




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.

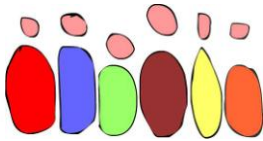






Background

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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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Strategies for patient involvement

PATIENT-FOCUSSED CPGs



Quality patient-oriented CPGs.

When?

How?

?

Participation?

Consultation?

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 **Quality Program for the Spanish NHS**

 **Spanish CPG Development Program**

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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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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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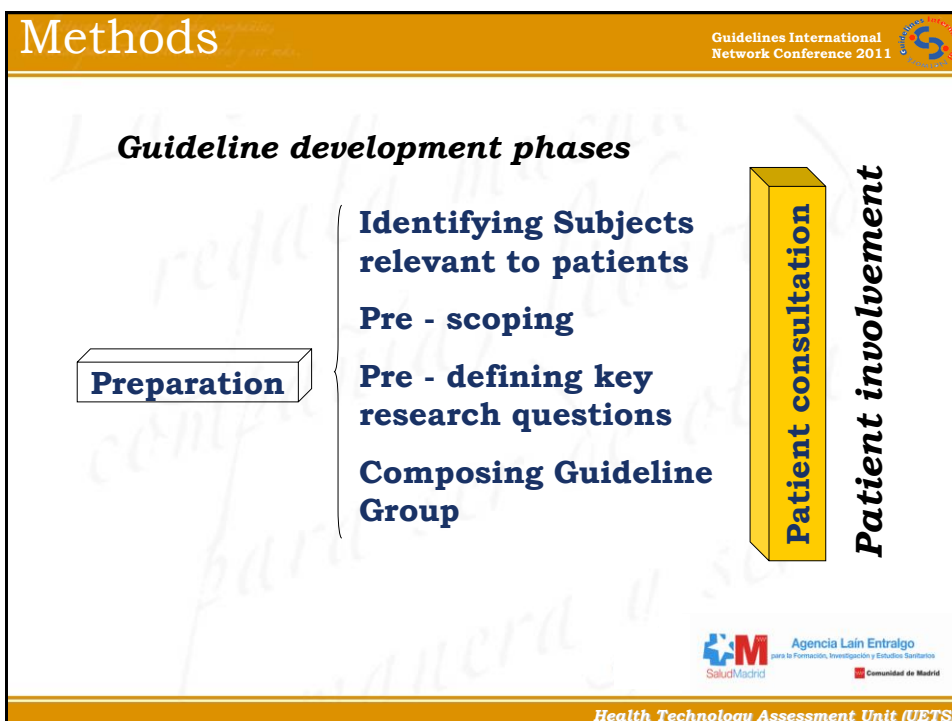
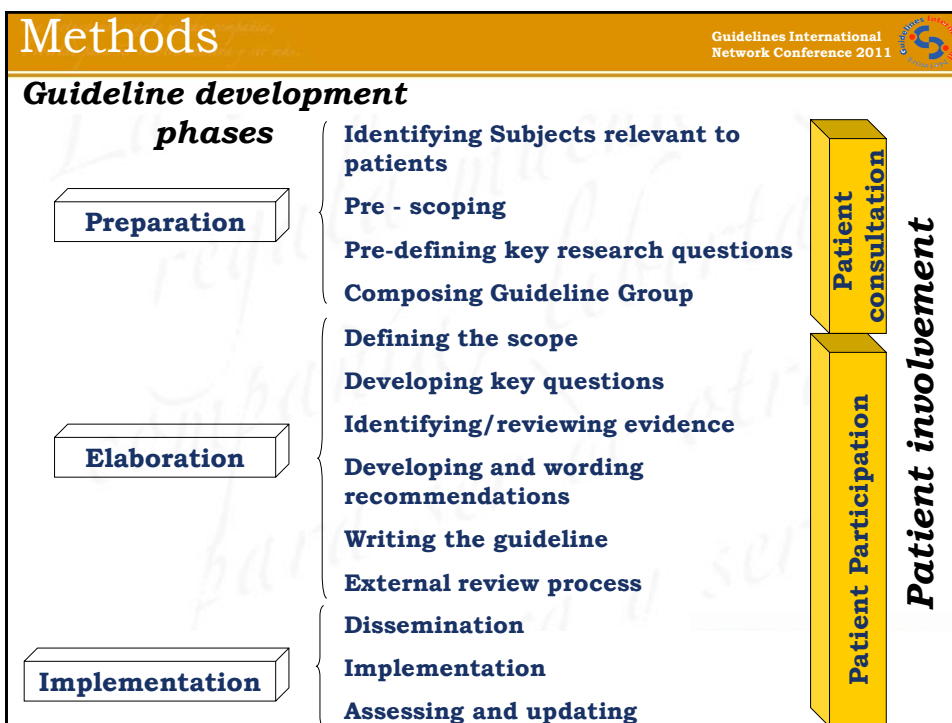
Objective Guidelines International Network Conference 2011 

