



**Qualitative approach and users' view: from information explosion to the elaboration of social intervention guidelines**

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**HAS**

HAUTE AUTORITÉ DE SANTÉ

# The French National Authority for Health

- An independent, public scientific advisory body
- Purpose : advance quality health

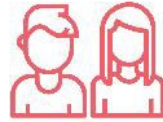
*Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO definition)*

- Area of action: healthcare and social care services

# Three core missions



**Assess and appraise** pharmaceuticals, devices and procedures for inclusion on the national list of reimbursed products and services.



**Recommend** best practices for health care professionals and elaborate public health guidelines.



**Measure and improve** the quality of care delivered in health and social care organizations.

**Advance quality in health and social care to serve both individual and collective interests**

# Recommend best practices and elaborate guidelines

## ... ○ Clinical and Organizational Practice

- Best clinical practice
- Healthcare pathways
- Relevant care
- Patient safety

## ... ○ Vaccination

- Guidelines
- Recommendations

## ... ○ Social Care Practice

- Guidelines
- Practical tools

## ... ○ Public Health

- Guidelines
- Health economics recommendations

**Serving as a reference for professionals and the public**

# Measure and Improve Quality

... ○ Accreditation of healthcare organizations

... ○ Accreditation of practitioners and medical teams (high-risk specialty care)

... ○ Indicators of quality care and safety

... ○ Evaluation of social care services

**Improve practices and inform the public**

# Summary

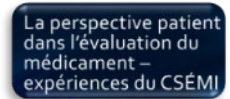
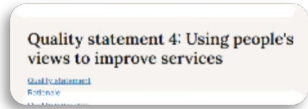
1. Users' view from the perspective in bibliometrics
2. Concepts developed in qualitative approaches
3. Integration of the users' view in our guidelines

# Context

- ... ○ A growing interest in users' view

- ... ○ Rise of studies/publications with qualitative methods

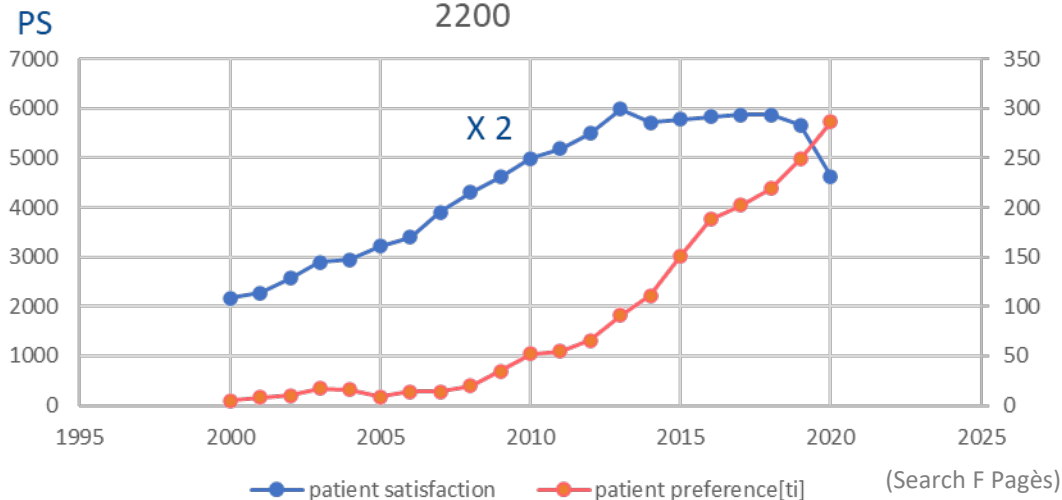
These publications are based on an ongoing development of concepts (satisfaction/experience) in the social field.



# Users' view

## ... ○ Great increase in publications on patients' experience

Evolution of number of publications indexed with Mesh term "patient satisfaction" in PubMed 2000-2200



### Bibliometrics « patient experience»

- No Mesh term → « patient satisfaction» (created in 1992)  
1st papers about « how to measure it »  
And « how it is correlated with quality of Health care »
- Patient experience (searched in title)



# Users' view

- ... ○ **But less the case in the social field because of certain characteristics:**
  - Depending on the country, the term care can cover the health and social sectors
  - The social field covers a very wide range of populations (elderly, person with disabilities, child protection, addiction, homeless...)
  - Services and facilities can support people for very long period of time and for all activities of daily life
  - Service users may have specific difficulties in sharing their views
    - Less extensive and sometimes good quality bibliography
    - Confirm the relevance in developing international cooperation work (concepts/methods)

# Satisfaction

## ... ○ Questions about the relevance of this concept (according to some authors):

- Not sufficiently well defined
- Strongly influenced by individual expectations and preferences
- Highly variable levels of satisfaction for the same delivered service
- Low discriminatory capacity because of very high scores

