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# Sharing best practices in patient involvement in research

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# Why are patients needed in research ?

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**Scientific research =**

**researchers, care professionals, grant providers, and...**

**Patients.**

**Examples of patient's participation in research:**

- **INVOLVE (UK), started initially in 1996**
- **Dutch initiatives including Netherlands Asthma Foundation**

## Example: INVOLVE (UK)

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### What is it:

- national UK advisory Group
- funded by National Institute for Health Research
- established in 2003 as successor of consumers in health care research

### Aim:

promote & support active public involvement in public health and social care research.

### Hypothesis:

involving public/patients leads to research that is:

- more relevant to people's/patient's needs and concerns
- more reliable
- more likely to be used

<http://www.invo.org.uk/>

## Example: INVOLVE study – role of patient in research

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### **How does a researcher see the involvement of a patient:**

- 1) viewing the public as co-researchers;**
- 2) providing the public with information about research, through working with patients as research participants;**
- 3) a moral obligation because the public funds research through taxes;**
- 4) the need to comply with instructions on application forms for funding, ethical and governance approval;**
- 5) better targeting of research towards the people it is for.**

# Dutch initiatives how to involve patients

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**Individual project**

**“Professional patient” input**  
(e.g. employee, reviewer, member board)

**Practical methodologies** (e.g. needs/practices)

**Education**

**Share patient’s practices as input for trainees**

**Patient-driven research**

e.g. comorbidity

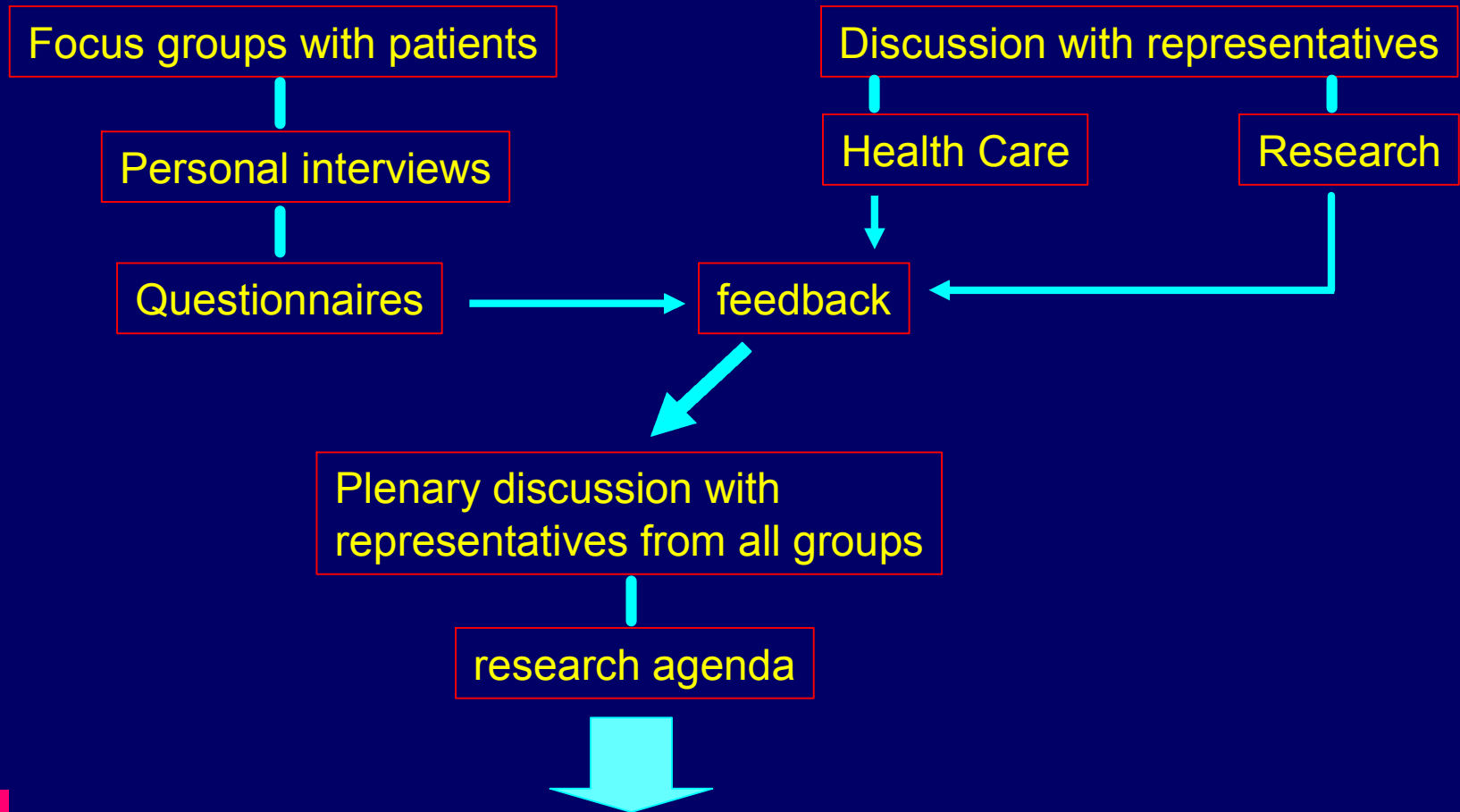
**Advisory board**

e.g. TOOLS,  
Client Consult

**Research**

**Research policy of organisation**

# Example: Netherlands Asthma Foundation & Medical Research Council



**Generic example for different organisations to get patient's involvement in research policy**

## How to find each other: recommendations to patient's organisations

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1. Try to find your ambitions: passive or active
2. Know what your capabilities are
3. Be visible to researchers
4. Know what research topics are “on”
5. Know who is involved in this research
6. Look for dialogue
7. Build relationships
8. Find your ambassadors in research
9. Show initiative
10. Together with other patient's organisations

## Conclusions

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### **Patient's participation in research:**

- Provides patient's influence on research, better care & cure
- Provides research relevant to patients
- Patient's perspective is included in all aspects of research
- Stimulates patient's organisation: development, knowledge
- Better chances for implementation of results relevant to disease