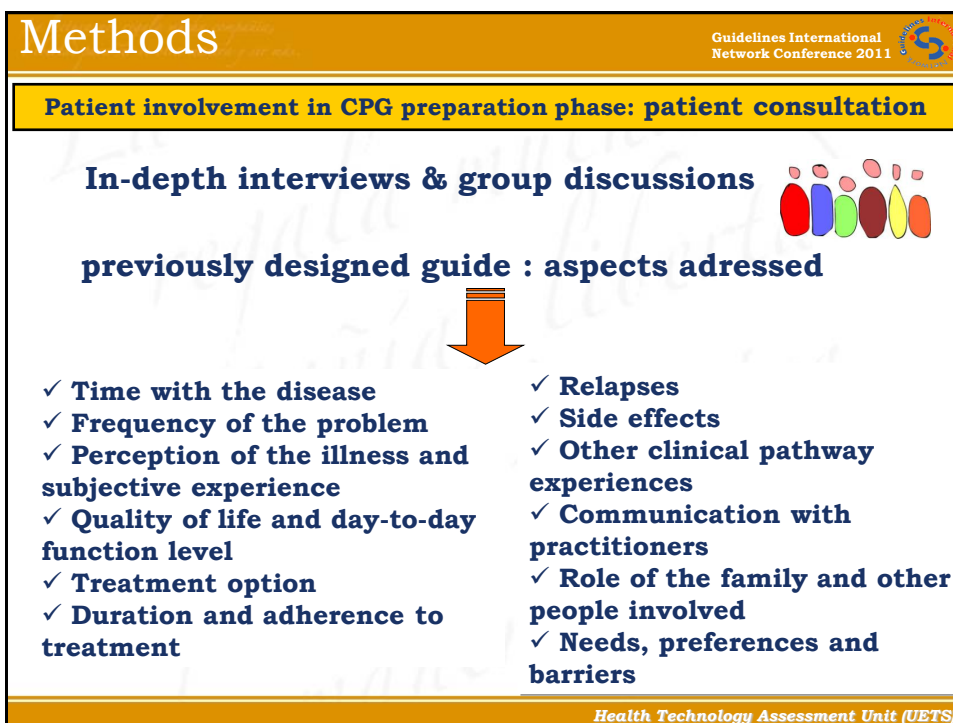
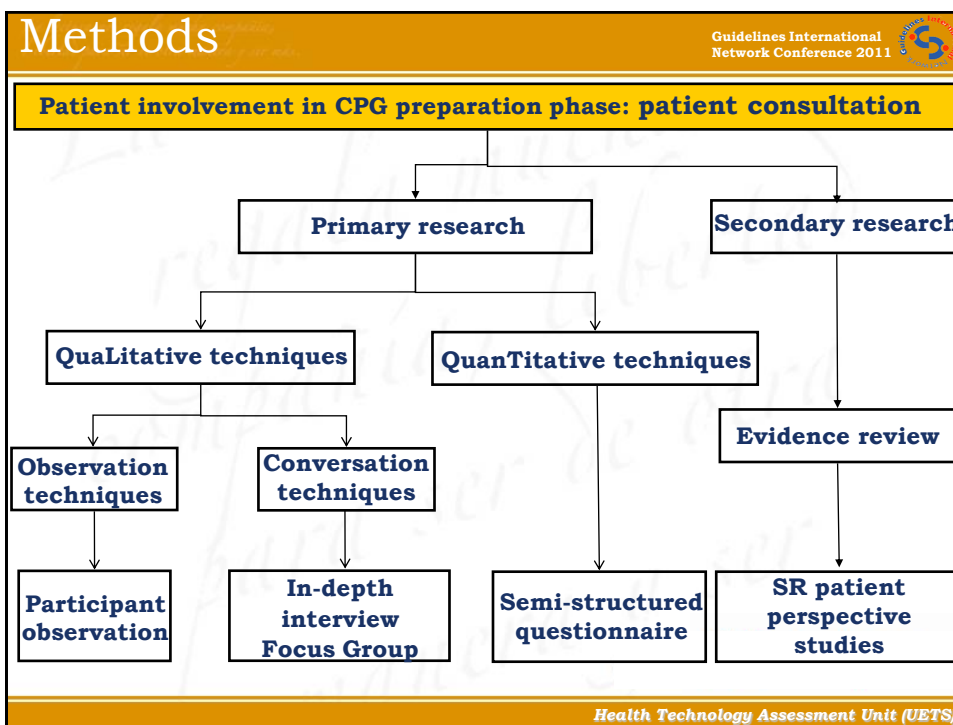
 **CPG**

