EMPATHiE

The EMPATHiE tender: EMPOWERING PATIENTS IN THE MANAGEMENT OF CHRONIC DISEASES: but viewed from a different aspect……

"He TEXTED His FIRST WORD TODAY."

http://www.gocomics.com/theflyingmccoys

We live in a digital age.

We have all adopted smart phones so rapidly
that we forget that most of us have only been carrying a small mobile computer in our purse or pocket for about 7 years or less….

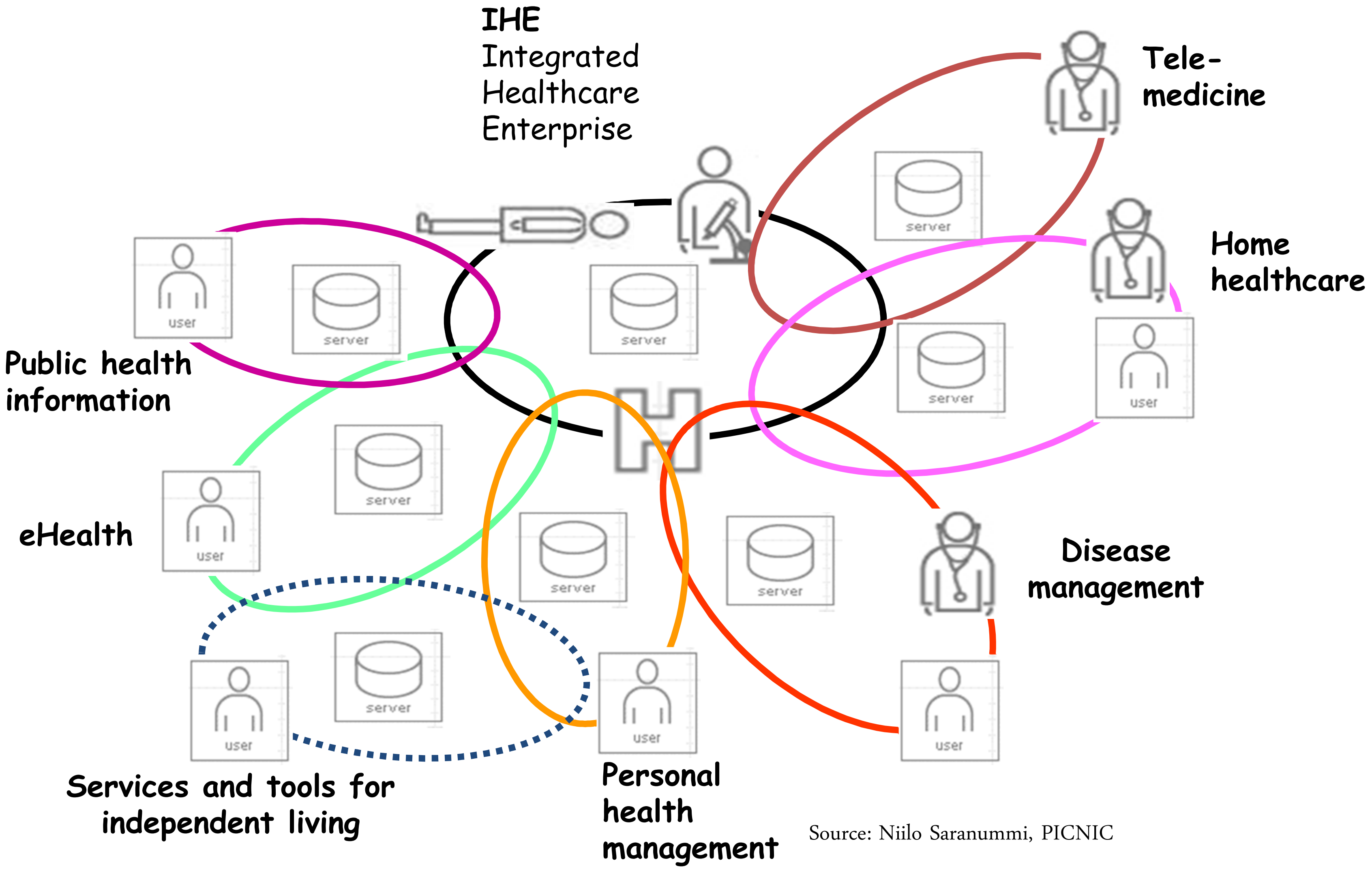
But if we work in health service provision or health policy we also may forget that our ‘customers’ (patients and citizens) also may have smart phones or similar devices

Telematics for **health** is a WHO composite term for both tele-medicine and tele-**health**, or any **health**-related activities carried out over distance by means of information communication technologies (adopted as a policy by the WHO Council in 1998)

EHTEL (the European Health Telematics Association) was established in 1999.

Notice that there is no suggestion of 'empowerment' here: ICT is being applied to healthcare to allow professionals and patients to **overcome distance when it is a barrier to the conventional delivery of services**

Why should I need eHealth? To overcome structures?



