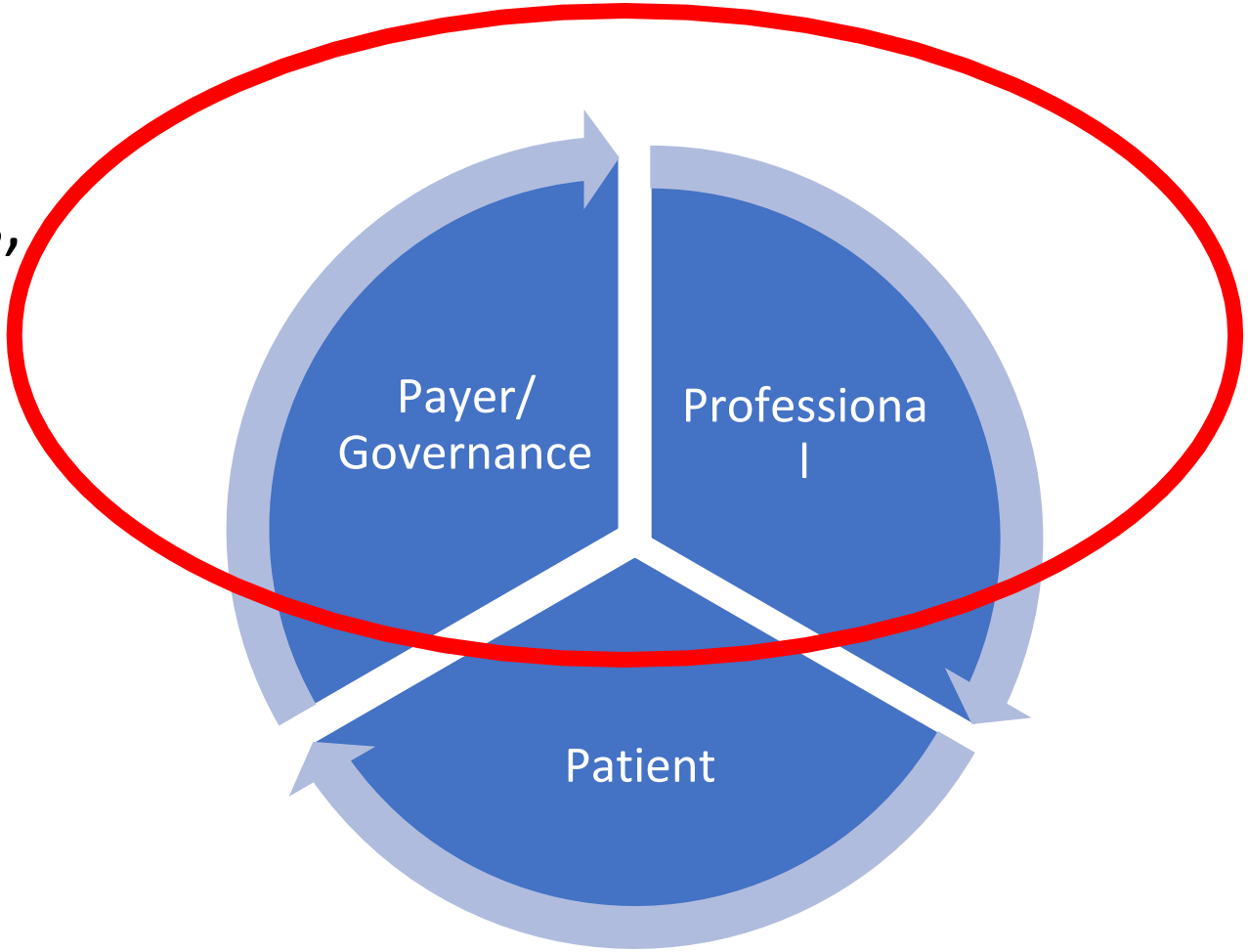
- I own my body and my health
- I have a right and duty to take care of your my health
- I need support in taking on that role, within the context of my life

The goals of system and professionals:

- Technical ecxcellence of care
- Cost-benefit ratio
- Defined by professionally defined outcomes
- A logic which does not include volatile, fluid and difficult to define personal preferences, values and needs.

Why is PCC so difficult?

- We pay more attention to the **professional** and **system** values, needs and preferences

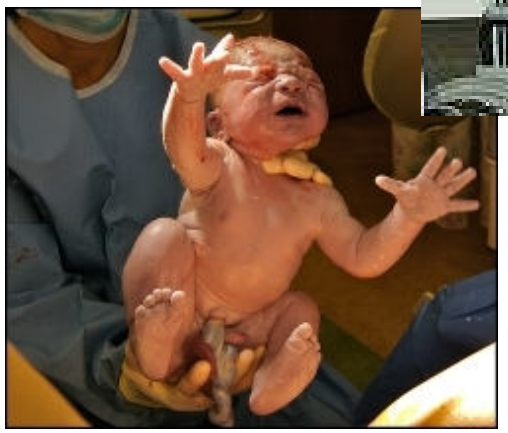


What if we do nothing?

What is of value?

Survival

A healthy child



Travel?

Grand children?

Sex?

