

Let's talk about power!

Patients transforming healthcare

Karin Althén, independent peer patient improver

David Gilbert, director, InHealth Associates

Sara Riggare, patient researcher, Uppsala University



Karin Althén

No competing interests



David Gilbert



Sara Riggare



co- production factory





process

performance

co- thinking

co- design

co- creation

co- production

JUST DO IT!





co- thinking

co- design

co- creation

co- production

JUST DO IT!

Ärligt talat om psykisk (o)hälsa

Varmt välkomna att ta del av två digitala föreläsningstillfällen om psykisk ohälsa. Berättelser som berör, från dem som vågar prata om sina innersta tankar och känslor. Om livet och för livet. En ovanlig och unik möjlighet, **utan kostnad eller föranmälan**. Ditt deltagande syns inte för andra.

Väl mött, precis som du är!

/Karin Althén, Peer, En återhämtningsinriktad psykiatri i Jönköpings län



Sänds digitalt på: plus.rjl.se/halsocafe

Torsdag 12 november
17:00-18:00

Mitt liv, min återhämtning...

En finstämd och känslofylld berättelse om att erövra sin självkänsla och sitt självförtroende, först i mitten av livet och på egen hand. Det är aldrig för sent att prioritera sig själv.

Föreläsare:
Jessica Jonsson, Peer



"I sällskapsrummet på en psykiatrisk klinik"

Läsning av utvalda dikter. Korta, kolsvarta och komiska små underverk som både värmer och värker. Dåliga gener och dåliga vanor kan verkligen vara en tillgång.

Medverkande:
Joakim Becker, poet och författare



Torsdag 26 november
17:00-18:00

"Hur kan någon som är så snygg må så dåligt?"

En unik kombination av scenkonst och föreläsning. En resa genom medgång, motgång och livet däremellan.

Föreläsare:
Maria Ljungström, Peer
med musikern Mancan



**Kostnadsfritt
och utan
föranmälan på:
[plus.rjl.se/
halsocafe](https://plus.rjl.se/halsocafe)**

För dig som inte har möjlighet att se detta med egen dator, välkommen att titta tillsammans på NBV, Ågatan 19 i Tranås.
Anmäl ditt deltagande till Anette Oscarsson på anette.oscarsson@nbv.se eller 0733-25 49 87 - först till kvarn!



process

co- thinking

co- design

co- creation

co- production

performance



JUST DO IT!





Karin Althén



David Gilbert

Director of InHealth Associates Ltd, that provides consultancy support for organisations



Sara Riggare

Patient (lived experience) Leadership – the basics

*People affected by life-changing illness, injury or disability who want to influence change
(People who have been through stuff, who know stuff, who want to change stuff)*

- People bring **jewels** of wisdom & insight from caves of suffering PLUS life-expertise – we should value both
- Patients bring embodied qualities of **authentic leadership** – ways of being and ways of seeing
- We foreground the **relational** and **connected** aspects of care – collaboration is in our bones
- We can do many things and have many **different roles** – only one of which is ‘improvement’
- Traditional forms of engagement don’t work, are not fit for purpose and **preserve the status quo**

Benefits:

- Via an institutional lens: Improve and transform healthcare via power-sharing at all levels
- Via ‘patient’ lens: Provides meaningful opportunities & progression for people – a second chance for those with first-hand expertise