IHE
Integrated
Healthcare
Enterprise

**Tele-
medicine**

**Home
healthcare**

**Public health
information**

eHealth

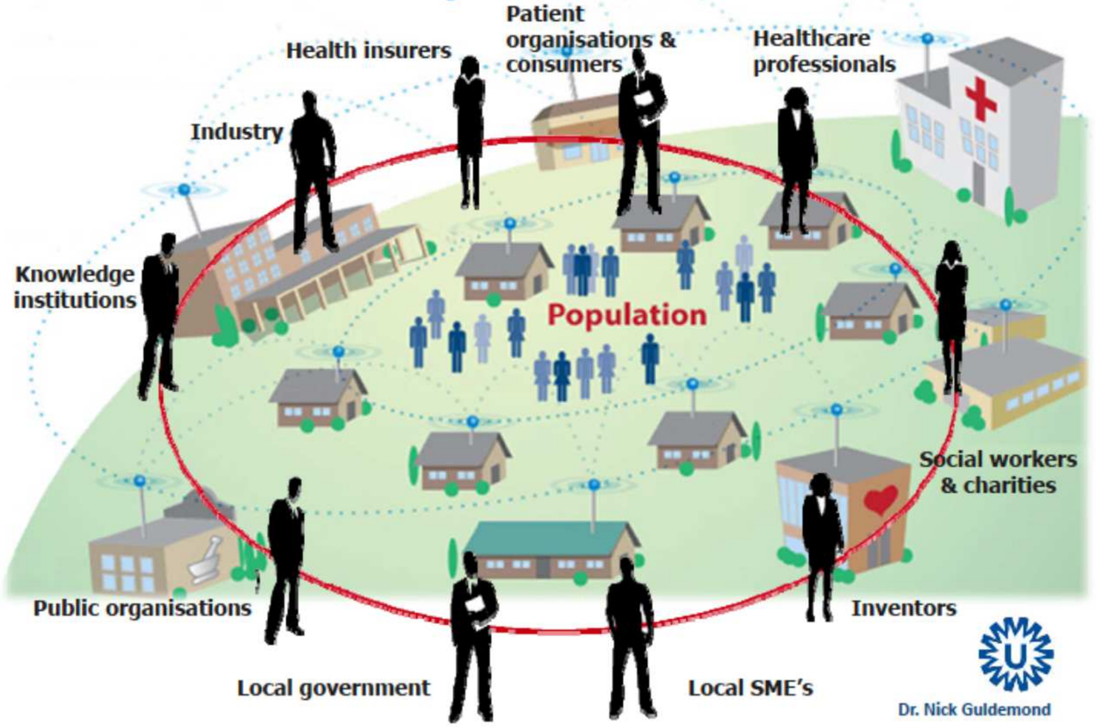
**Disease
management**

**Services and tools for
independent living**

**Personal
health
management**

Source: Niilo Saranummi, PICNIC

Community Based Co-creation



Dr. Nick Guldemond

Athens, May 2014

Roles *are* changing…

"Doctor and physician are outdated terms.
I'm your biological tech support specialist."

As a reaction to the prevailing paternalism of the previous 100 or more years**, as early as the beginning of the 1960s there were academic physicians such as Szasz et al that had challenged the prevailing social order**, just as it was being challenged in other spheres at that time.

The key elements here were **the principles of choice over issues that affected one's life, autonomy and pro-active involvement**.

By the 1970s there were signs of **a move from a disease-centred model of healthcare to a person-centred model**, which almost by definition challenged the concept of the passive patient, but even today there is some disagreement over what 'patient-centred' means.

Although since the 1990s the principle of patient involvement has been actively embraced as a policy, in practice it has proved hard to embed, due to the strength of existing attitudes, on both sides.

Ironically it has been the rapid technical development of ICT that has provided the **potential substrate for a significant acceleration in the process of transformational change**.

Dr Google……


THE PATIENTS KNOW MORE ABOUT THEIR DISEASES THAN ME. I MUST GET FASTER MODEM, HIGHER SPEED INTERNET ACCESS THAN THEM
©Morgosia

EMPATHiE

The EMPATHiE tender:
EMPOWERING PATIENTS IN THE MANAGEMENT OF CHRONIC DISEASES

http://ec.europa.eu/health/patient_safety/key_documents/index_en.htm

Funded by
the Health Programme
of the European Union

Background to the bid

In early 2013 the European Health Futures Forum (EHFF) took the opportunity to convene a Network of interested parties (currently 22 European stakeholders including patient organisations, other NGOs, Institutes and University departments) to make a successful offer to participate in the EIP-AHA to provide expertise on PE for the action group on integrated care, B3. **This group became the Empathie Network.**

Subsequently a Consortium drawn from members of the Network was awarded the tender to be described, with a kick-off in November 2013 and completion in the latter part of 2014.

Empowering patients in the management of chronic diseases: objectives -

To help understand the concept of Patient Empowerment as a prerequisite to exercising patient rights.

