




Guidelines International Network Conference 2011

Seoul, Korea. August 2011

## Patient involvement in clinical practice guidelines – methodological approach

Javier Gracia, Petra Díaz del Campo  
**Health Technology Assessment Unit (UETS)**  
 Madrid, Spain.

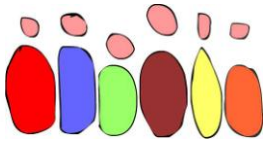






## Background

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### Patient involvement in CPGs : advantages

- **Key questions more relevant for patients**
- **Better judgment of evidence**
- **Better implementation of CPGs**
- **Greater confidence of patients**







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**Background** Guidelines International Network Conference 2011 

**Strategies for patient involvement**

**PATIENT-FOCUSSED CPGs**



**Quality patient-oriented CPGs.**

**When?**

**How?**

?

**Participation?**

**Consultation?**

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**Background** Guidelines International Network Conference 2011 

 **Quality Program for the Spanish NHS**

 **Spanish CPG Development Program**

 **Agencia Iain Entralgo**  
para la Formación, Investigación y Estudios Sanitarios

 **Comunidad de Madrid**

**Since 2006** – 



**Anxiety disorders CPG**



**patient information**



**Insomnia CPG**



**patient information**

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**Background** Guidelines International Network Conference 2011 

**Quality Program for the Spanish NHS**

**Spanish CPG Development Program**

Plan de Calidad del Sistema Nacional de Salud 

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**Since 2006 –** 

**Autism spectrum disorders CPG**  **patient information** 

**Sleep disorders in children & adolescents CPG** 

**Stroke CPG**  **patient information** 

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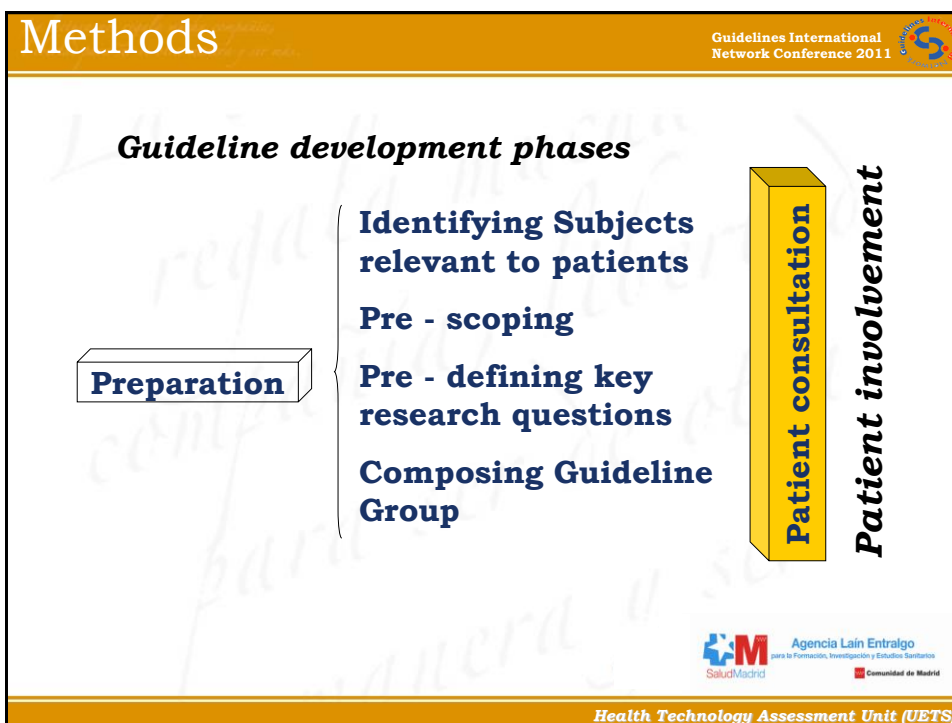
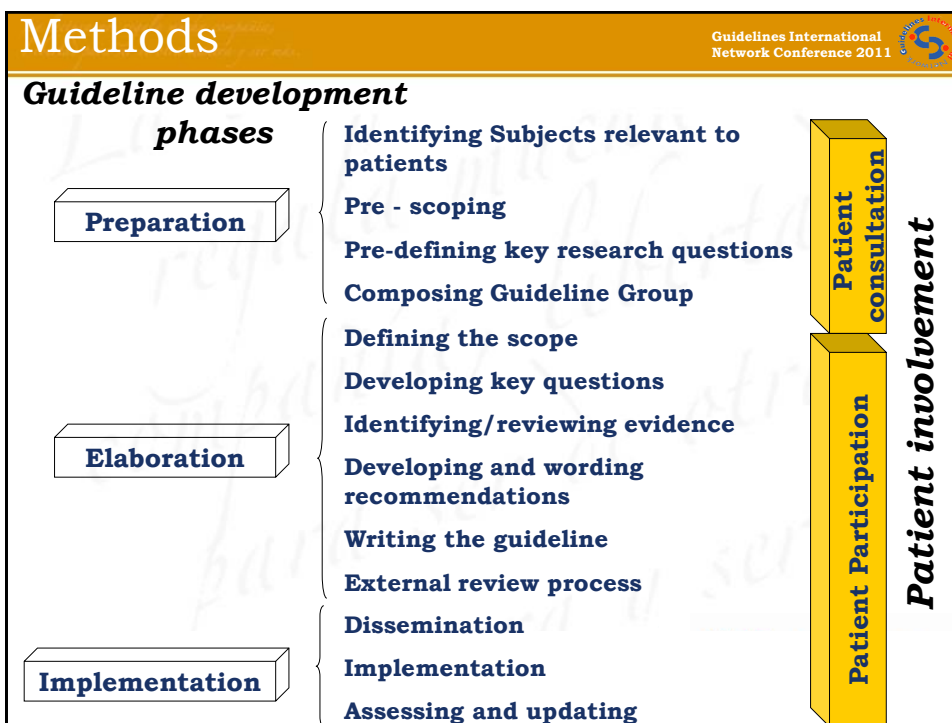
**Objective** Guidelines International Network Conference 2011 