Qualities of an Effective Patient (Lived Experience) Leader

1. Within Yourself
2. With Others
3. In The Longer Term

1. Within Yourself

1.1 Valuing self and processing experience

1.2 Kindness and compassion – towards self and others (the hardest skill of all)

1.3 Courage and strength – bravery to be out there and strength to keep going

1.4 Looking after yourself - Avoiding becoming unwell

2. With Others

2.1 Noticing, listening, pausing – being mindful

2.2 Exploration – being curious, helpful and reliable

2.3 Speaking up and landing what you need to say

2.4 When things get tough – conflict and holding difficult conversations

3. In The Longer Term

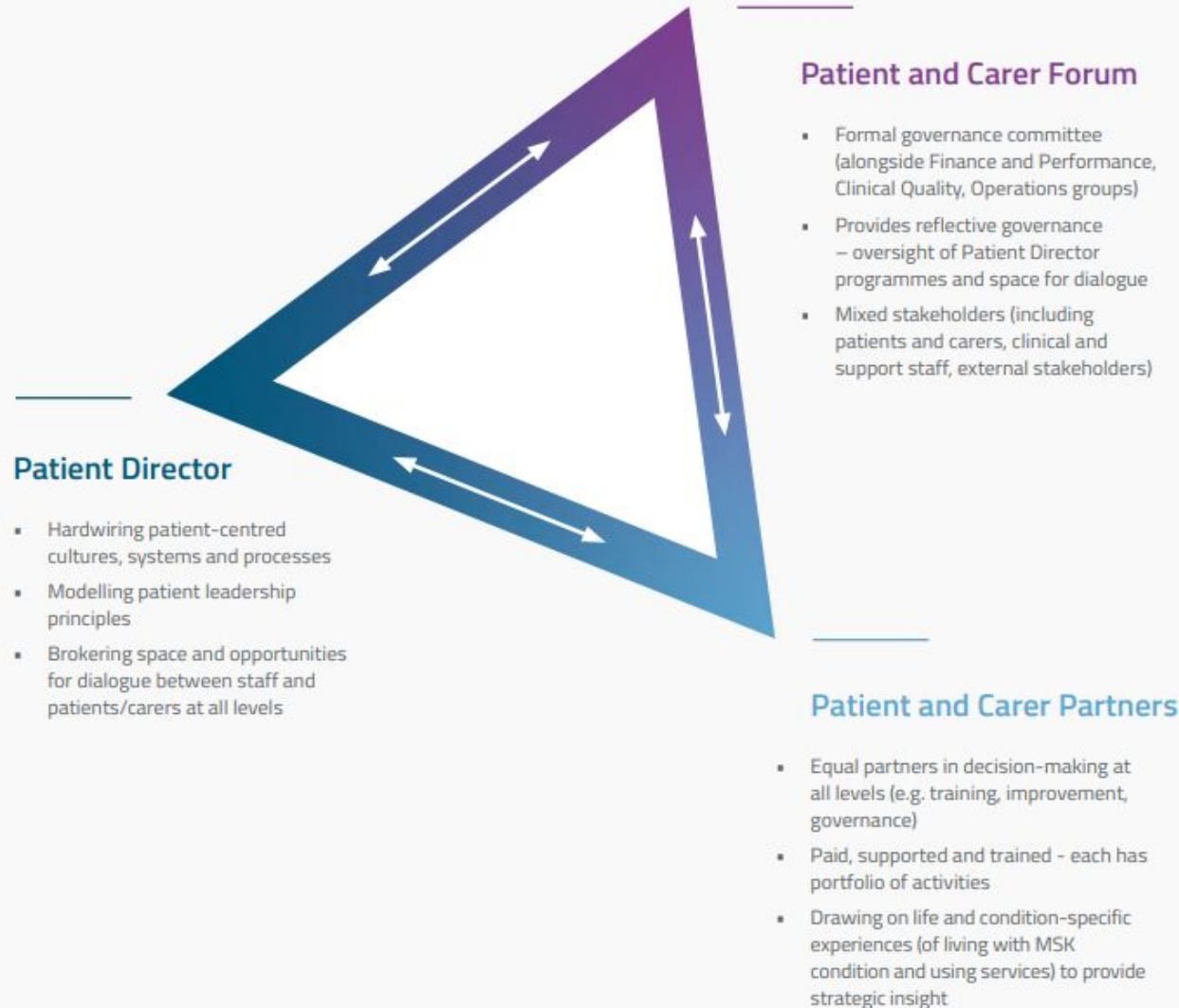
3.1 Working with professionals and staff - developing credibility and legitimacy

3.2 Working with allies – bringing others in and on, dealing with ego

3.3 Understanding context – power, need and whose knowledge counts

3.4 Planning with purpose – getting clear but being ready to busk

The Patient Leadership Triangle



Embedding Patient (Lived Experience) Leadership

- **Leicestershire Partnership** – embedding the Triangle in its three directorates
- **Tees, Eske and Wear Valley** – support to recruit two Patient Directors
- **Midlands Partnership Trust** – support for new ‘Director of Lived Experience Practice’
- **Norfolk and Waveney ICB** – patient leadership in digital transformation
- **Pinnacle Health**, New Zealand – support for embedding patient leadership aligned with Māori-led healthcare
- **St Giles-Wise Partnership** – Engaging People on Probation across England and Wales
- **GamLearn** – working with people with gambling harm
- **Foundations in Patient (Lived Experience) Programmes** – 15 cohorts plus in-house programmes