The specific objectives are:

To identify **best practices** for patient empowerment

To identify **facilitators and barriers** to empowering patients

To develop a **method to validate transferability** of good practices

To develop **scenarios of EU future collaboration** on this subject

Target groups
Patients with chronic cardiovascular diseases (CVD or stroke)
Patients with chronic respiratory diseases (COPD)
Patients with chronic diabetes (type 1 and 2)
Patients with mental health (schizophrenia or chronic depression)
Complex patients (co-morbidity)

Patient Empowerment – Operational definition

An **empowered patient** has control over the management of their conditions in daily life. They take action to improve the quality of their life and have the necessary knowledge, skills, attitudes and self-awareness to adjust their behaviour and to work in partnership with others where necessary, to achieve optimal well-being.

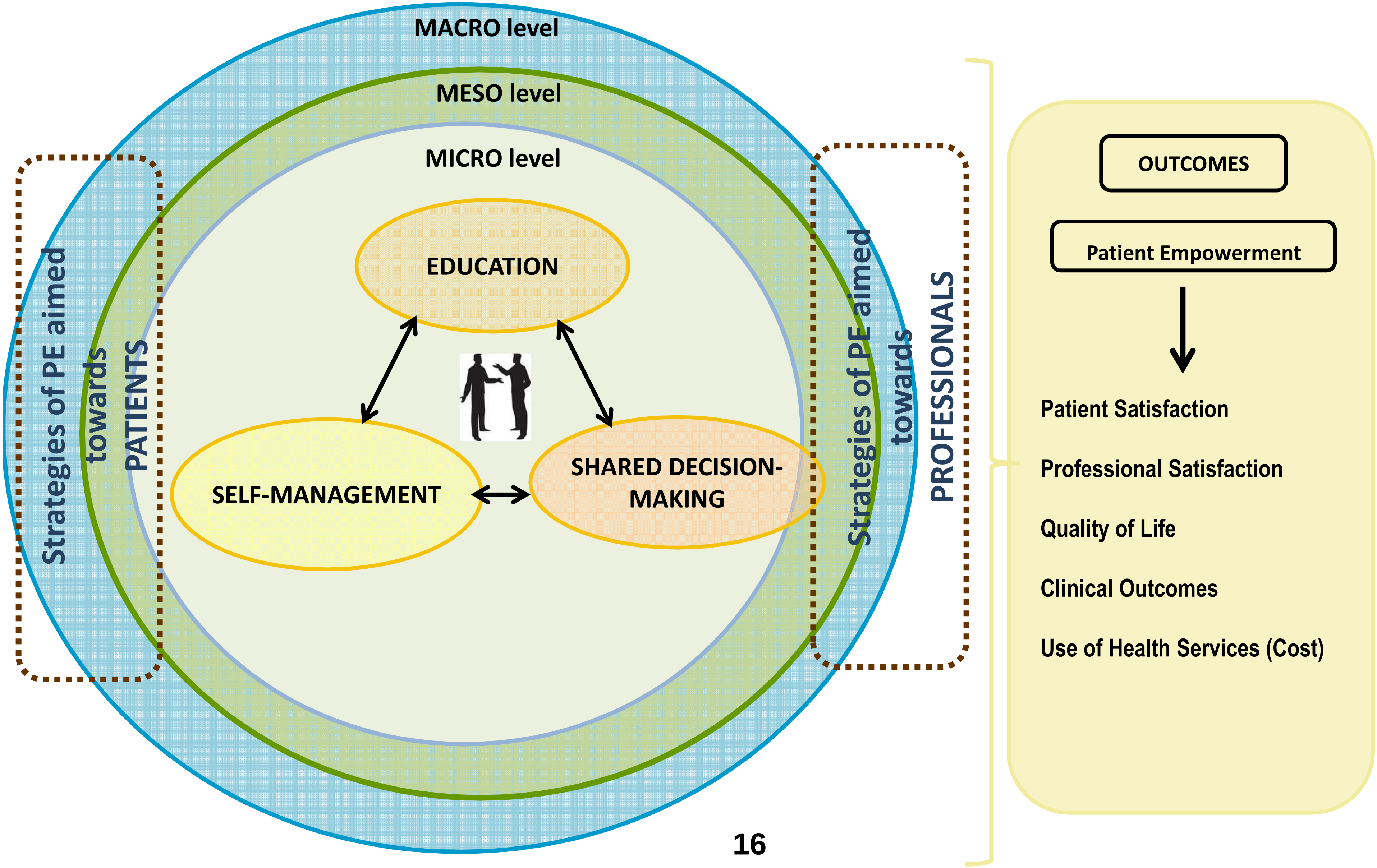
Patient Empowerment
Person-centred care
Involvement
Support
Health Literacy
Active
Equip
Respect
Partnership
Self-management
Community
Shared treatment decision-making

Patient Empowerment interventions – Operational definition

Empowerment interventions aim to equip patients (and their informal caregivers whenever appropriate) with the capacity to participate in decisions related to their condition, to create awareness and develop competences of healthcare professionals and improve the preparedness of the healthcare system to tackle this paradigm.