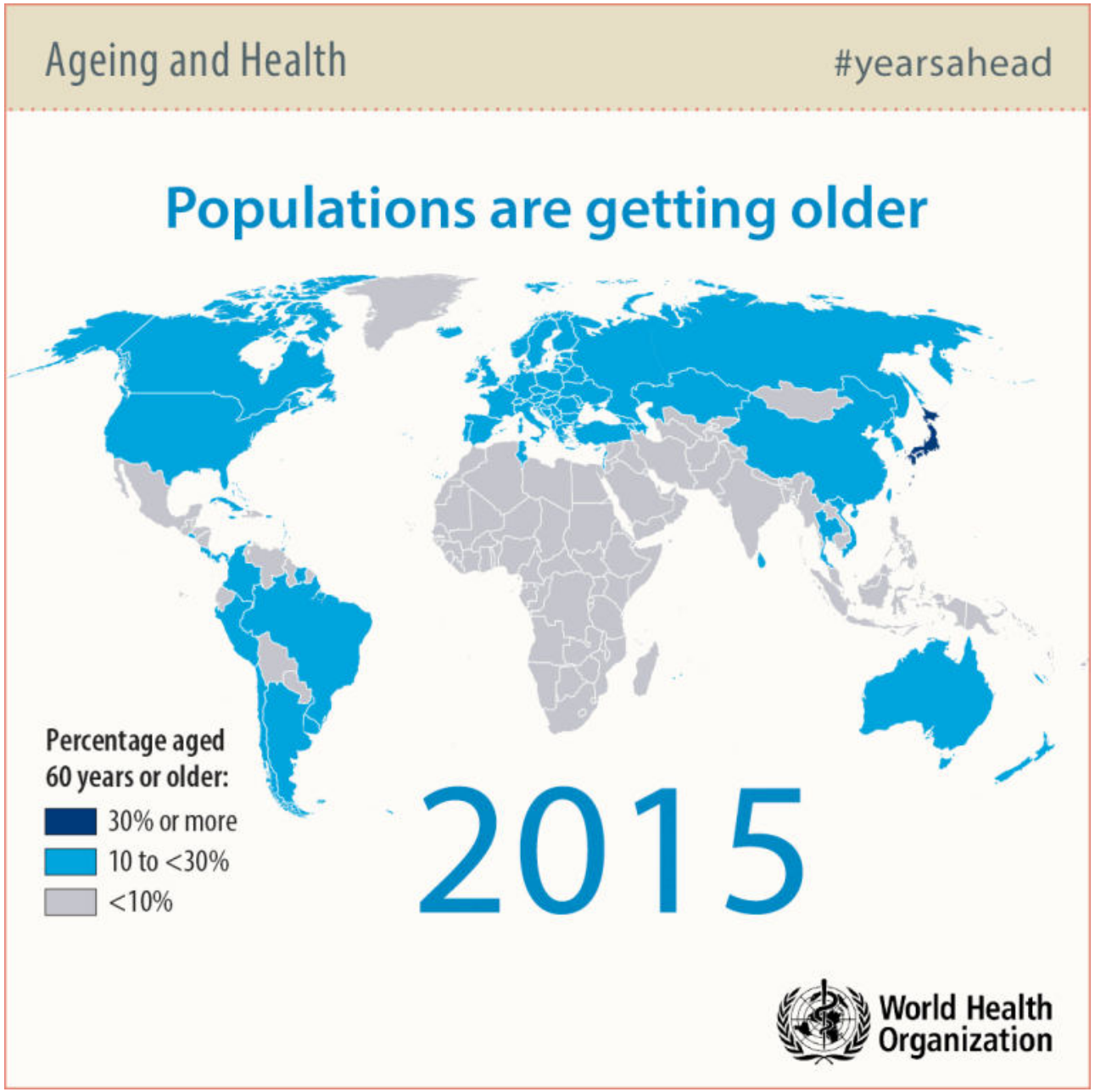
ACT on

Emergencies

Episodic needs

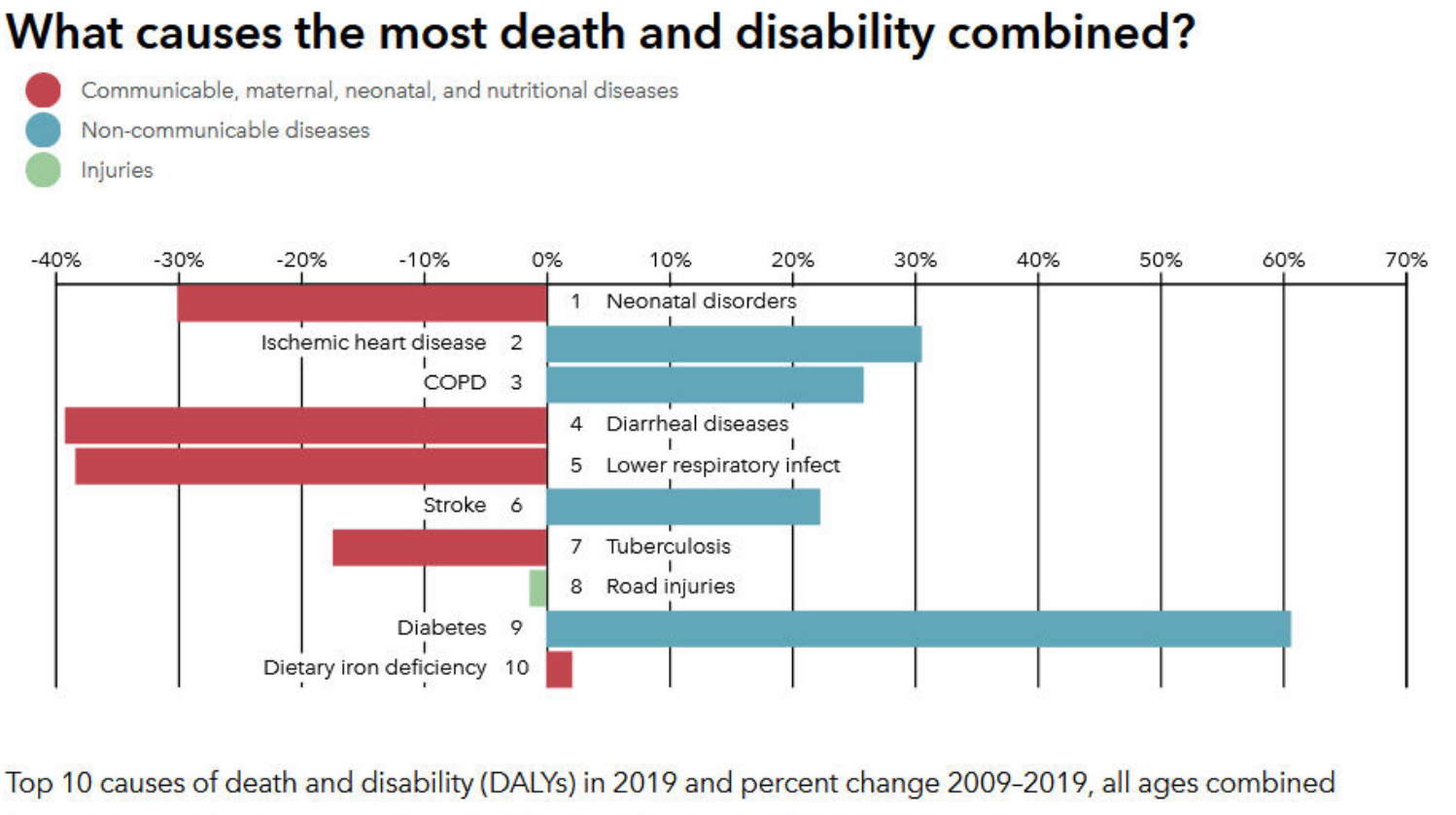
ACT - with

Long-term needs



Public health measures are successful! We are growing older all over the globe.