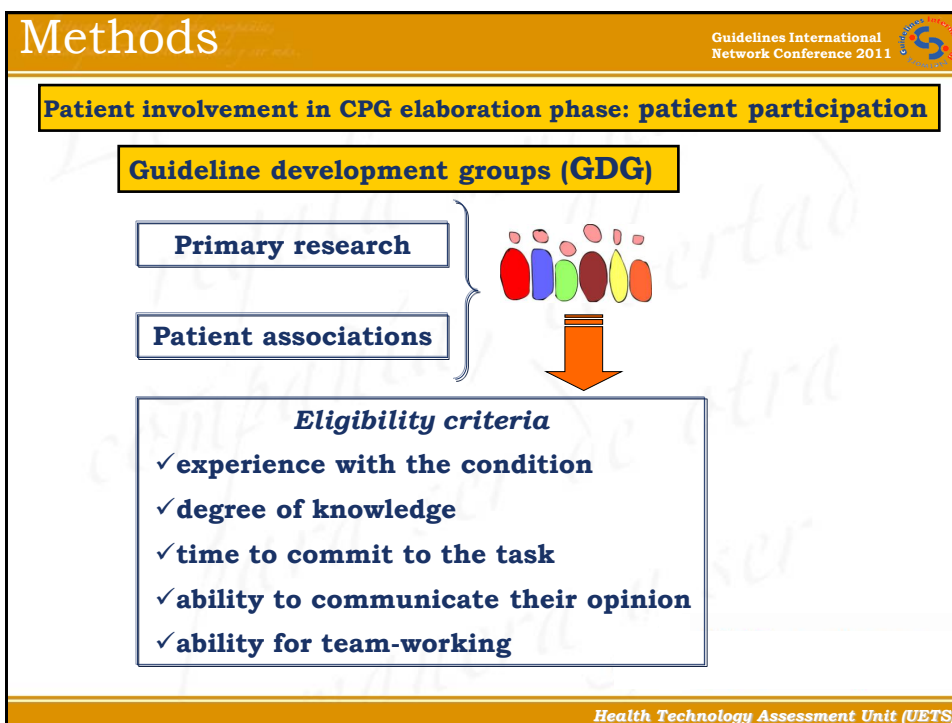
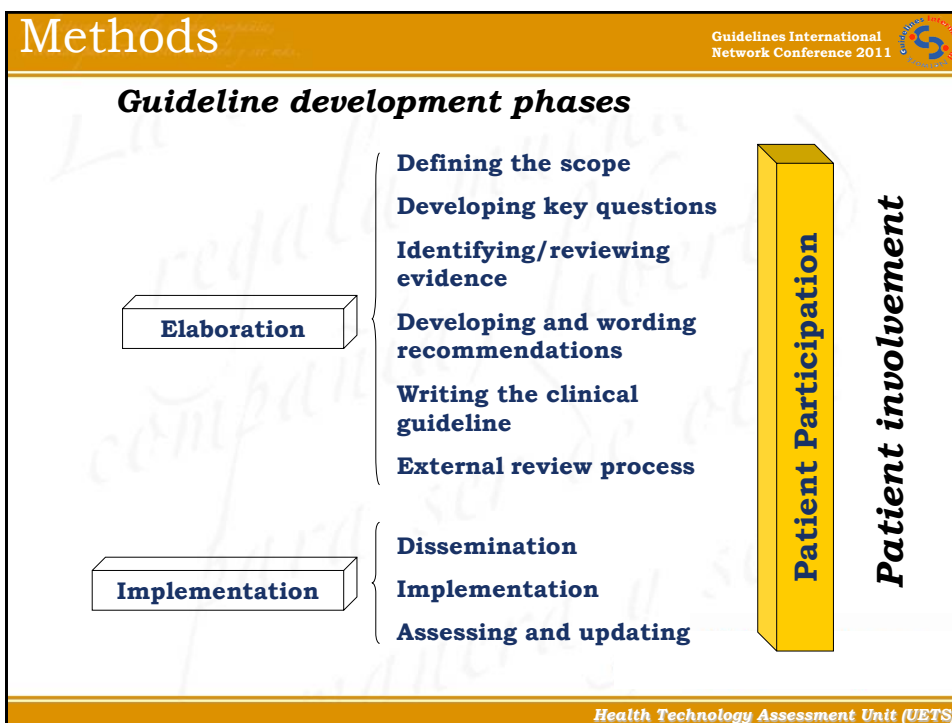
to present a patient involvement strategy: patient consultation & participation