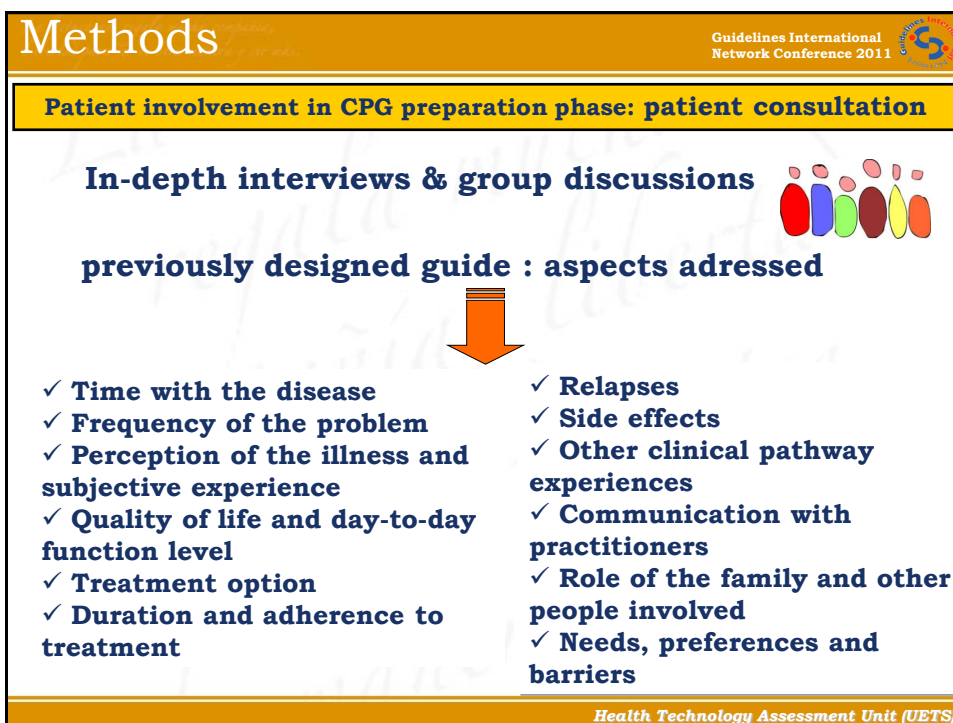
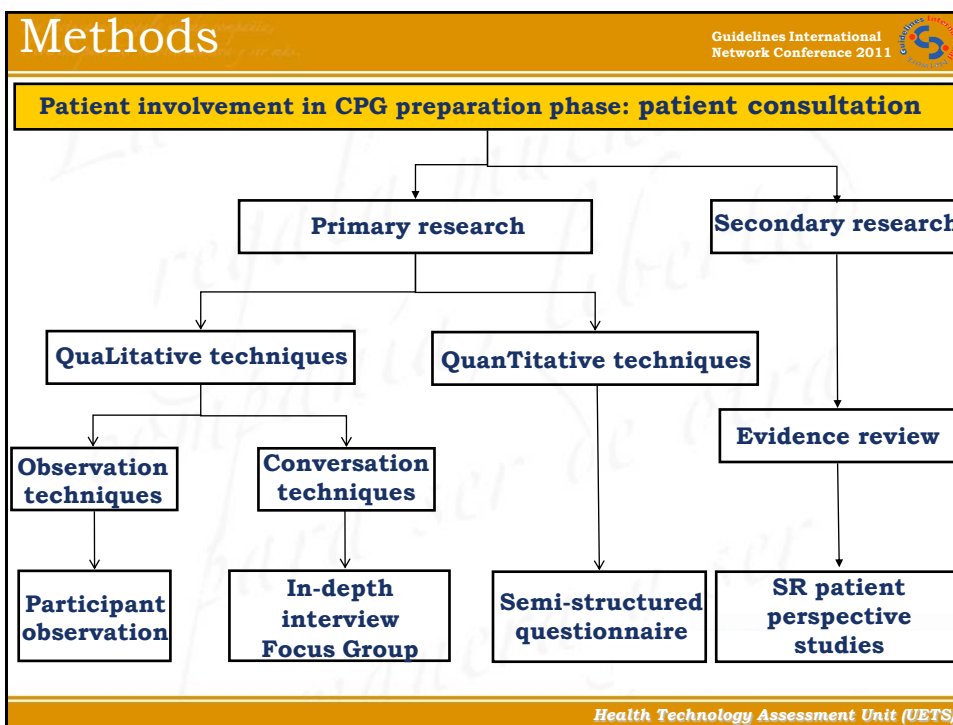
 **CPG**