India – Mortality an disability statistics

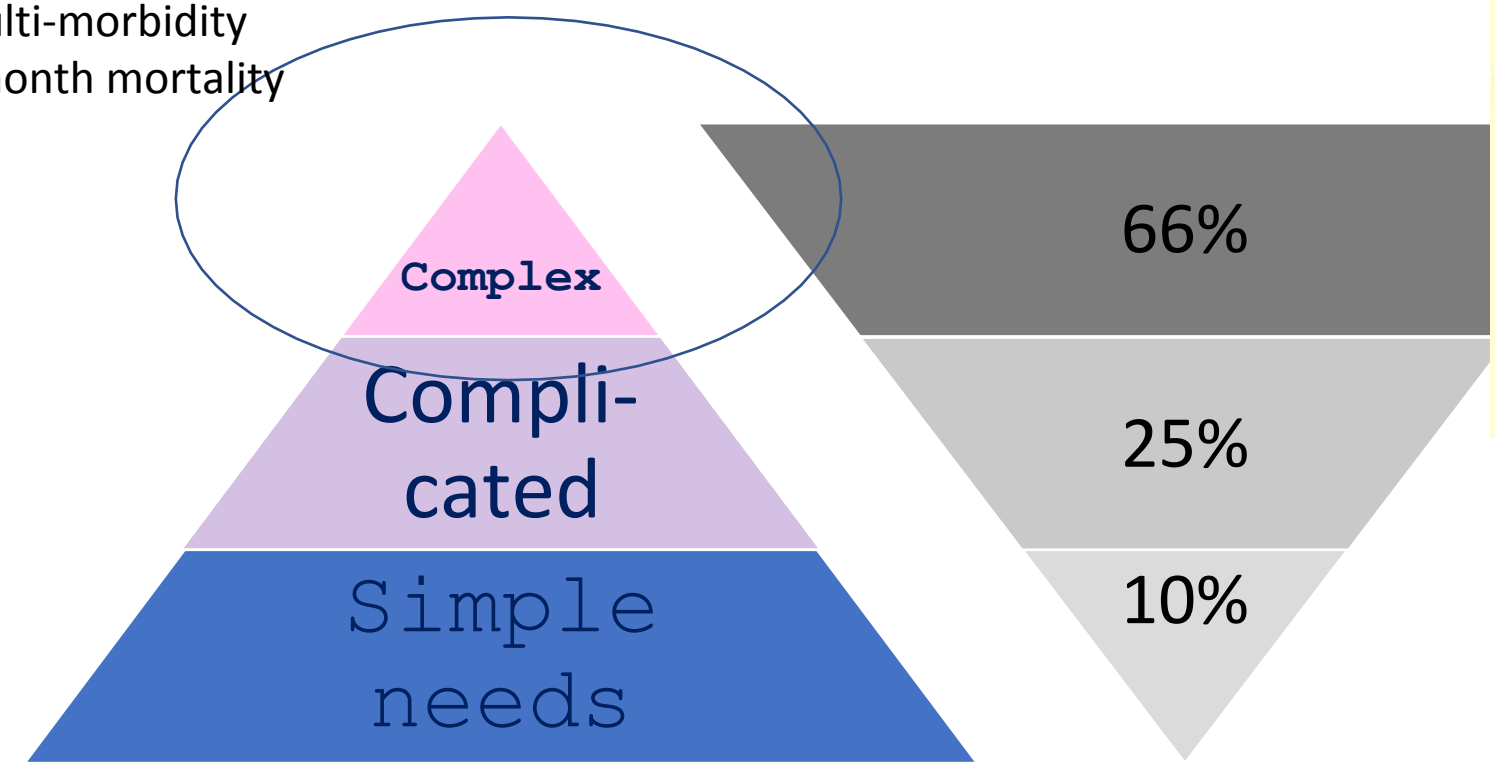


Top 10 causes of death and disability (DALYs) in 2019 and percent change 2009–2019, all ages combined

See related publication: https://doi.org/10.1016/S0140-6736(20)30925-9

10% top spenders:

- 91 % - chronic conditions
- 70% - multi-morbidity
- 13% - 6month mortality



Wang L, Si L, Cocker F, Palmer AJ, Sanderson K. A Systematic Review of Cost-of-Illness Studies of Multimorbidity. Applied health economics and health policy. 2017:1-15. PMID: 28856585. doi: 10.1007/s40258-017-0346-6.

