The citizen as contributor to collaboration and knowledge development

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Why citizen involvement?

- **An end in itself** (democracy, human rights, transparency)

- **A means to another end** (relevance, quality of healthcare, better IT-systems)

- **The capacitating rationale** (a means to enable meaningful/responsible choices)

- **The legitimizing rationale** (for potentially unpopular decisions, trust-building)

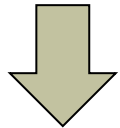# Levels of patient/citizen involvement in healthcare

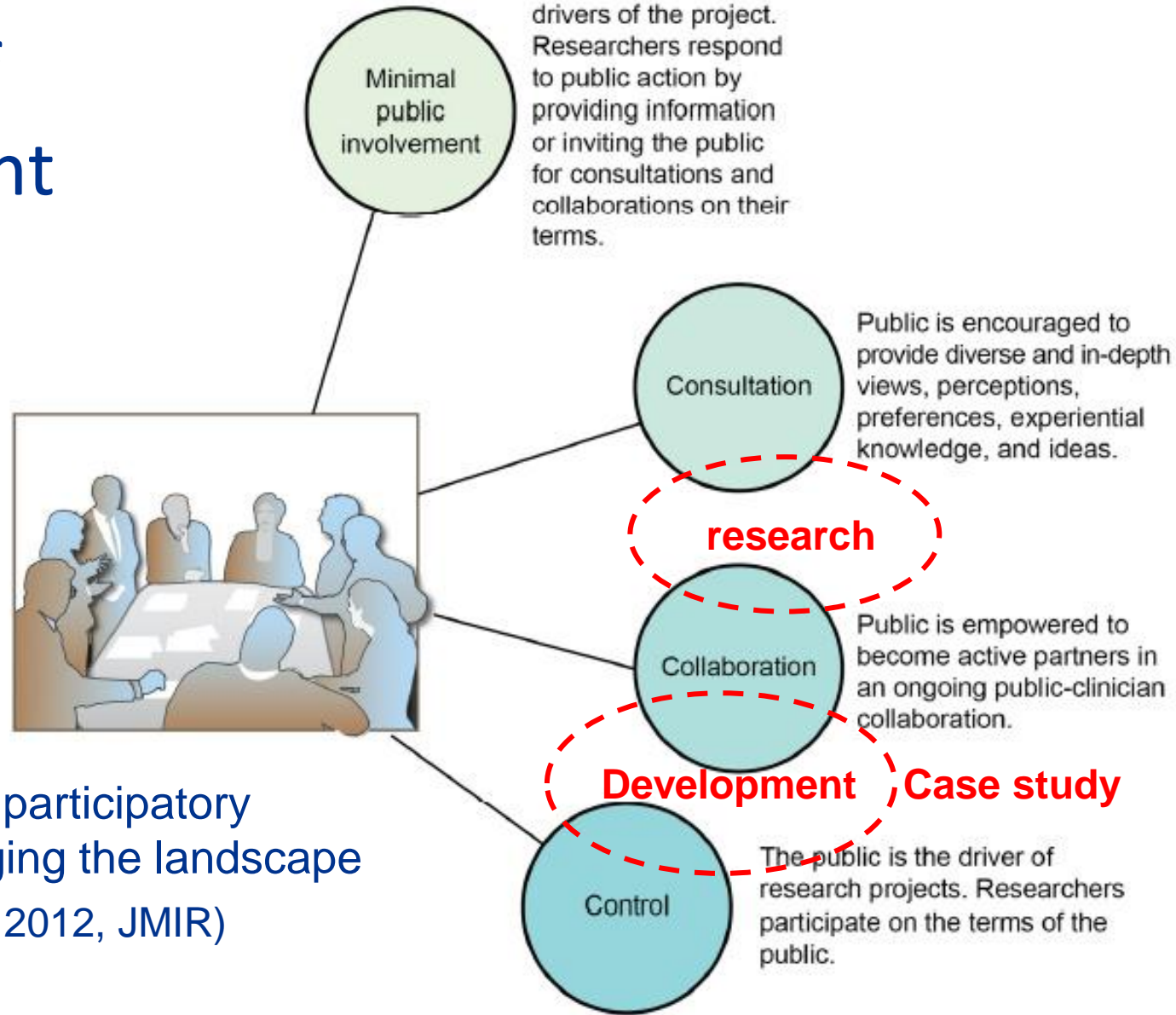Policy level - representation
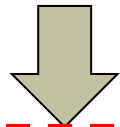
Organizational/program/project level
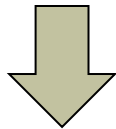
Patient-provider interaction

Active involvement in personal health

Types and degrees of innvolvement in health research

Minimal public involvement — Researchers are the drivers of the project. Researchers respond to public action by providing information or inviting the public for consultations and collaborations on their terms.