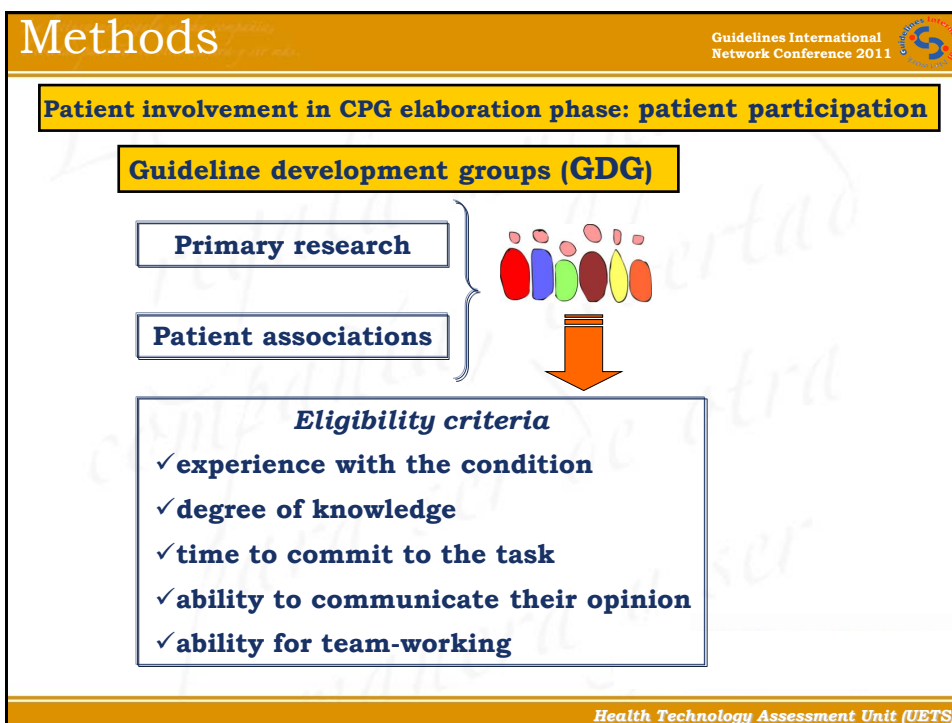
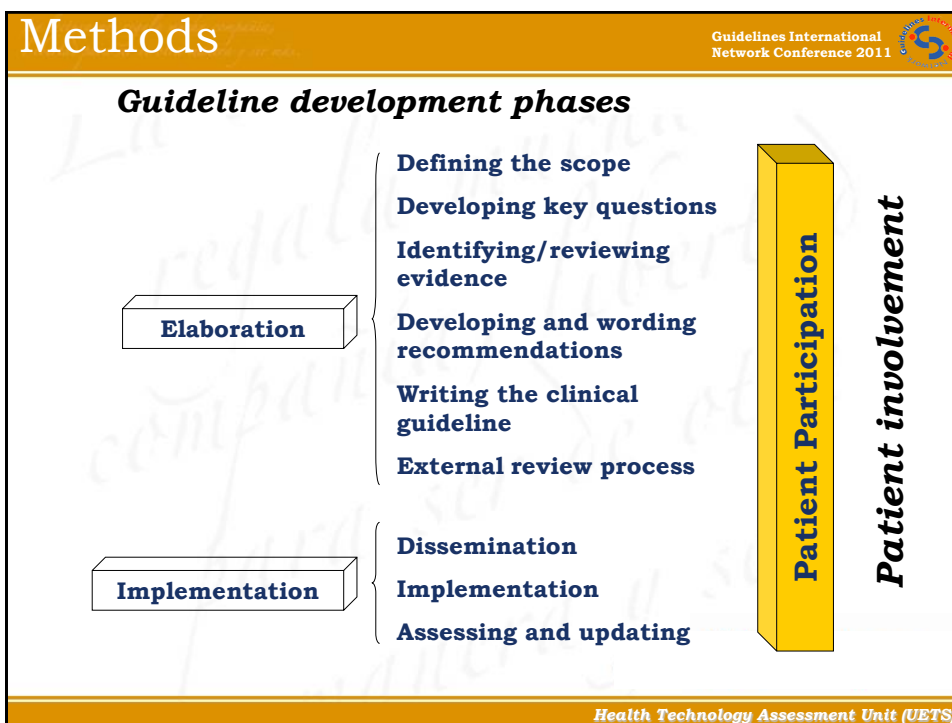
**to present a patient involvement strategy: patient consultation & participation**