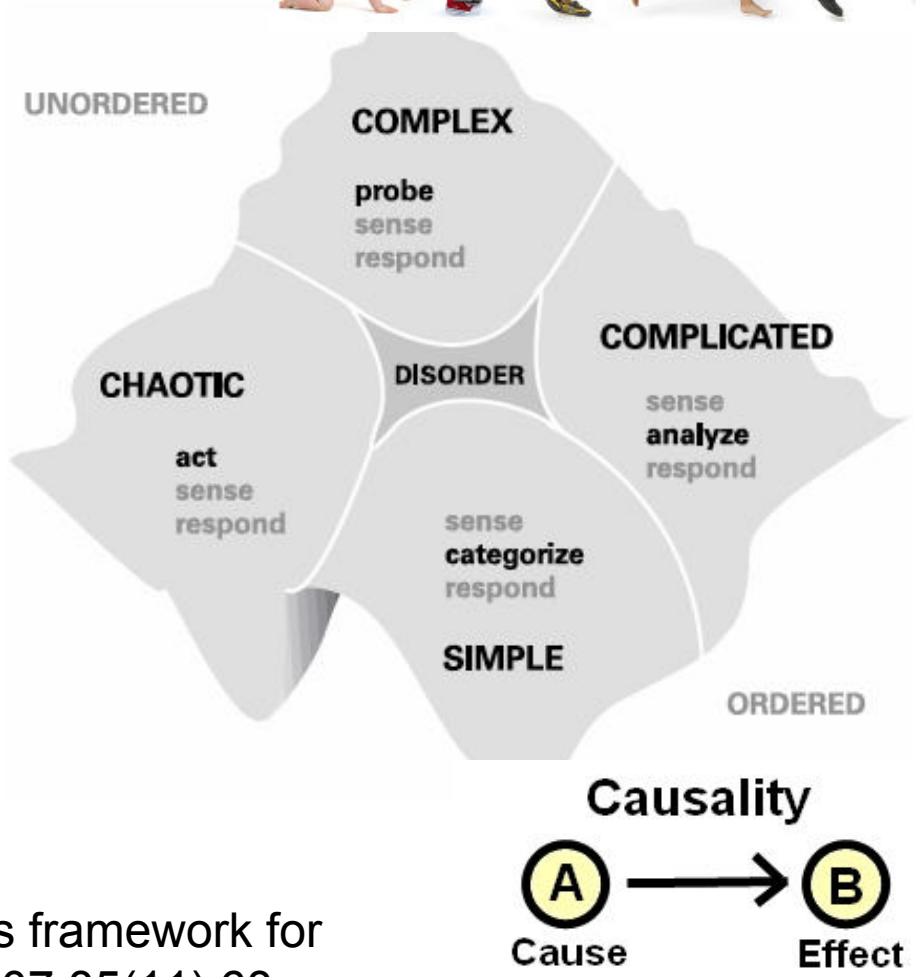
We must work **with** patients to achieve sustainable care

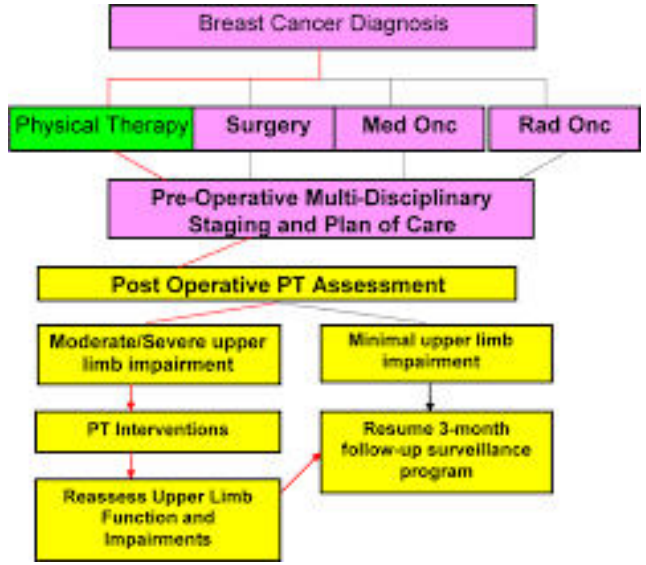
How can we change?

Complexity

Child care

War



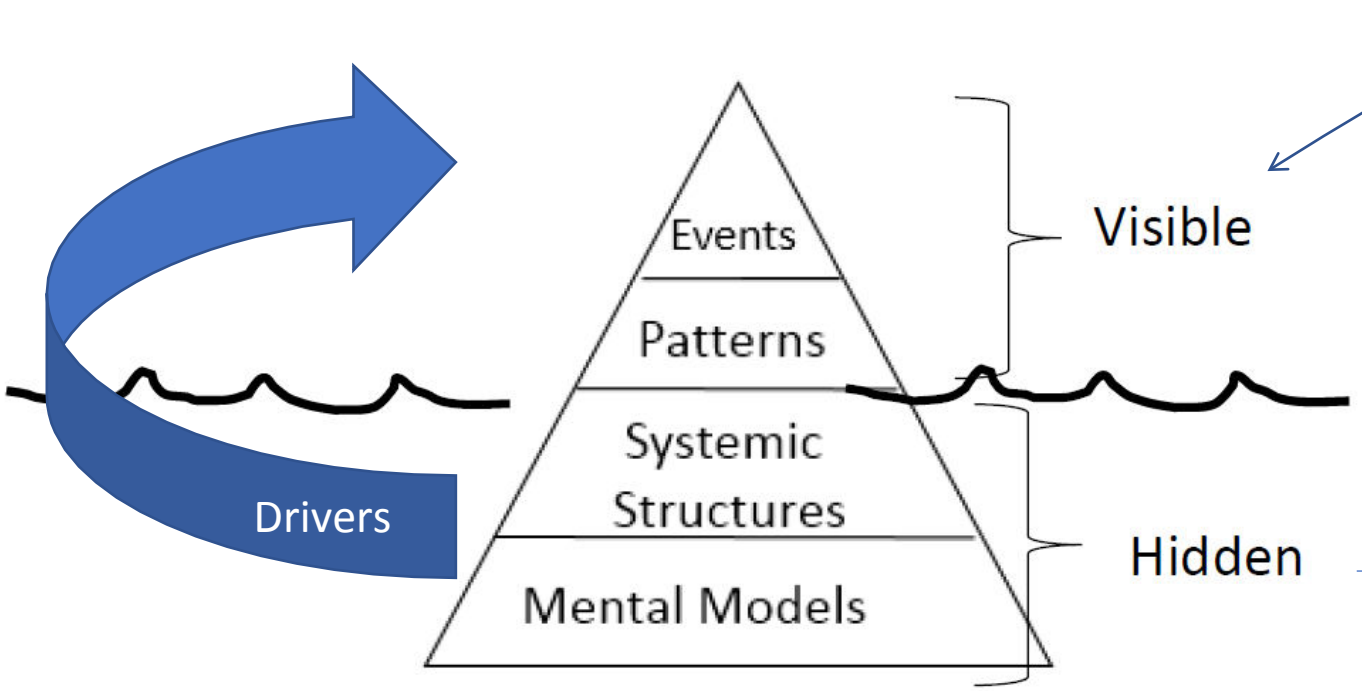


Standardized pathway

Snowden DJ, Boone ME. A leader's framework for decision making. Harv Bus Rev. 2007;85(11):68.