Consultation — Public is encouraged to provide diverse and in-depth views, perceptions, preferences, experiential knowledge, and ideas.

research

Collaboration — Public is empowered to become active partners in an ongoing public-clinician collaboration.

Development **Case study**

Control — The public is the driver of research projects. Researchers participate on the terms of the public.

Social media and participatory medicine is changing the landscape of science (Swan, 2012, JMIR)

INVOLVE, National Institute for Health Research, UK..

"… defines public involvement in research as research being carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them."

- Underlines the need to balance the (so far) privileged role of clinicians and researchers in setting research agendas, questions posed, methods, etc.

- Citizens as equal stakeholders

As requirements/incentives for public involvement in research increases…

..so do calls for:

- Documentation of effect
- In-depth descriptions of processes of involvement

Case study of user involvement – «PsyConnect»

Online support for self-management and collaboration in community mental health

Start: 2012-2014 (work in progress)

Presentation:

- *Background*

- *Examples of discussions and rationales for decisions*

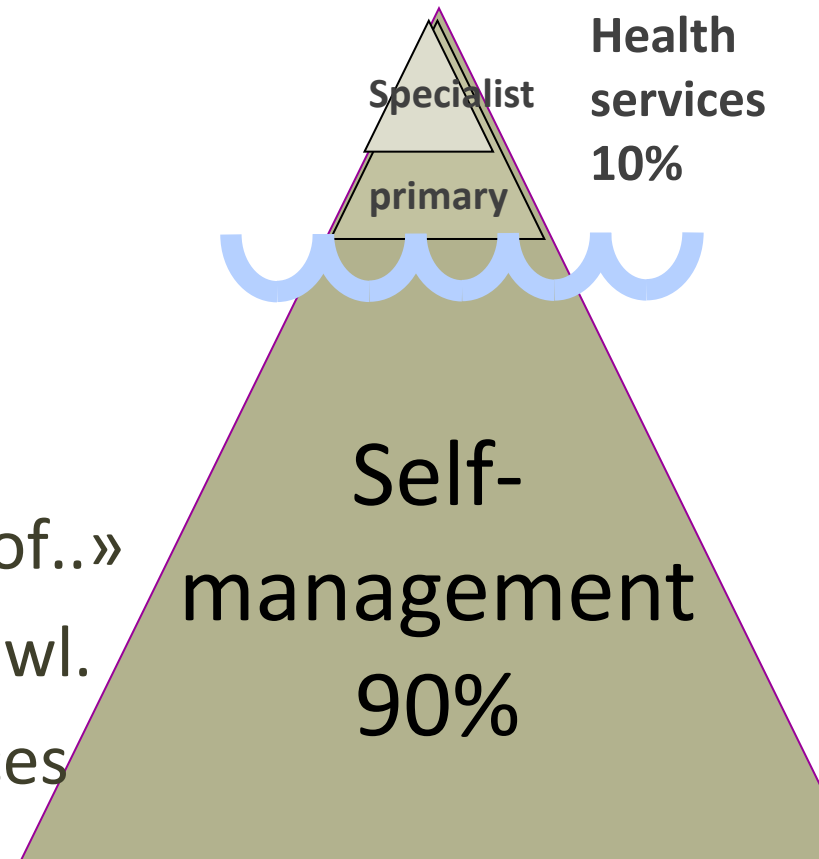# Ideas presented to community mental health stakeholders

(Service users, Vestre Viken Coping and Learning Center (LMS); Asker Municipality; Blakstad Hosptial and outpatient clinic (DPS):

- Research supporting ideas for online tools

    - self-management

    - online assisted self-help tools

- Building blocks available - «Connect-platform»

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What we know has effect for self-management of chronic conditions…

- Knowledge + skills
- Services adapted to individually defined values, goals, plans
- Monitoring that enhances self-insight
- Support for «a good life in spite of..»
- Social support – experiential knowl.
- Team-based organizing of services

Health services 10%

Specialist

primary

Self-management 90%

Lorig K, et al: *Living a Healthy Life with Chronic Conditions*, 2000

Active involvement in self-management has effect

Analysis of 67 review-studies (Coulter, BMJ, 2007)