Image credit: http://fmgators.ymcacassclay.org/2013/05/16/reminders-practice-island-park-summer/

Conceptual framework



MACRO level

MESO level

MICRO level

Strategies of PE aimed towards PATIENTS

EDUCATION

SELF-MANAGEMENT

SHARED DECISION-MAKING

Strategies of PE aimed towards PROFESSIONALS

OUTCOMES

Patient Empowerment

Patient Satisfaction

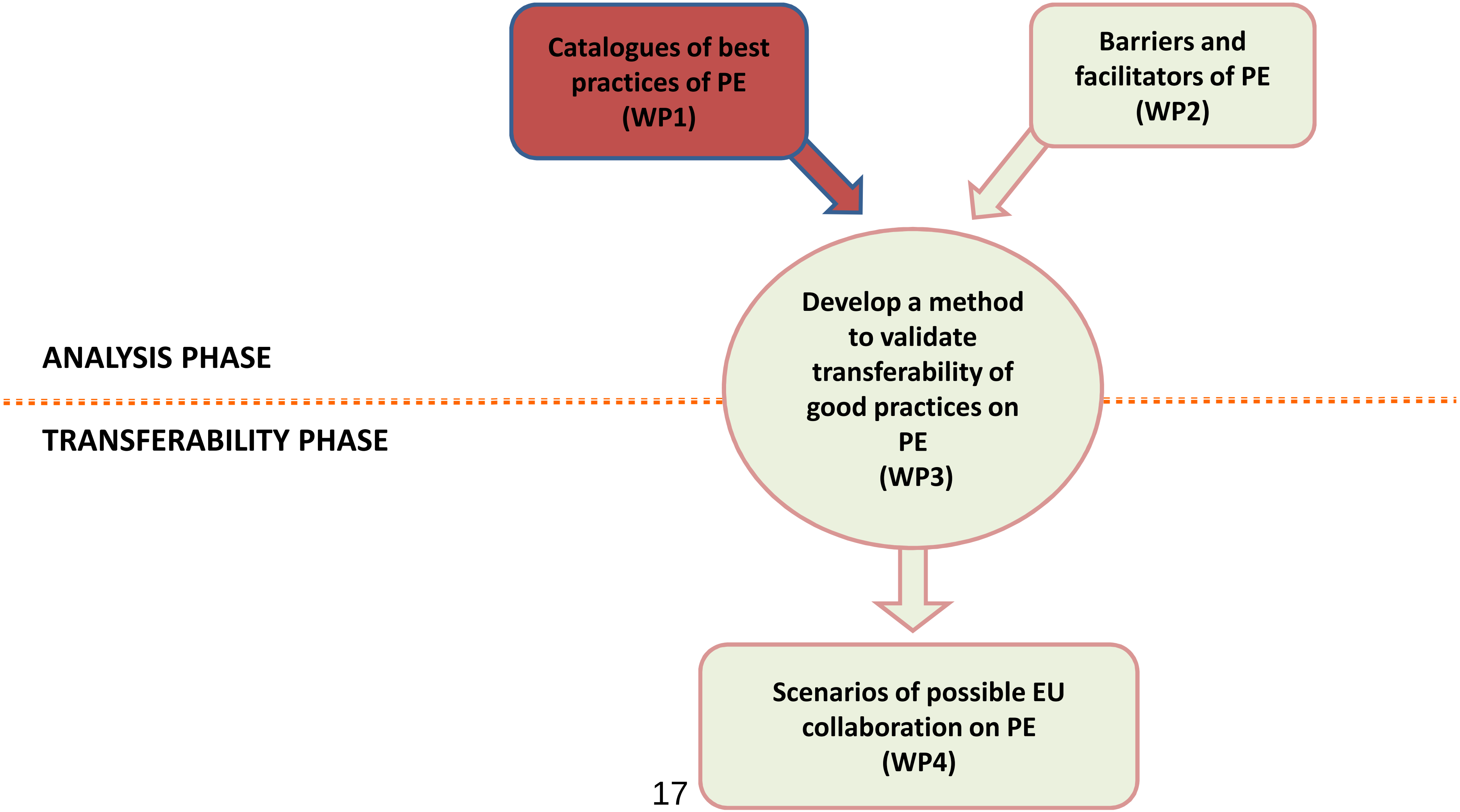
Professional Satisfaction

Quality of Life

Clinical Outcomes

Use of Health Services (Cost)

PROJECT PHASE



Catalogues of best practices of PE (WP1)

Barriers and facilitators of PE (WP2)

ANALYSIS PHASE

Develop a method to validate transferability of good practices on PE (WP3)

TRANSFERABILITY PHASE

Scenarios of possible EU collaboration on PE (WP4)