Cardio-pulmonary Resucitation

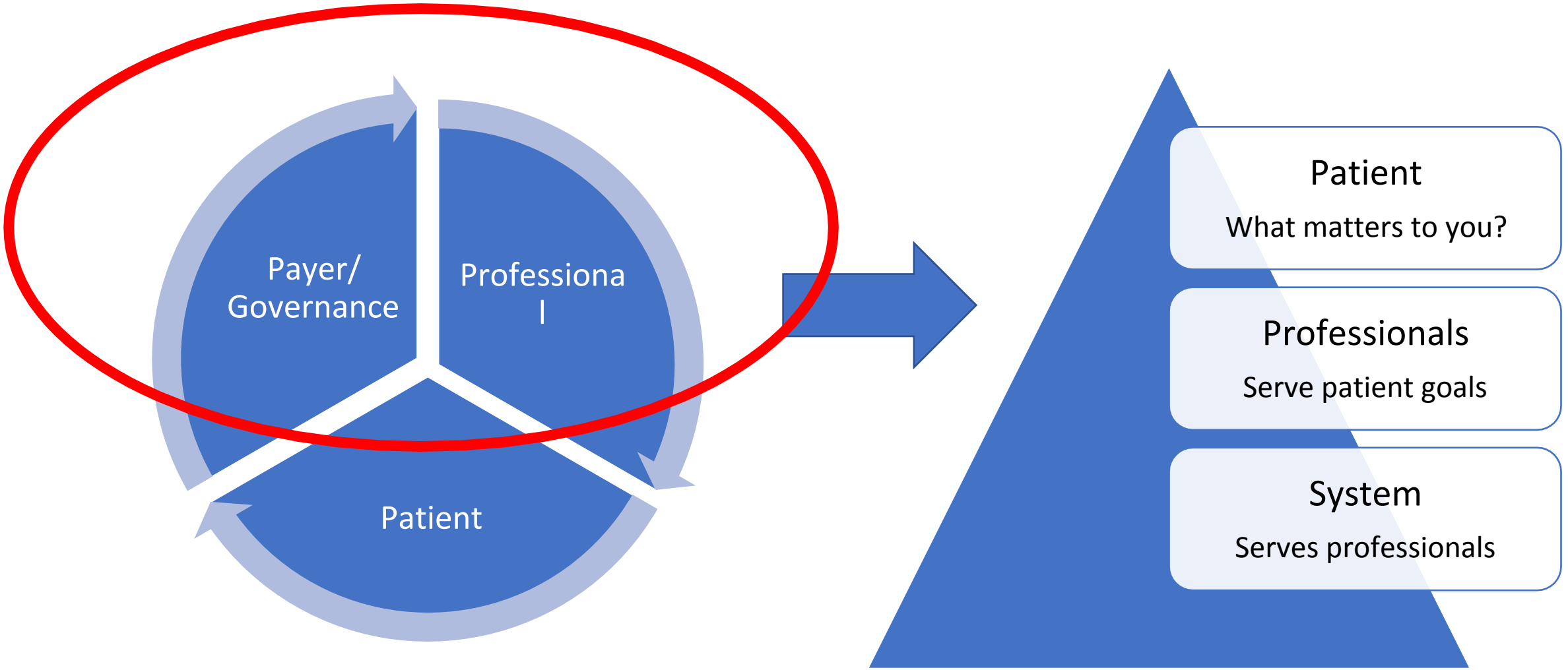
In complex systems=> The iceberg model



- Elements – stable
- Interconnections
- Purpose/ Function

Monat JP, Gannon TF. What is systems thinking? A review of selected literature plus recommendations. American Journal of Systems Science. 2015;4(1):11-26.

New mental model

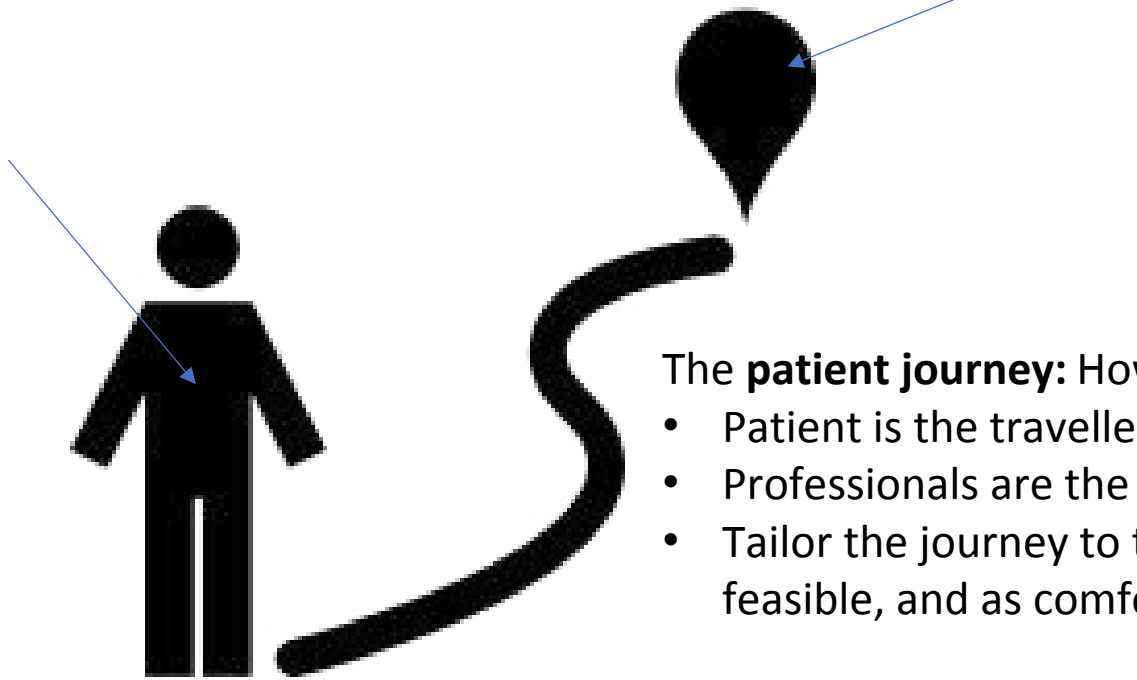


New language

New language => documentation => information flow
=> Makes mental model tangible

- Who is the **person?**
  - Identity
  - Health challenge impact?