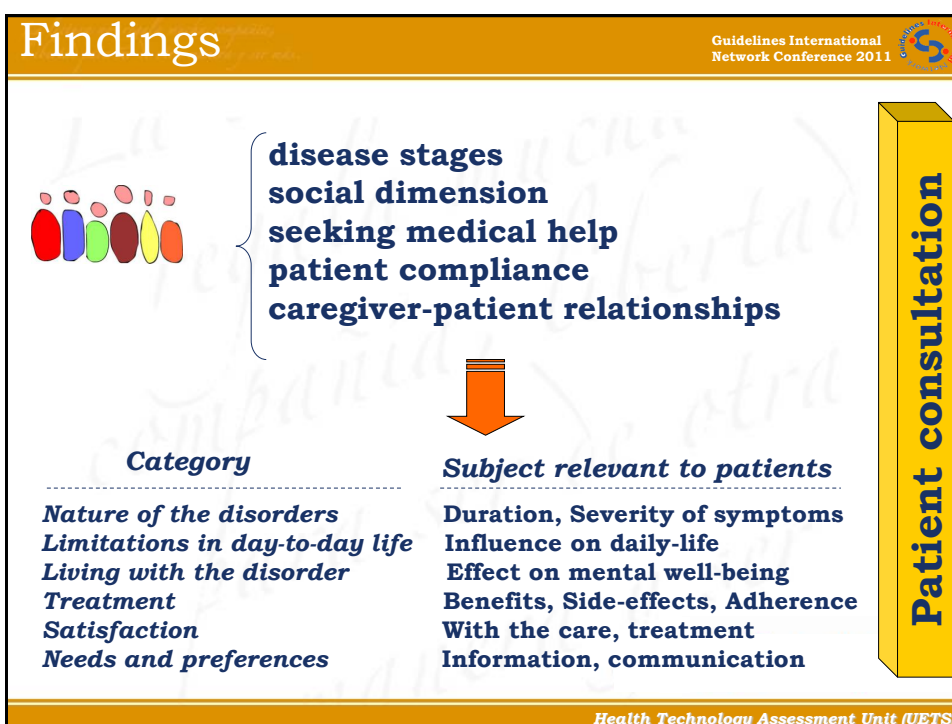
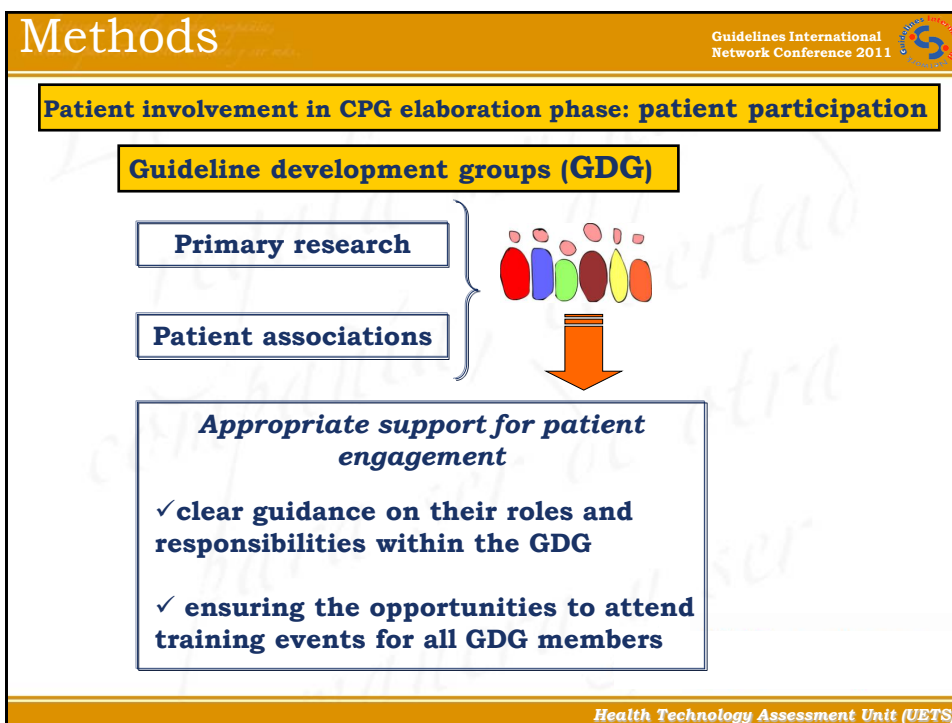
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## Findings