WP1 - CATALOGUE OF BEST PRACTICES – DESCRIPTIVE RESULTS

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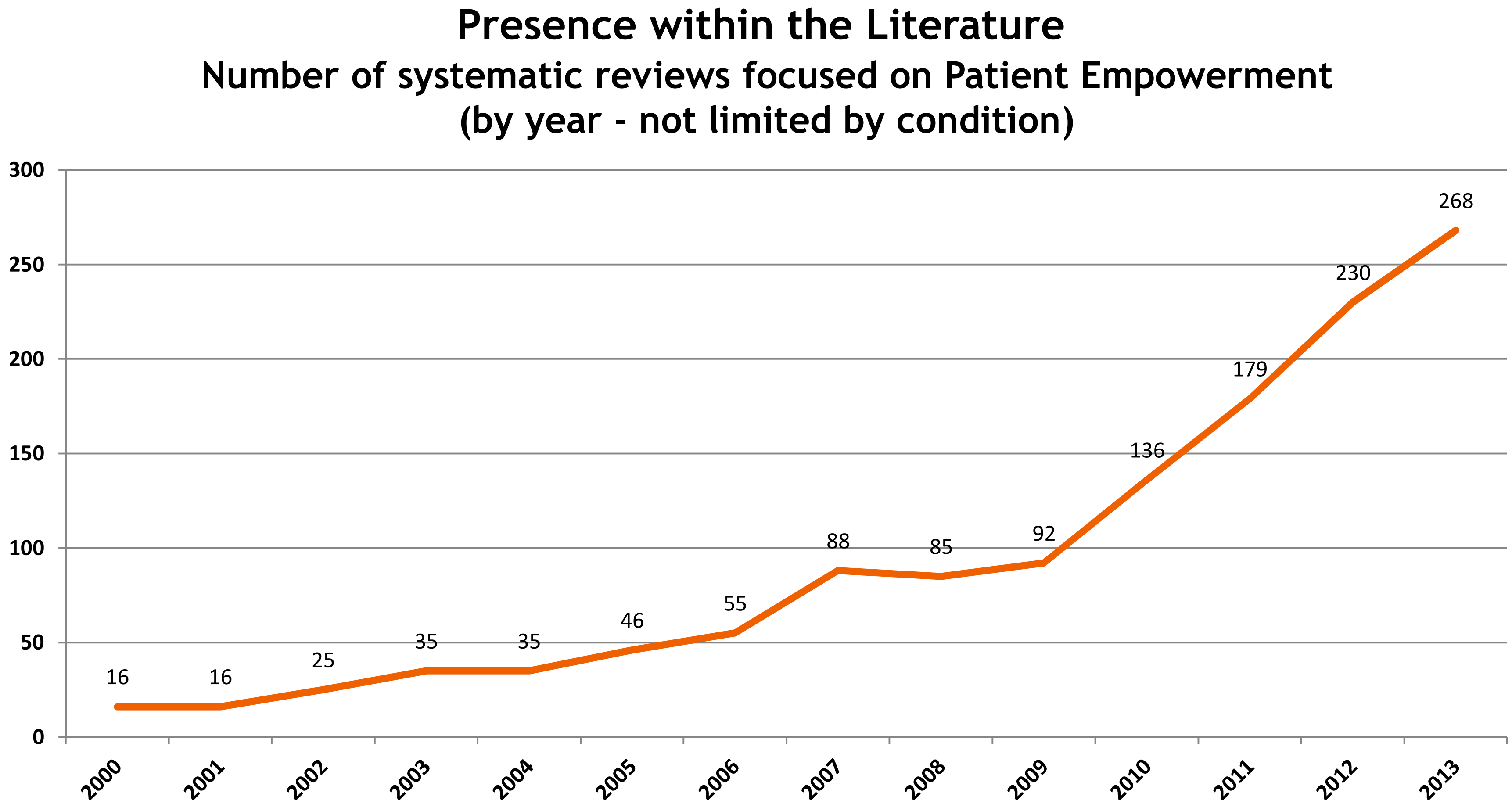
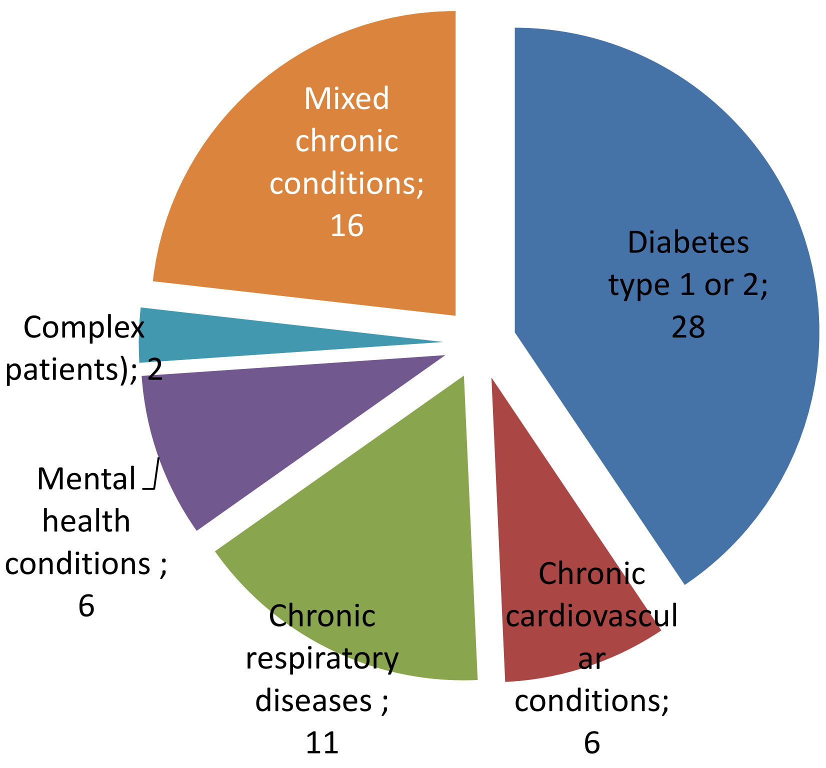
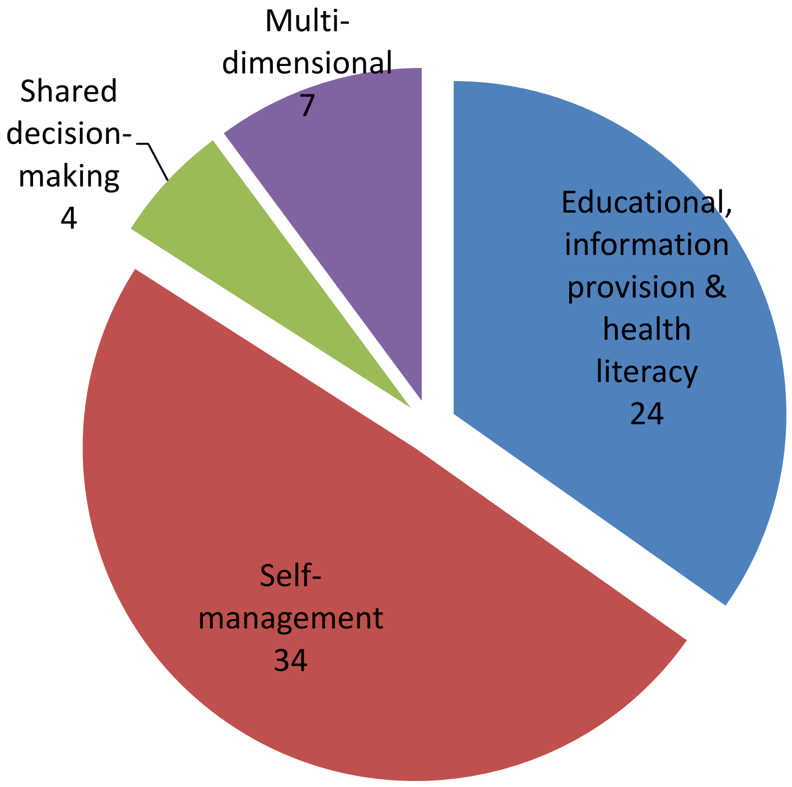


