

# **Coinvolgere i pazienti nella ricerca e nella diffusione dei risultati:**

*cosa possiamo imparare dalle esperienze straniere?*

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## **Contenuto della presentazione**

- Perché coinvolgere i pazienti
- Modelli/modalità di coinvolgimento
- Esperienze
  - La Cochrane Collaboration
  - Il programma R&D inglese
  - La James Lind Collaboration
  - Altre esperienze
- Criticità e condizioni di fattibilità

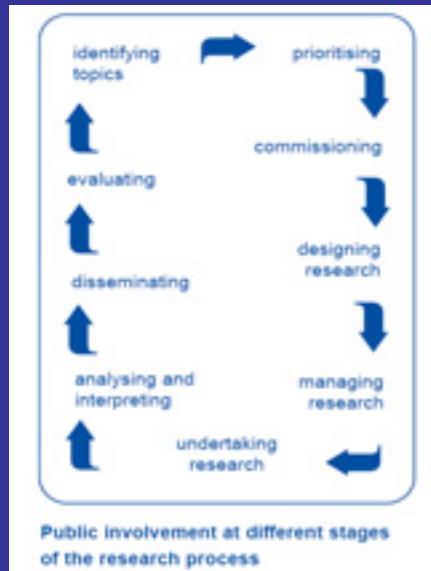
## **Perchè coinvolgere i pazienti**

- Per un principio di equità e democrazia
- Perchè i pazienti esprimono diverse priorità e richiamano l'attenzione su aree orfane di ricerca

## **Modelli di coinvolgimento**

- Singoli individui o gruppi di pazienti
- Consultazione occasionale o coinvolgimento permanente all'interno di gruppi di lavoro collaborativi
- Formali indagini condotte da gruppi di ricercatori o di associazioni
- Attraverso programmi sistematici di empowerment

## Possibilità di coinvolgimento



## Principali contributi che possono essere ottenuti attraverso il coinvolgimento dei pazienti

- Le motivazioni della ricerca
- Maggiore completezza su quanto già si conosce
- Chiarezza dei quesiti
- Rilevanza degli outcome
- Indicazioni per la ricerca futura

## The Cochrane Collaboration

- The Cochrane Collaboration publishes systematic reviews of healthcare interventions in the Cochrane Database of Systematic Reviews (CDSR) within *The Cochrane Library*
- 50 review groups, covering all areas of health care
- Consumer involvement functions differently in each group

## Consumers in Cochrane

- Comment on Cochrane reviews
- Identify review topics
- Disseminate the results of Cochrane reviews
- Handsearch healthcare journals for relevant studies
- Contribute to writing lay summaries (synopses) of systematic reviews
- Translate materials including healthcare articles and newsletters

## Consumers in Cochrane



## NHS Research and Development

Three research programmes:

- Health Technology Assessment
- Service Delivery and Organisation
- New and Emerging Applications of Technology

Three cross-cutting programmes:

- Methodology
- Research Capacity
- INVOLVE/ Consumer involvement

## Public Involvement pages

- Public Involvement Index
- Newsletter
- FAQ
- Resources
- Links

### The contribution of the public to the HTA programme:

The HTA programme has been actively involving "service users" in all stages of its process since 2007. These pages explain what those stages are, what **health technology** means, and how the public can get involved. They also allow access to the resources developed for service users by the HTA programme.

- \* [Identifying topics for research](#)
- \* [Choosing which topics should become research priorities](#)
- \* [The peer review process](#)
- \* [Public involvement in conducting research](#)
- \* [Payment for service users advising the HTA programme](#)
- \* [HTA-commissioned research into consumer involvement in R&D agenda-setting for the NHS](#)

An 'Evaluation of public influence on the HTA programme' was commissioned by the NCHTA and a free standing executive summary of the study's findings, conclusions and recommendations has been published.

- \* [Evaluation of public influence on the HTA programme](#)