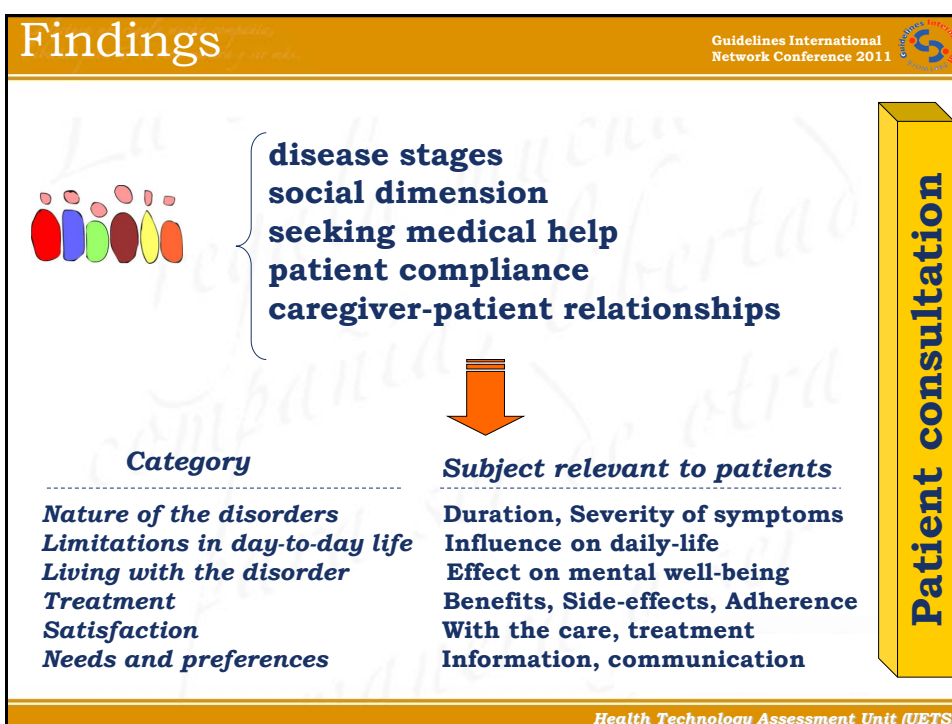
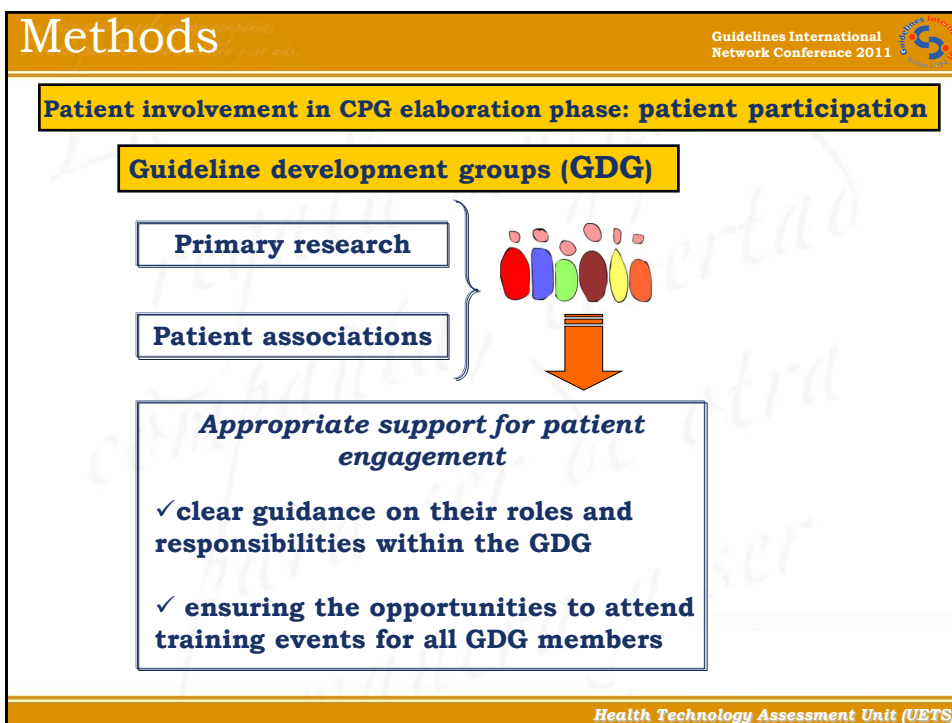
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Findings

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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

Guidelines International Network Conference 2011

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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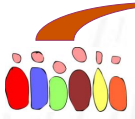
Nation-wide patient involvement initiative

Patient involvement WG - handbook

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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 familia muere...
compartida...
para ser...
manera...*

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Seoul, Korea. August 2011

THANK YOU VERY MUCH!

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