Percent of studies that found positive effects on:

	Pasient knowl.	Pasient satisfaction	Health service usage	Health
Active involvement in care	100 %	60 %	56 %	78 %

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Available building blocks - «Connect-platform» included:

- Secure patient-provider messaging

- Symptom monitoring

- Tailored advice for self-mangement

- Discussion forum

- Blogg

- Diary

Research supporting the efficacy of the tools for cancer patients

Evidence shows that online self-help tools can be effective in mental health

- Condition-specific applications

- Mild conditions

- Few studies in community settings

Questions posed to community mental health stakeholders:

Service users, Vestre Viken Coping and Learning Center (LMS); Asker Municipality; Blakstad Hosptial and outpatient clinic (DPS):

"Do stakeholders think that they can benefit from a tool like this (Connect)? If so....

Will they commitment to involvement in answering the question:

How should it be adapted/designed to best meet the needs of service users in community mental health?

Research-practice team

LSM, Asker municipality, Blakstad, DPS, OUS, NST:

- service users (1 employed 80%, 2 on hourly basis)
- clinicians
- researchers
- IT-folks

Monthly meetings, email/tlf., access to available tools

Funding: NFR, Extra Fond. – (2012 – 2014)

Among issues discussed…

- What goals/outcomes?

- What target groups?

- What functionality?

- Whose ownership/responsibility?

Whose opinions weighed most heavily?

- services users

- clinicians

- researchers

Discussions about goals/outcomes

"PsyConnect" (both the project and tool) aims
to support service users in:

1) Gaining an <u>overview and greater control</u> over aspects of their personal lives that affect their health and well-being

2) <u>Legitimizing</u> their personal knowledge, strengths and values in the formation of services provided by healthcare

3) Experiencing a greater sense of <u>continuity</u> in relations with, and between, providers

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Target group?

*"I've had numerous diagnoses over the years and none of them seem to influence the treatment I receive. I want a tool that **I** can use over time, independent of my current condition, or the theory of whomever happens to be my provider(s) at a given time"*

(collective paraphrased quote from service users)

(cont.) Target group?

Service users argued for...

- Independence from diagnoses (mental/physical)
- Those with needs for long-term follow-up in community – where continuity and coordination is challenging
- Likely also useful for those with periodic and mild conditions

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Functionality? Symptom-monitoring:

«In bad periods I'd cross off everything»

«Better to describe how things are in our lives»

«Focus on what we do that helps»

Functionality?

«My control panel»:

My status
- **Life domains**
- **Medications**
- **Resources**
- **Network**

Exercises

Evaluations

Crisis plan

Monitoring

Activities

Reminders

What's important in my life (values)

My goals
- **Subgoals**

Mine medisiner ❓ 🖨

Mine resepter (ekstern side)   + Legg til medikament

Faste medisiner

Medikament	Dosering	Hensikt	Spørsmål til legen
Vinorelbin	A lot	None	Legg til spørsmål
Legg til erfaring			Arkiver Endre
Herceptin	1 mg	Cellgift	Legg til spørsmål
Legg til erfaring			Arkiver Endre
Uroxlan	1 ml	Dermatitis	Er dette strengt tatt nødvendig?
Legg til erfaring			Arkiver Endre

Medisiner ved behov

Medikament	Dosering	Hensikt	Spørsmål til legen
Methotrexat	1 ml	Nerves	Kåre
"Makes me really sleepy after a coulpe of houres"			Arkiver Endre
Nandrolon	1 mg	Itch	Legg til spørsmål

Clinicians' concerns about responsibility

"Does merely having access to the service users' site make me (legally) responsible for correcting faulty information, or responding to alarming symptoms, even though I don't see it? "

"What is the status of user-generated information relative to medical records? Can PsyConnect evolve into a parallel medical record?"

Service users' concerns and responses to the decision to not give clinicians access:

- *"This will diminish clinicians' sense of responsibility for engaging with us through PsyConnect"*

- *"This will underline service user ownership and responsibility - both of the tool and of our own recovery process."*

Clinician input

- Interaction with electronic medical record is a must

- Agreements for use (non-acute, response time)

- Concerns about availability/getting swamped

Animasjonsfilm om prosjektets visjoner

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Closing reflections...

- Effect of service user involvement ?

- Representativeness?

- Will the concept translate into practice?

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