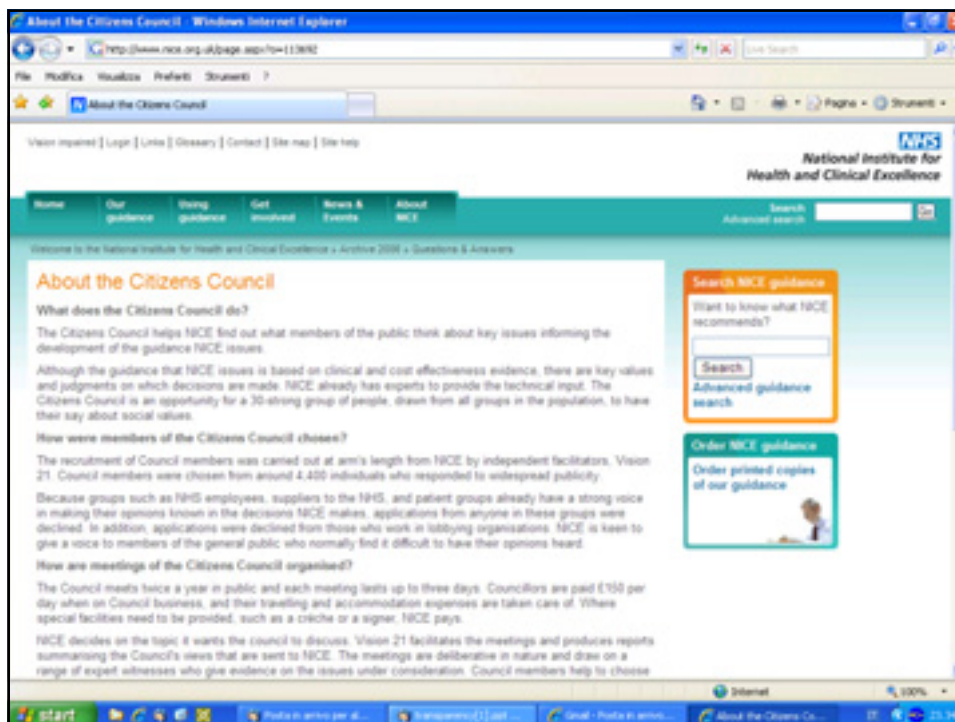
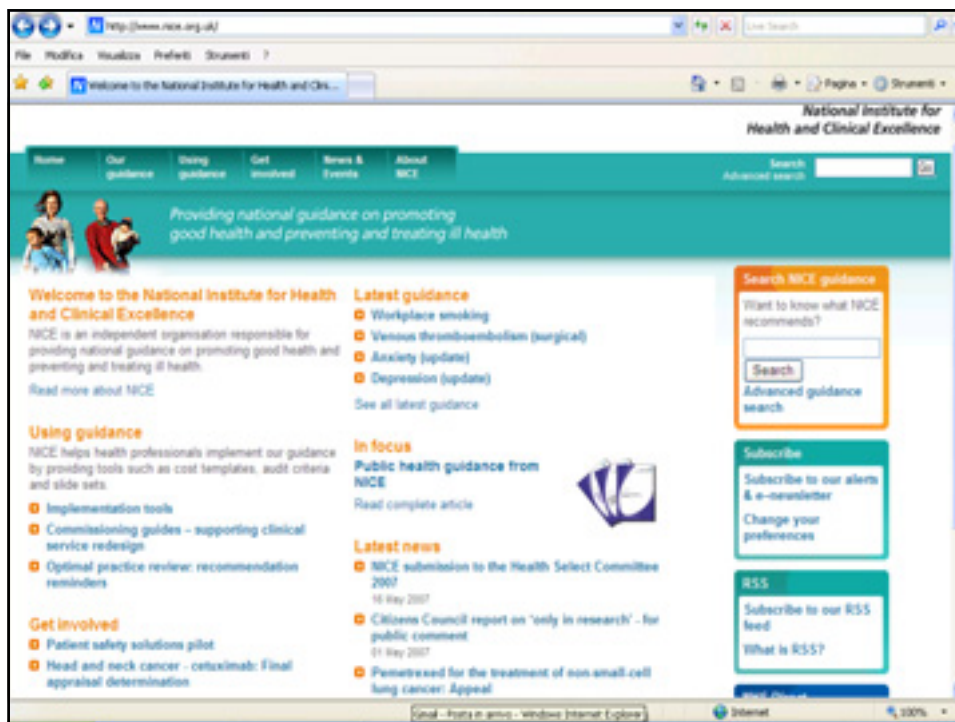
If you are interested in getting involved in the work of the HTA programme, please contact our Patient and Public Involvement Manager on 023 8039 3756 or email [Ma@hta.ac.uk](mailto:Ma@hta.ac.uk)

Further details of public involvement in the HTA programme are available in our [Information Sheet](#) (pdf file, 23KB). The programme also has a dedicated [Public Involvement FAQ](#) page and a quarterly [newsletter](#) for service users, service user resources pages and useful links.

The HTA programme has adopted the policy of the [NHS R&D INVOLVE](#) programme which now recommends terminology such as "the public" and "people who use services" rather than "consumers". This site is being amended gradually, as far as possible, to reflect this.

The model of public involvement described on this site is one which has been developed in the context of an NHS R&D programme tackling a wide range of diseases and conditions, and is just one of a variety of possible models of public involvement.