CATALOGUE OF BEST PRACTICES– LITERATURE REVIEW, DESCRIPTIVE RESULTS(1118 SR)

Distribution by condition



Distribution by dimension



Selected N= 69 SR; 1728 articles (SRs filtered using AMSTAR score and assessed impact)

WP2 Methodology – Identification of barriers and facilitators

Exploration of topics - Focus groups

18 Countries - 170 persons (+50% patients)

Identification 952 important facilitators and barriers
(1/3 facilitators and 2/3 barriers) → 19 clustered topics

Prioritization – Survey

26 countries - 869 persons (+50% patients)

Identification of 5 top clustered topics

Top 5 clustered aspects

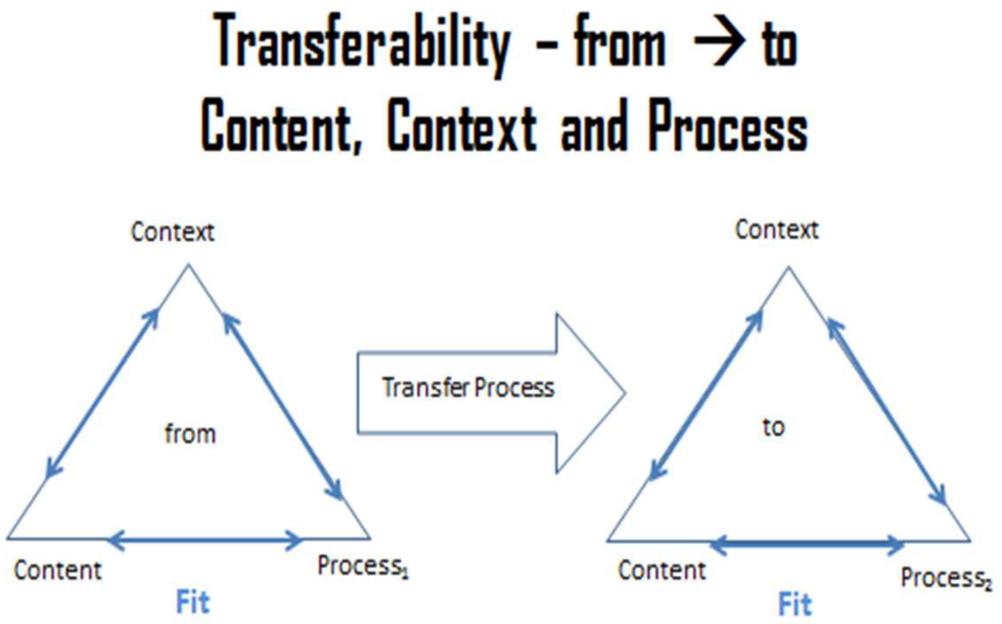
Priority	Topics important for patient empowerment
1	It helps that the healthcare professional has enough time to communicate with the patient
2	It helps that the healthcare professional has a holistic view of the patient
3	It helps that healthcare is well coordinated
4	It helps if the patient feels responsible for his/her own health
5	It helps that healthcare professionals work together

Slight differences in ranking when examined by respondent group or by Region

Method for transferability of good practices

Findings of WP1 and WP2 linked to literature reviews concerning innovation, adoption and emergence of Good Practices in organizations; especially from social science and improvement science research.