Karin Althén

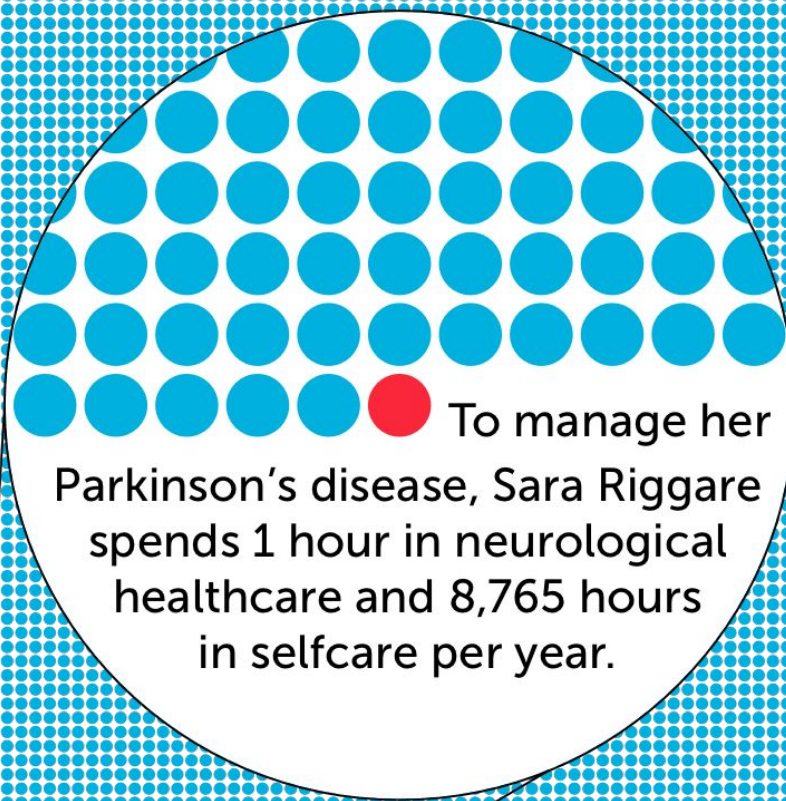


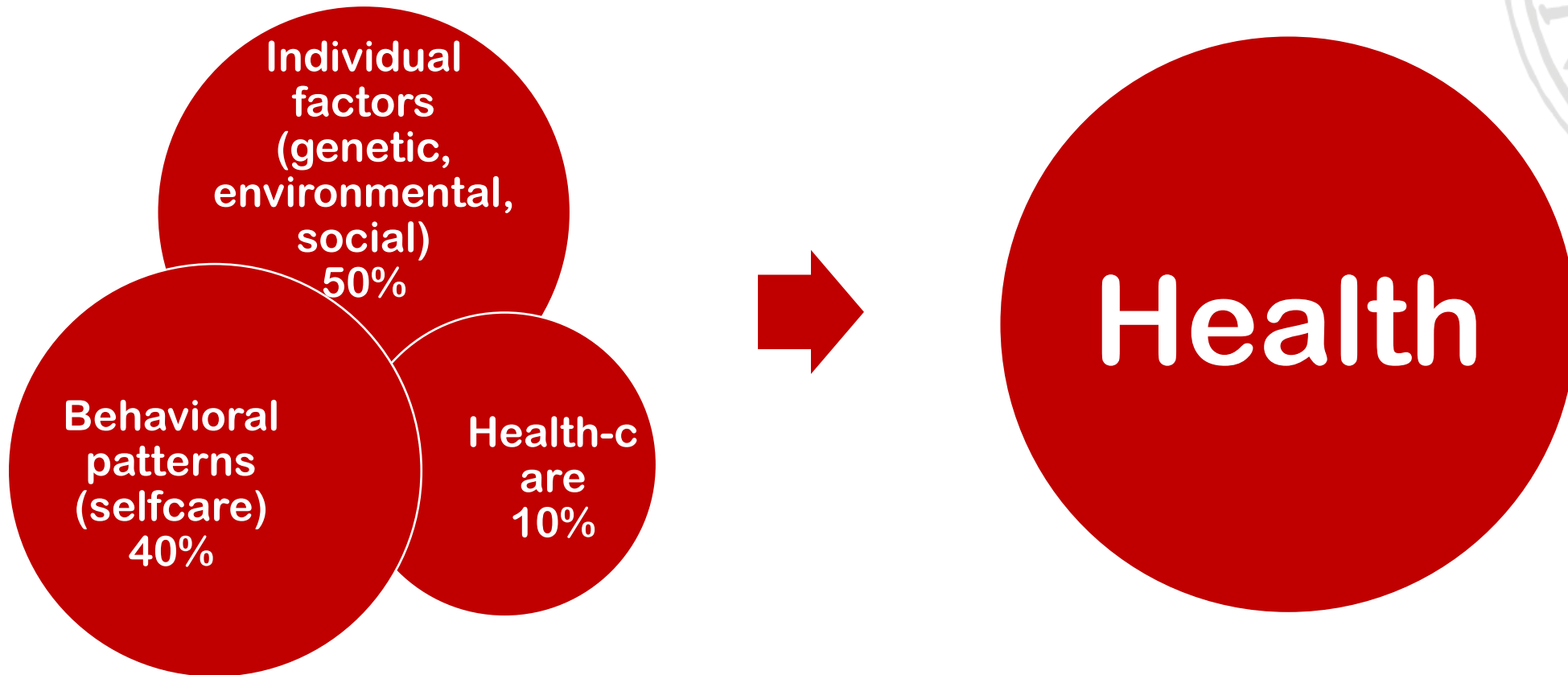
David Gilbert

No competing interests