As INVOLVE comments on its website, "It is not reasonable to expect one or two people to be representative of all people who use similar services. But then it's not reasonable to expect one doctor to be representative of all doctors either. It would





## The Premise

The current healthcare research agenda doesn't serve the interests of patients, the public or clinicians efficiently because of

perverse commercial and academic influences

Within  
**treatment evaluation**  
there are  
**two important problems**

### **First problem**

Researchers ignoring  
patients' & clinicians' questions

## Second problem

Researchers addressing  
the right questions  
in the wrong way

OMERACT 7 Workshop

### Incorporating the Patient Perspective into Outcome Assessment in Rheumatoid Arthritis — Progress at OMERACT 7

JOHN R. KIRWAN, SARAH E. HEWLETT, TURID HEIBERG, ROD A. HUGHES, MAGGIE CARR, MAGGIE HEHIR,  
TORE K. KVIEEN, PATRICIA MINNOCK, STANTON P. NEWMAN, ENID M. QUEST, ERIK TAAL, and JANNEY WALE

- Patients and professionals view the outcome of rheumatoid arthritis differently
- Many outcomes that patients find important are not measured at all by researchers

## New drugs for Alzheimer's disease – A consumer perspective

### Researchers

- Improvement of 3+ points on the ADCog
- Delay in admission to institutional care
- Maintenance of ADLs

### Patients

- Improvements in mood
- Increased confidence
- Reduction in fear and distress

### Carers

- Reduction in caring for challenging behaviours
- Reduction in anxiety
- Improved sleep

Julia Cream and  
Harry Cayton  
*CPD Bulletin Old Age  
Psychiatry 2001;2:80-  
82*

### John Kirwan and Enid Quest

James Lind Alliance meeting, 3 Dec 2005  
[see [www.lindalliance.org](http://www.lindalliance.org)]

**Priority symptom for research emerging  
from a survey of patients was not pain**

# Fatigue!

## Committee membership



NHS R&D programmes

- 1 or 2 consumers
- Little or no reflection on working together
- No records of consumers' views
- Few or no lessons learnt

## Town meeting



USA, National Institute for Occupational Safety and Health

- Town meetings in Chicago, Boston and Seattle
- Health professionals, researchers, organised labour, workers, businesses, consumers, state and local health officials, elected officials, general public

## Participatory action research

Academic institution in California

- Young people from low income families
- Choosing and conducting their own research
- Addressed pollution in a fishing bay, lack of youth recreation places, library closures, alcoholism in the home, local environmental politics



## Participatory research

International bioscience agency



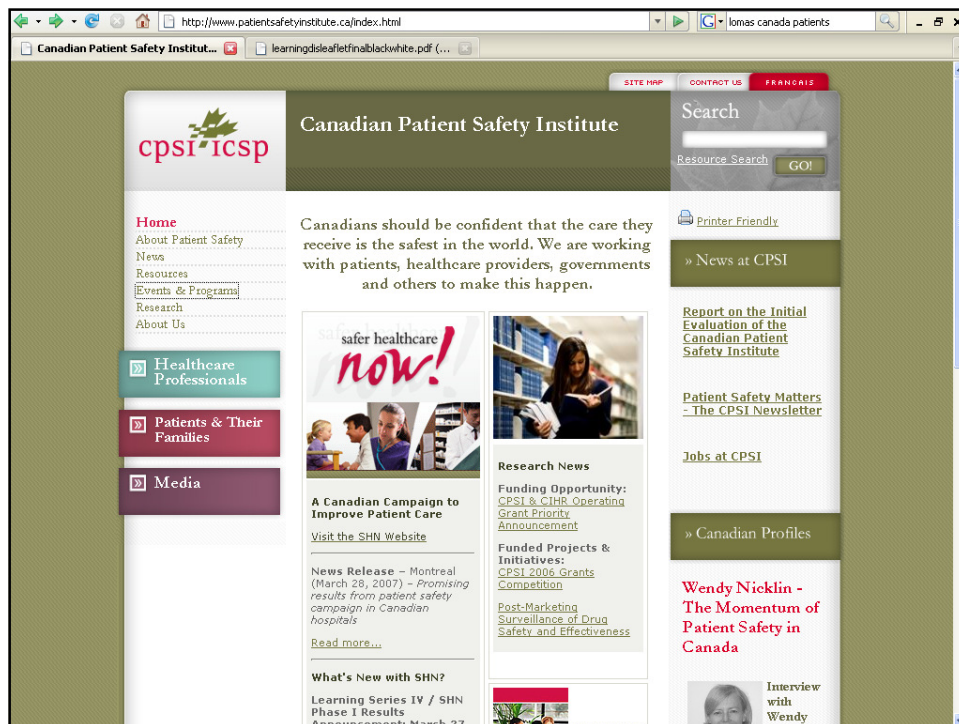
- Subsistence farmers in Kenya
- Trained through discovery based learning, to choose topics and carry out their own research
- Soil pest and disease management for nursery beds, and use of milk sprays to control leaf diseases in tomato

## One-to-one and group interviews

University researchers



- Arthritis patients
- Interviews and questionnaires
- What treatments had they tried?
- Which treatments deserved more research?
- All treatments – including education and advice, physical therapy and complimentary therapy



## Le principali criticità

- Superare le barriere culturali
- Creare le condizioni di fattibilità
  - Definire criteri espliciti di rappresentatività
  - Training and empowerment
  - Tempo protetto e riconosciuto per i rappresentanti
  - Budget dedicati
  - Vigilanza sui conflitti di interesse e le possibili manipolazioni