

# Parallel symposium 2A

## Presentation of the forthcoming ODHIN project



Do general public have a role in the translation of science  
into policy?

Joan Colom & Lúdia Segura



Generalitat de Catalunya  
**Departament de Salut**

## Index

- Terminology
- Do patients have a role in the ODHIN project?
- Remarks and issues to be addressed
- Background on patient involvement
- The bigger picture
- Potential benefits
- Potential barriers
- Framework on patient involvement
- Evidence of patient involvement
- Impact of patient involvement
- Patient involvement in ODHIN

## Terminology

Different terms to describe people who use health and social care services□

□Patient

□Users

□Careers

□Clients

□General Public

□Patients' representatives

□Consumers

## Do patients have a role in the ODHIN project?

- Source of individual information/outcome data (satisfaction, acceptability, accessibility, level of awareness, level of consumption, alcohol related problems, etc).
- Informed consent and ethic approval
- Intervention oriented (motivational interview) and tailored to patients
- Information and feedback from/to patients
- Communication tools (website and factsheets) and deliverables adapted

## Remarks and issues to be addressed in ODHIN

*“It is targeted mainly towards professionals and decision makers□ there is a missing actor the “patient” that in the case of the life style interventions plays a crucial role. Taking into account these premises, a more innovative approach to dissemination including web 2.0 facilities and mass media and tailored information to the different stakeholders should be considered. It would also be advisable to include patients and patient’s representatives in the dissemination meetings.”*

## Background on patient involvement

- “The people have the right and duty to participate individually and collectively in the planning and implementation of their health care”

*WHO's Alma Ata declaration (1978)*

- Ethical imperative of patient autonomy and informed choice.

- Goal in itself by encouraging participative democracy, public accountability and transparency.



# The bigger picture of patient involvement

To inform or participate in

- decision about health care for populations, healthcare policies and planning
- clinical policies (clinical practice guidelines, etc)
- patient information materials
- healthcare research (design of clinical or epidemiologic studies, identification of relevant outcomes, priority setting, etc)
- education of health professionals (curriculum design and assessment, feedback on communication style.

## Potential benefits of “patient” involvement

- More accessible and acceptable health services
- Improving (better) health and quality of life
- Greater quality and clinical relevance of research
- Health services better tailored to patients' needs (concerns) and better care
- Policy and planning decisions that are more patient focused
- Improved communications between organizations and the communities they serve
- Improved implementation of research



## Potential barriers to “patient” involvement

- Resistances (criticism, undermined role, etc) and more challenging demands (unrealistic) for professionals
- Costlier and longer projects/studies
- Biased views on certain health issues (impartiality threaten)
- Low participation or non consistent participation (not meaningful for patients and their representatives, lack of support, anxiety, etc).

## Framework on patient involvement

- Degree/modes of involvement □ from non participation, through information, collaboration, consultation to partnership and patient control.
- Methods of involvement □ individuals or groups (pre-existing or convened for that purpose).
- Types □ consultative fora, written consultation, collaborative committee, permanent consumer panel, surveys, interviews, etc).

## Evidence of patient involvement

- Scarcity of studies (comparison studies) in general.
- Some evidence on impact (desirable or non desirable effects)
- Low on how to achieve effective consumer involvement (how to recruit, degree of effective involvement).

*Nilsen ES et al 2010 (Cochrane review)*

## Impact of patient involvement

- Improvement in the clarity of the information material (relevant, readable and understandable) and the knowledge of people who read the material.
- Small differences in satisfaction survey results when consumer interviewers are used instead of staff interviewers.
- Little effect of the participation of consumers in the development of consent documents.

# Improving patient involvement in ODHIN

- Ongoing partnerships (or repeated consultations) from the very beginning and at all stages (collaborative learning) to□
  - Elicit patient needs (information, etc)
  - Discuss design (recruitment, treatment conditions, etc), tools, materials , dissemination strategies
  - Explore solutions and improvements
- Clear key factors such as remit (terms of reference), role, relationships and responsibilities

# Improving patient involvement in ODHIN

## •Methods□

- Focus groups to know their view's?
- Consultation panel?
- Patient as teacher to identify good practices and improve professionals skills?
- Patient diary to analyze in detail the patient's view
- Improving practice questionnaire (IPQ) (communication skills, access, availability, information giving, etc
- Comparison study?

## •Recruitment process□

- Who? Patients only? Heavy drinkers? Staff?
- How? Existing groups? Convened groups?

## •Role in dissemination strategy