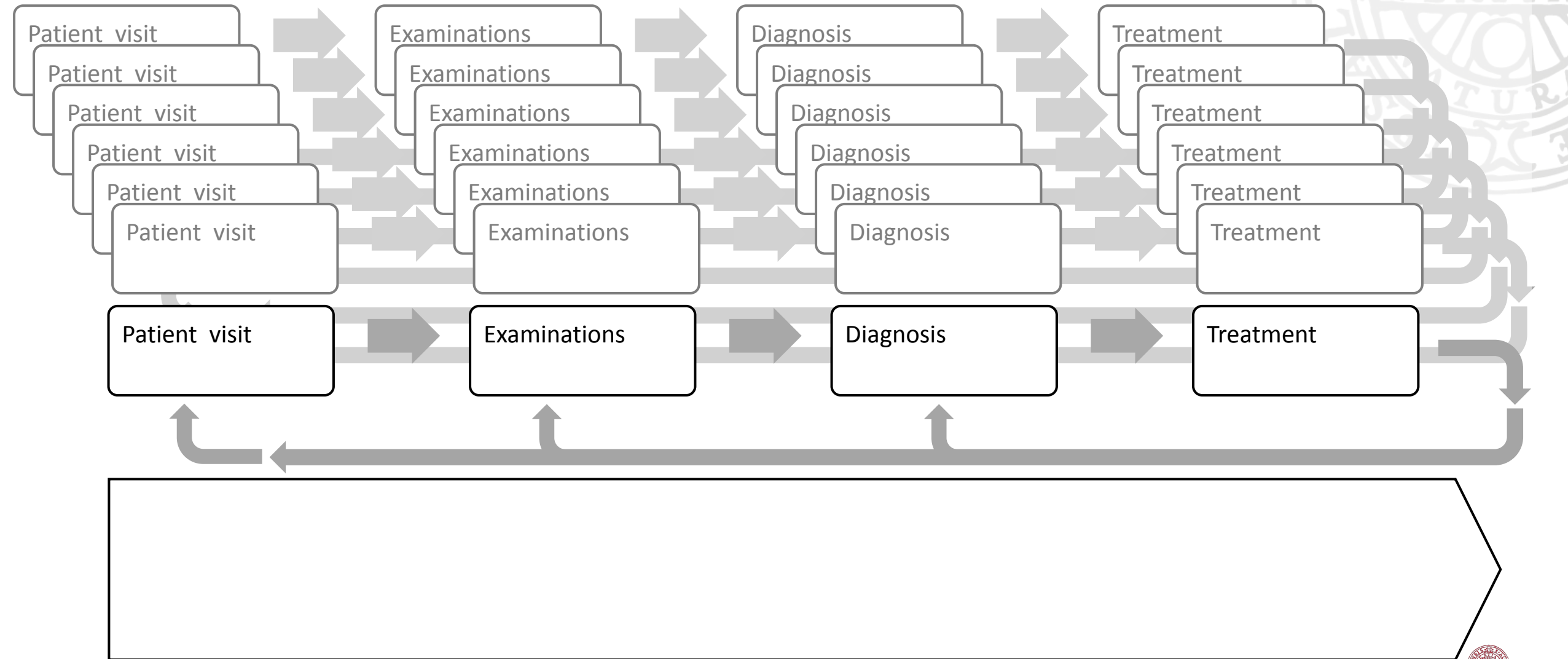
Sara Riggare



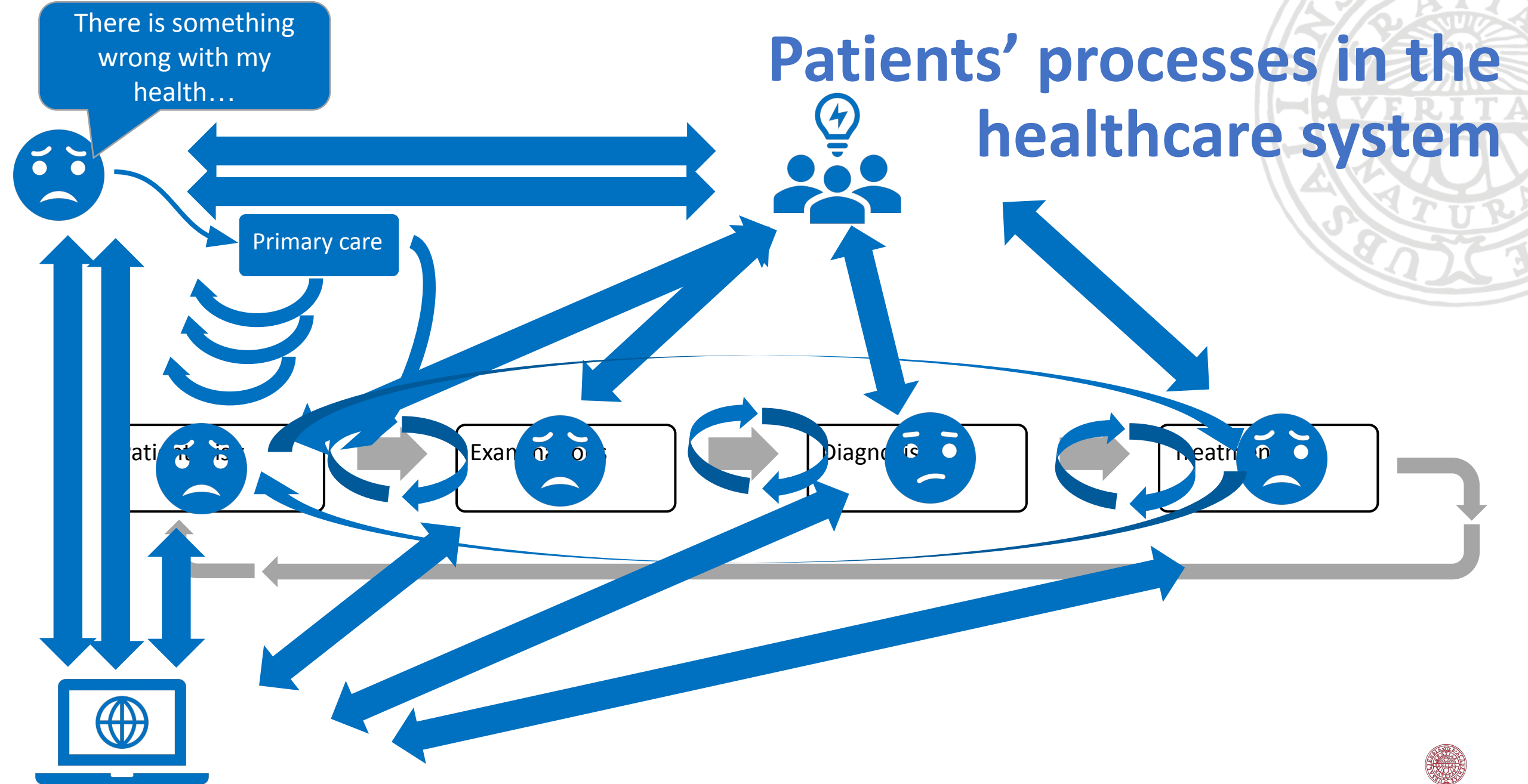


Från: S. A. Schroeder, "We Can Do Better - Improving the Health of the American People," N. Engl. J. Med., vol. 357, no. 12, pp. 1221–1228, 2007.