- What matters to you?
- Translated into **Goals** for care



The **patient journey:** How do we get to the goal?

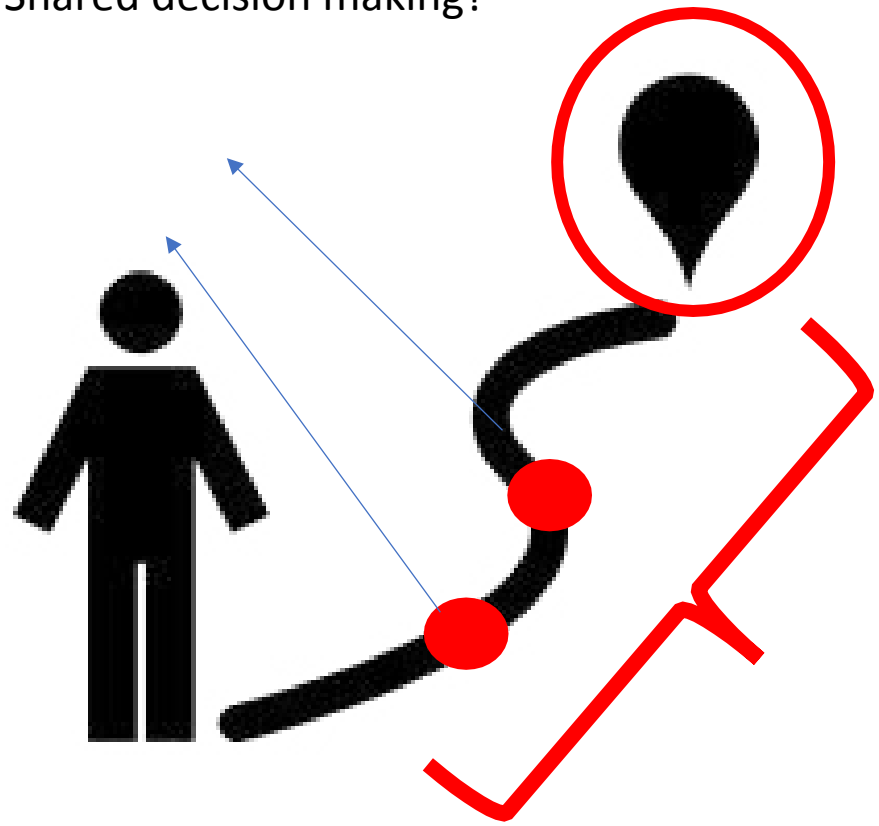
- Patient is the traveller
- Professionals are the «travel agents»
- Tailor the journey to the traveller: Meaningful, feasible, and as comfortable as possible

New feedback loops

How to check on our progress?

The episode:

- Shared decision making?



What matters?
What is the goal?
Did we meet the goal?
If not – what can we learn?

A series of events => journey

- Gaps and discontinuity
- Challenging events?
- Contradictions?

The magic of PCC - One person = > one goal => one plan => Integrated care

- One common goal – across all professional and organizations – has a coordinating effect.
- What matters to you?
- Translation => goals for care and priorities
- Identify all relevant resources – and identify how each role contributes to the overarching goal
- The plan needs to be concrete: Who does what when?
- The right resource is available at the right time and place.

PCC – my health =>
My self care

The main agents of proactive care

In all but extreme cases, is the patient manages his/ her care 24/7

Measurements and documentation of PCC

Pasient ID:

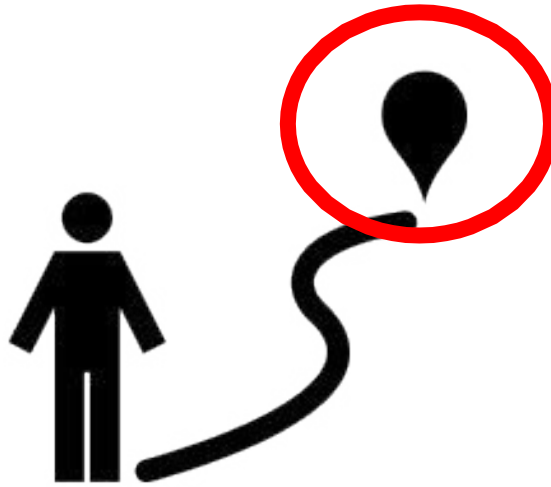
What matters to you?

How difficult is it for you to do this activity now?

0 1 2 3 4 5 6 7 8 9 10

High difficulty _____ No difficulty

	1. samtale	2. samtale
I want to live at home	5	10
I want my right leg to be stronger	3	5
I wish to stop using oxygen	5	10
Mean	4,3	8,3
Experienced change	8,3 - 4,3 =	4