"Practice content +Context + Implementation Process → Outcome"


Transferability - from → to Content, Context and Process

Transferability model from one setting to another based on Pettigrew

Model tested post-hoc with four interventions chosen from the literature, to demonstrate potential practical value. Three CHAFEA approved EU Experts assessed face validity.

Four models of physician-patient relationship (from Reach, 2014)

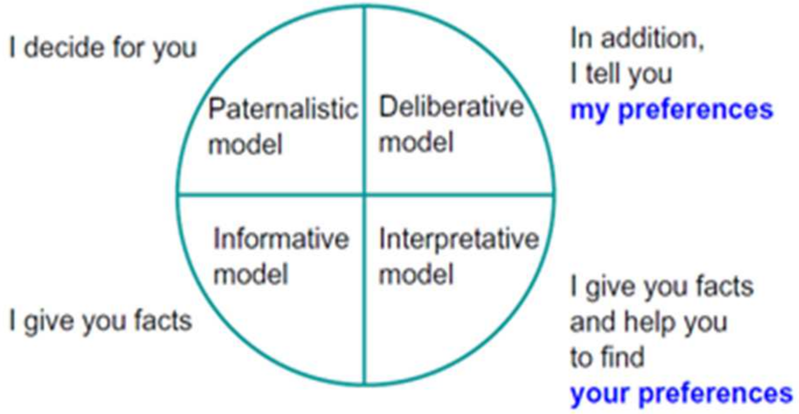


Figure 2 Four models of the physician–patient relationship, definitions from Emanuel and Emanuel.[35]

The role of Education and respect for Autonomy in the physician-patient relationship

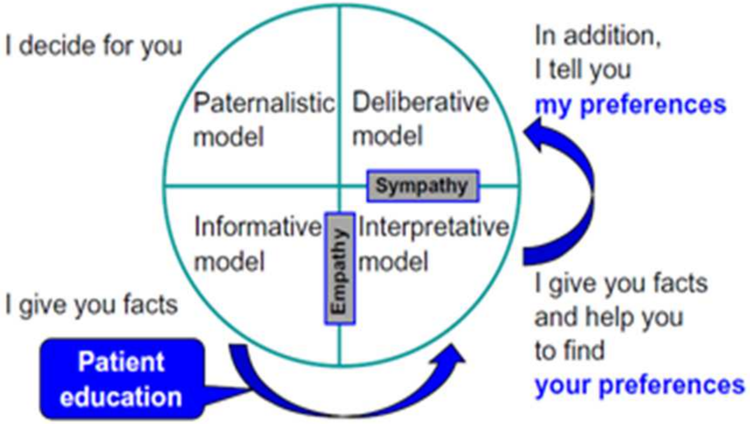


Figure 3 A model of care in chronic diseases: patient education as an ethical pathway. A definition of patient education: patient education is the empowering process that in chronic care not only provides information to the patients but also leads them to an interpretation of their own preferences and a deliberation between their, and the HCP's, preferences.

WP4 Methodology - Scenarios of possible EU collaboration on Patient Empowerment

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Exploration of possible scenarios

Inputs from WP1 & 2
Development of initial scenarios

Inputs from WP3
Development of feasibility criteria

Explored in 2 workshops with relevant stakeholders

Development and prioritization

104 respondents online survey

40 stakeholder interviews

Selection and refinement of the 4 final scenarios

From the overall consultation process **four final scenarios** were developed with consideration of 1) the effort needed to start collaborating, 2) effectiveness in achieving patient empowerment, 3) perceived costs, 4) EU added value, 5) benefits and perceived risks and 6) barriers and success factors.
The scenarios are:

- **“The informed patient”**
- **“New professional skills, knowledge and attitudes”**
- **“Self-management supported by technology”**
- **“Transparent quality data for patient choice”**

Future actions of the EMPATHIE Network (1)

Platform of experts in self-care in minor conditions (PiSCE tender)

Contribution to Chrodis JA as collaborating partner

Continuing participation in Joint Action PASQ (FAD & EPF)

Future actions of the EMPATHIE Network (2)

Contributing to European Innovation Partnership on Active and Healthy Aging: B3 Action area and Synergies group, A2 Action area etc.