Healthcare processes



Patients' processes in the healthcare system



Patients' roles are changing

research in...

healthcare

Active role

- Conducts research using their own experiences from illness/health challenges

Patient researcher

Partly active role

- Participatory research

Research partner

Passive role

- Subject in studies initiated and led by researchers

Research participant

Active role

- Also contributes to system improvements as a change agent

"Spetspatient"

Partly active role

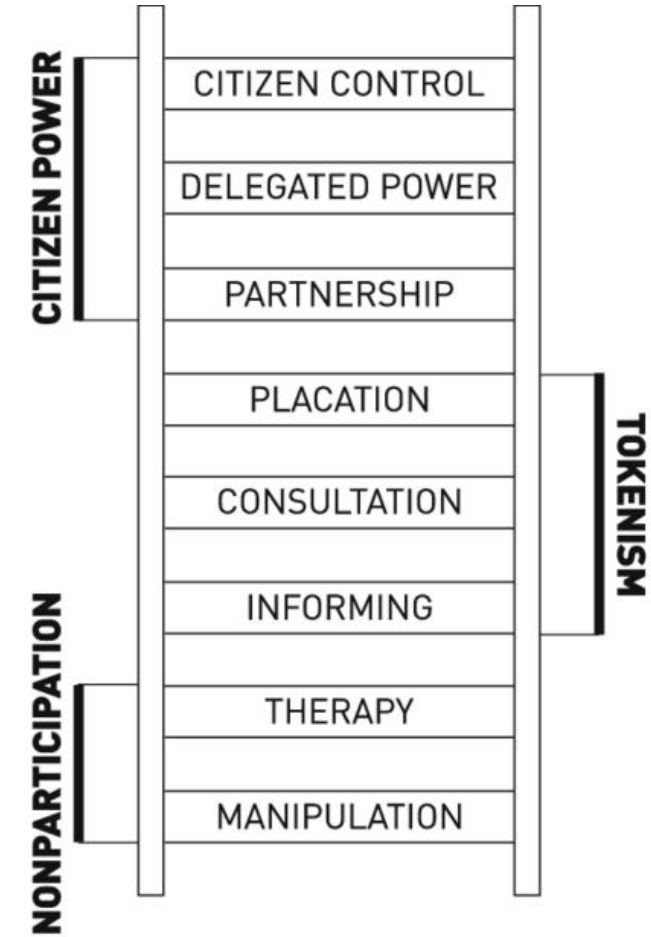
- Participatory healthcare

Active selfcarer

Passive role

- Paternalistic healthcare

Passive patient



Arnstein, Sherry R. "A Ladder of Citizen Participation," JAIP, Vol. 35, No. 4, July 1969, pp. 216-224

Spetspatients are... (examples)

... active in their own healthcare, and...

... contribute to developing
“their own” healthcare provider

...contribute to project in “their
own” region/municipality

... help authorities

... help on a
national level

... help companies,
eg medtech/
pharma

... help researchers



Selfcare expert



Activist



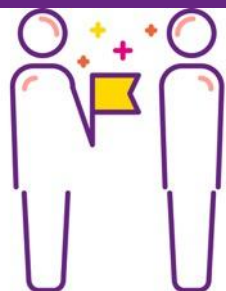
Communicator



Entrepreneur



Innovator



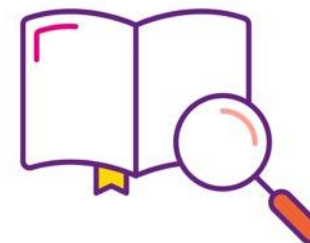
Mentor



Tracker



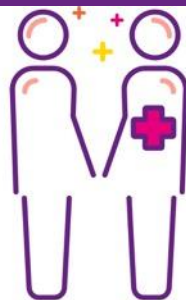
Hacker



Knowledge seeker



Patient researcher



Healthcare partner



Healthcare coordinator



If I can manage my health care
with one hand

I'm able to use the other one
for living life!



Image by Karin Althén



UPPSALA
UNIVERSITET



Karin Althén

Thank you!



David Gilbert



Sara Riggare