By Anders Vege

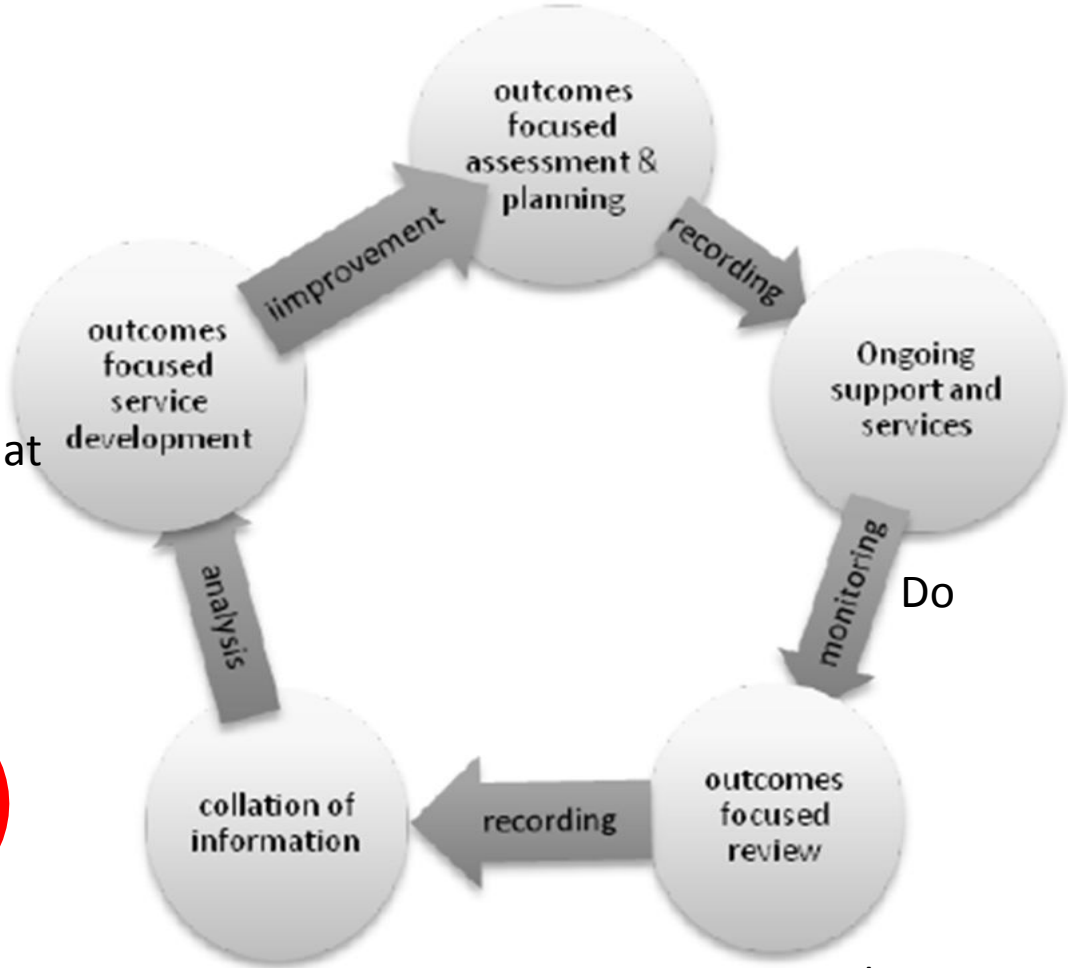
Meaningful & Measurable

A Collaborative Action Research Project

Developing Approaches to the Analysis & Use of Personal Outcomes Data

Emma Miller

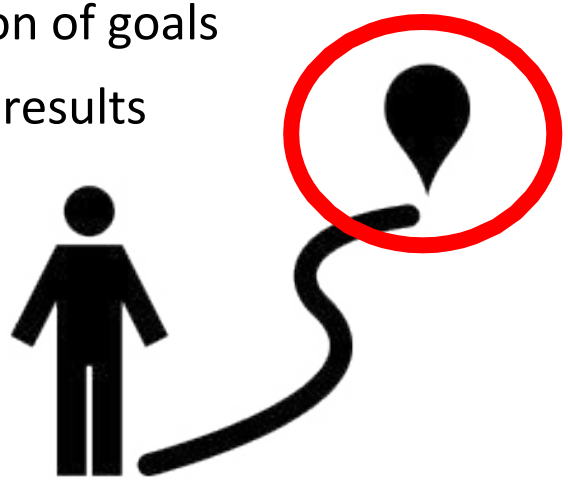
«What matters?» - explore and plan



Learning and development – what should change?

Do

- Qualitative data
- Systematic documentation of goals
- Systematic evaluation of results



What did we achieve?

Evaluation

https://ihub.scot/media/2126/po-learning.pdf

WEEKLY REABLEMENT REVIEW TOOL	
Personal outcome: seeing people	***Action***
Myra wants to get back to meeting her friends Agnes and Cathy in Dobbies café every Wednesday. Although Myra has made a good recovery from her fall a couple of months ago, she still feels a bit nervous about getting the bus to the garden centre.	Contact the local volunteer befriending service to provide an escort for a few weeks until Myra feels confident travelling on her own Myra to contact her friends to make arrangements
READLEMENT FINAL REVIEW	
Personal outcome: seeing people	
Myra is delighted that she has re-established her old routines with her two closest friends	
Feeling safe	
Myra reported that after two weeks of support from the befriender to get the bus she realised that she was able to manage safely on her own	
Confidence/morale	
Myra feels that the weekly coffee date is giving her back a sense of herself	
Wellbeing	
Myra feels that still being part of things outside the house is giving her 'something to keep going for', and makes her feel well	

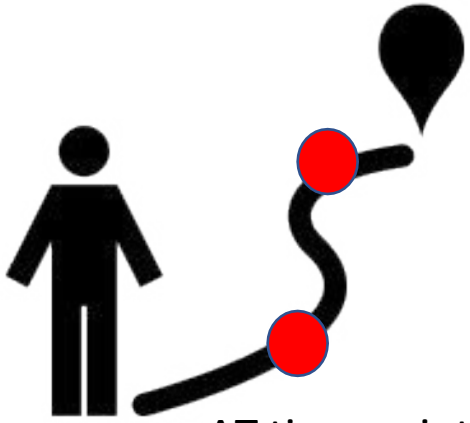
ISQua
Society for Quality in Health Care

Collaborate – Shared decision making

How much effort was made to help you understand your health issues?

How much effort was made to listen to the things that matter most to you about your health issues?

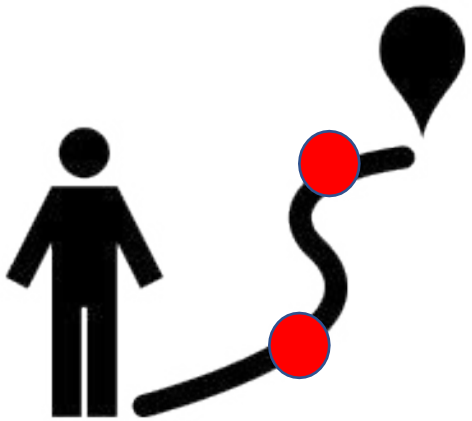
How much effort was made to include what matters most to you in choosing what to do next?



AT time points

Barr PJ, Thompson R, Walsh T, Grande SW, Ozanne EM, Elwyn G. The Psychometric Properties of CollaboRATE: A Fast and Frugal Patient-Reported Measure of the Shared Decision-Making Process. J Med Internet Res. 2014;16(1).