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### Guideline development groups (GDG)

- ✓ Truly multidisciplinary GDGs
- ✓ Scope and objectives
- ✓ Defined key questions
  - side-effects
  - treatment adherence
  - basic information
- ✓ Recommendations- contextualization & algorithms
- ✓ Patients' versions

Patient participation

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## Findings

Guidelines International Network Conference 2011


### Guideline development groups (GDGs)

#### Parents' versions for two different scenarios

Parents' information for a suspected social and communicative development problem



Parents' information for a diagnosed Autism Spectrum Disorder (ASD)



Patient participation

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## Findings

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### External review / Dissemination

- ✓ **External review process:**
  - reformulation of recommendations
  - patients' versions
    - need to assess family support before suggesting changes in lifestyle
- ✓ **Dissemination phase:**
  - patient associations - CPGs in their educational campaigns and conferences

**Patient participation**

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## Discussion (Conclusion)

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**PATIENT-ORIENTED CPG DEVELOPMENT**

↓

**Training & knowledge - qualitative research**

**Support - effective engagement**

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**PATIENT-ORIENTED CPG**


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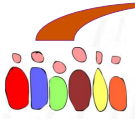
**Nation-wide patient involvement initiative**

**Patient involvement WG - handbook**

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**CPG**


**ACKNOWLEDGEMENTS**

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**Participants in Primary Research & GDGs:  
patients, patient representative, patient  
associations**



*More info at:*  
Diaz del Campo P, Gracia J, Blasco JA, et al. A strategy for patient involvement in clinical practice guidelines: methodological approaches *BMJ Qual Saf* (2011)

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*La salud es un regalo, pero la enfermedad es un préstamo.*  
*La vida es un regalo, pero el tiempo es un préstamo.*

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**THANK YOU VERY MUCH!**

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