Supporting EPF campaign on Patient Empowerment 2015-2016 (see: http://www.eu-patient.eu/events/past-events-june-2015/conference-on-patient-empowerment)

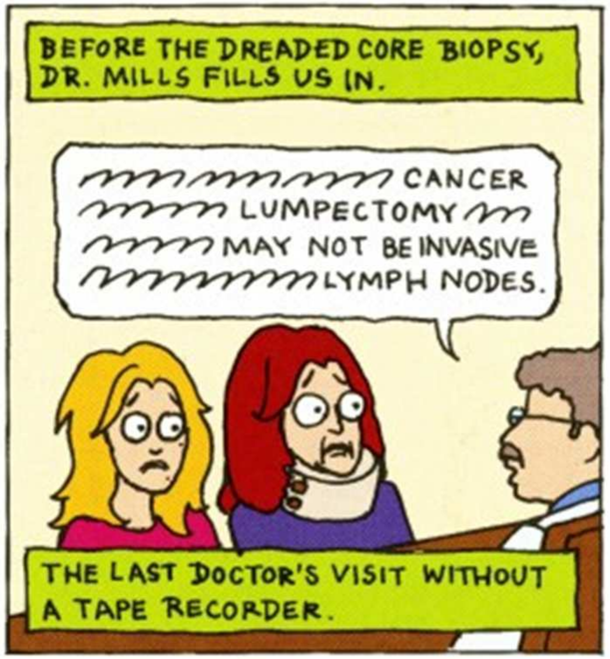
How does a project like EMPATHiE help us evaluate proposed good practices in relation to Patient Empowerment in various contexts, whether in the management of chronic disease, the use of eHealth or for example, these two combined?

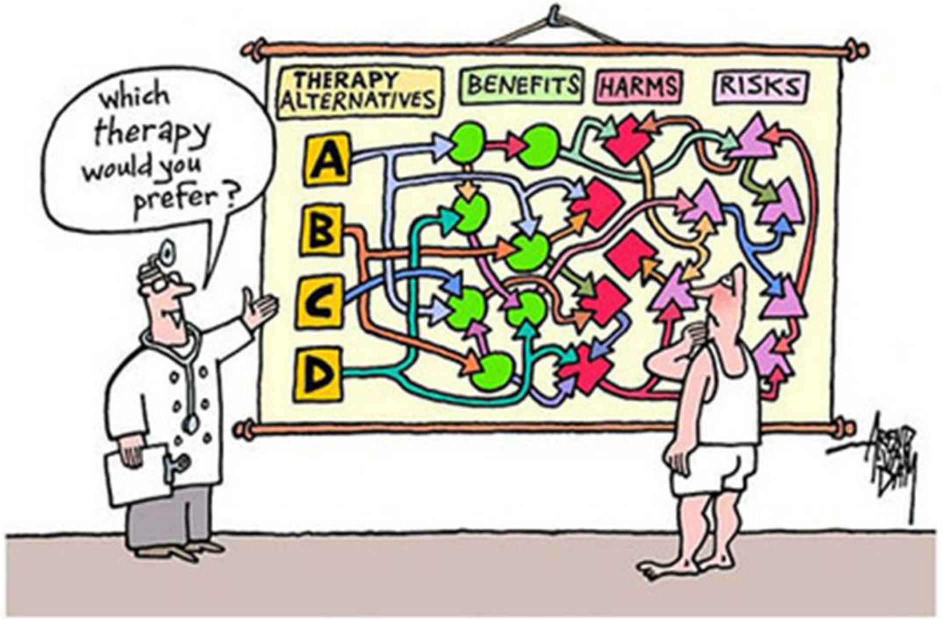
We could try some simple measures -

The paternalism test (co-production?)

CARTOONSTOCK .com
Search ID: forn2141

The communication test (a):





informed consent

The communication test (b):

The innovation test:

"This really is an innovative approach, but I'm afraid we can't consider it. It's never been done before."

If we are to argue that better practice leads to patient empowerment, we have to ask tough questions of ourselves: -

- How is **improvement in health literacy** assessed, if it is addressed at all?
- How is evidence of an **increased level of shared decision-making** assessed?
- Are patients **asked about their experience** of ‘best practices’ or eHealth tools that are meant to empower them?
- If constructive suggestions arise from focus group type exercises**, is subsequent implementation of these suggestions assessed?**
- What evidence is there that greater use of best practices **leads to changes in the structure and delivery of services (innovation)?**

And another challenge : the **ePatient**

Sometimes referred to as an "internet patient," e-patients see themselves as equal partners with their doctors in the healthcare process.

- A growing number of people say **the internet has played a crucial or important role as they helped another person** cope with a major illness.
- Since the advent of the Internet, **many clinicians have underestimated the benefits and overestimated the risks of online health resources** for patients.
- **Online support groups** have become an important healthcare resource. A new phenomenon **is the use of social media as an alternative,** something difficult to monitor by health providers.
- It is crucial for medical education to **take the e-patient into account**, and to prepare students for **medical practice that includes the e-patient**.

As our critical analysis suggests, it’s a long and winding road that leads to reaping the full potential benefits of greater patient empowerment but the key is what has always underpinned quality in healthcare: we measure

The Joint Action on Chronic Diseases and Promoting Healthy Ageing across the Life Cycle (JA-CHRODIS)*

Co-funded by
the Health Programme
of the European Union

* This presentation arises from the Joint Action addressing chronic diseases and healthy ageing across the life cycle (JA-CHRODIS), which has received funding from the European Union, under the framework of the Health Programme (2008-2013).

European Health Futures Forum

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