Consultations – The Outcomes Rating Scale



Session Rating Scale (SRS V.3.0)

Name _____ Age (Yrs): ____
ID# _____ Gender: _____
Session # ____ Date: _____

Please rate today's session by placing a mark on the line nearest to the description that best fits your experience.

Relationship

I did not feel heard, understood, and respected. I---------I I felt heard, understood, and respected.

Goals and Topics

We did *not* work on or talk about what I wanted to work on and talk about. I---------I We worked on and talked about what I wanted to work on and talk about.

Approach or Method

The therapist's approach is not a good fit for me. I---------I The therapist's approach is a good fit for me.

Overall

There was something missing in the session today. I---------I Overall, today's session was right for me.

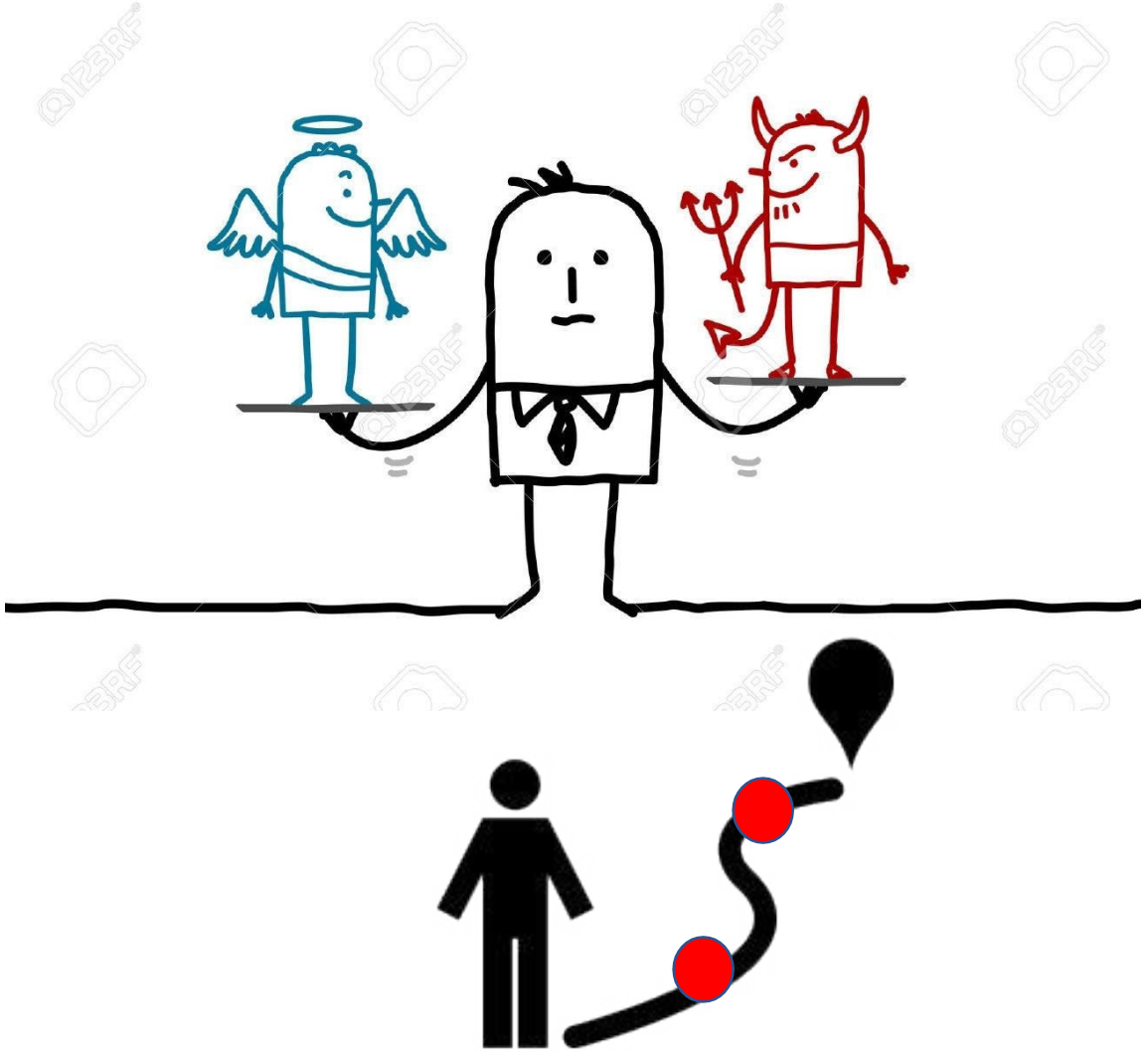
International Center for Clinical Excellence

www.scottdmiller.com

The patient narrative

- Narratives are particularly effective in raising issues relating to values, morals or feeling/emotions that may not be accessible otherwise.
- Narratives are useful in encouraging more person-centered awareness. Narrative shape decision making.

Morgan Chetty



Human Dignity – enacted through stories

- We live and create meaning through temporal, contingent stories that link past, present, and future in a way that tells us where we have been, where we are, and where we could be going …
- They turn mere chronology, one thing after another, into the purposeful action of plot, and thereby into meaning
- My dignity – resides in my story. The story of who I am.
- When communicated they generate a shared understanding, which in itself may shape the lives of both teller and listener

The aggregate experience of a dynamic pathway

Parsons A, Hooker C. Dignity and Narrative Medicine. Journal of Bioethical Inquiry. 2010;7(4):345-51.

Nasjonalt senter for
e-helseforskning

Questions – comments ?

gro.rosvold.berntsen@ehealthresearch.no

ISQua
International Society for Quality in Health Care

Links to resources on Person-centred Care

- What matters to you: https://wmty.world/
- Centre for Person Centred Care in Gothenberg, Sweden has a wonderful web site: https://www.gu.se/en/gpcc, which also has a number of links to other resources: https://www.gu.se/en/gpcc/external-links
- ISQUA: https://isqua.org/education/specialist-certificates/principles-of-person-centred-care.html
- Institute for HealthCare improvement: http://www.ihi.org/Topics/WhatMatters/Pages/default.aspx
- The Beryl Institute: https://www.theberylinstitute.org/?
- Picker: https://www.picker.org/
- WHO: https://www.who.int/news/item/28-05-2016-world-health-assembly-adopts-framework-on-integrated-people-centred-health-services