### ➤ Scientific differences:

Do not measure it

Use it only for very specific and concrete subjects

Associate it with the concept of experience

# Experience

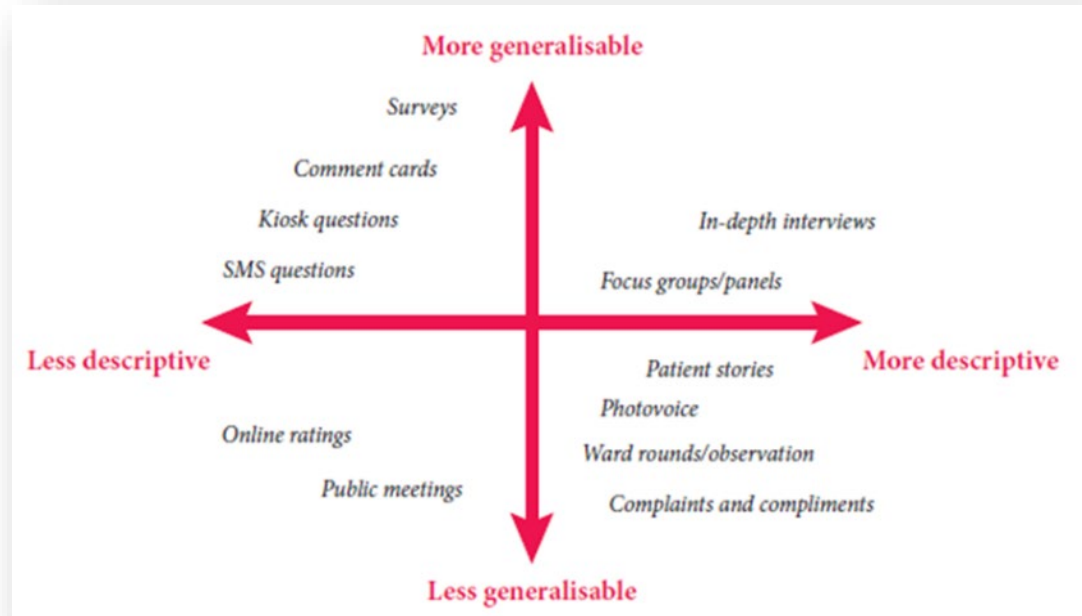
- ... ○ **A concept that is getting more precise**
  - An international consensus
  - Very relevant for the social field as a multidimensional approach (type, duration of support...)

*“Refers to the perceptions and facts experienced by users during clinical and non-clinical interactions with the actors of the health and social services system , and this, throughout the trajectory of care and services; that is to say, from the very first contact with the system to its last, from prevention and health promotion, to end-of-life care and services.” (IUPLSSS)*



# How to collect users' experiences?

- No strong scientific consensus currently
- Towards diversified methods



(NIHR)

# Which dimensions to collect?



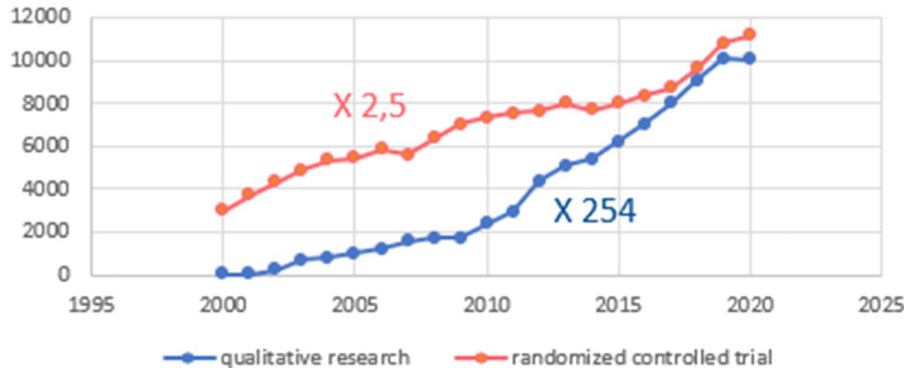
## Based on quality of life:

*“Quality of life is defined as an individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept incorporating in a complex way the persons' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment.” (WHO)*

# Qualitative data in literature

- ... ○ In health, EB model is prevalent, but may be suitable for collecting users' view
  - Great growth in qualitative studies

Evolution of number of publications indexed with Mesh term "qualitative research" in PubMed 2000-2200



- 2003 : Creation of Mesh term « qualitative research »
- 2012 : Creation of the Cochrane group GRADE-CERQual

(Search F Pagès)

# Qualitative data in literature

- • • ○ **Benefits of using qualitative methods**
  - Capture people's perceptions, representations and experiences
  - Study people in their own environment and allow them to express themselves in their own words
  - Particularly suitable for analysing the views of social service users

# Qualitative data in literature

... ○

## But...

- Methods sometimes misunderstood
  - May used by researchers and professionals who are not always acculturated to social sciences
  - Usual literature search strategies that may omit some social science theoretical framework
- 
- To be taken into account when assessment studies
  - Which again confirms the interest of international cooperation work





Given this dual evolution, how to integrate qualitative data on users' points of view in good practice guidelines?

# Best practice guidelines

## ... ○ What are they?

- Statements that support decision making in a specific circumstance
- Based on a triple expertise :
  - Scientific: a systematic evaluation of the most up-to-date scientific evidence,
  - Professionals 'opinion and experience
  - Users' experience and perspectives

*« Nothing about us without us »*

# Integration of users' experience involvement in developing guidelines

... ○ In different stages of the process...

...to ensure that users view is included and acknowledged





# Methodological challenges

- How to assess the quality of studies about users experience ?
- How to recruit users? What profile ?
  - ➔ Experiential knowledge versus experience
- How to involve users more successfully specially more vulnerable people ?



# Thank you for your attention

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