

## Workshop 10: PATIENT ENGAGEMENT IN HEALTH RESEARCH

### VALUE OF LESSONS LEARNED IN HTA AND POSSIBILITIES FOR CROSS CONTEXT TRANSFER OF EXPERIENCE

WORKSHOP: Patient engagement in health research  
ISPOR Europe, 5 November, 2019, Copenhagen, Denmark



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Q&A



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- HTA is...



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### *Live Content Slide*

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**Poll: What was the dominant idea for  
establishing HTA?**

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# What will this workshop bring?



- **Purpose:**
  - Is HTA definition universal and can be adapted for all healthcare settings?
  - Can the rest of the world replicate the EUPATI approaches to HTA?
  - What are experiences of HTA in specific diseases?
  - Is HTA really capturing patients' experiences, preferences and needs?
- **Discussion leaders:**
  - **Tamás Bereczky**, European Patients Academy for Therapeutic Innovation (EUPATI)
  - **Wendy Weidner**, Alzheimer's Disease International (ADI)
  - **Kawaldip Sehmi**, International Alliance of Patient Organisations (IAPO)
- **Moderator: Neda Milevska Kostova**, IAPO

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**Poll: In reality, HTA brings most benefits to which stakeholders?**

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## Patients create value also in the HTA process

Tamás Bereczky

European Patients Academy for Therapeutic Innovation  
(EUPATI)

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## Patient involvement in HTA is becoming the norm



- Good practices from NICE, BfArM, Sweden, Switzerland etc.
- Clinical Trials Regulation and local implementation legislation require patient involvement
- HTA is an essential point for patients to voice their interests
- Active outreach is needed to include more populations and voices



## EUPATI Guidance documents to support systematic involvement of patients

After extensive consultation, EUPATI has developed guidances for the involvement of patient organisations with stakeholders

- in industry-led R&D
- in HTA
- in regulatory processes
- in ethics committees

Publication in December 2016



Source: EUPATI Guidance documents on patient involvement <https://www.eupati.eu/guidance-patient-involvement/>, → EUPATI.eu → Resources →

Guidances  
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## EUPATI guidance for patient involvement – Why?

- Patients and patient organisations to be involved more widely
  - include early and post-approval stages, not confined to clinical development
- In HTA:
  - EUnetHTA HTA Core Model® - technical; patients as sources of evidence not insight
  - several sources of recommendations and good practice for involvement, but dispersed e.g. HTAi, EPF, national HTA bodies
  - huge variation in practice between nations; no European legislation
  - clear default statement that collaboration is important and valuable to patients and to process

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# EUPATI guidance for patient involvement in HTA – Process



- Review of key documents
  - HTAi “values and quality standards” – consensus exercise
  - EPF survey of patient organisations and HTA bodies
  - input templates from HTAi and national bodies
  - other published literature
- Technical input to first draft
  - Karen Facey, HTAi, EPF, Victoria Thomas/Lizzie Amis (NICE)
- Internal review
  - EUPATI partners: patient organisations, industry, HTA bodies
- Public consultation
  - patient organisations, industry, HTA bodies

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## Practical examples and good practices



- EUPATI Webinar: Guidance on Patient Involvement on HTA
- EUPATI Webinar: Experience with Patient Involvement in HTA Processes
- EUPATI Webinar: Strengthening patient involvement in Health Technology Assessment (HTA)

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## Why is it important to be involved?

- To get pharma/relevant stakeholders to listen to patients and involve them in a consistent way
- To show that patients are well trained and knowledgeable
- To establish trust with pharma and other relevant stakeholders
- You can help decision makers understand how important a new drug can be for you and your fellow patients

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## Lessons learnt

- If pharma companies know that you have sound knowledge and add value to their proposition they will seek your expertise
- It doesn't matter if you don't have previous experience of HTA, if they ask you to get involved it's because your input is valuable
- Always get involved if they offer you the chance, even if you don't feel you know enough about the subject. There is plenty of information available to gain extra knowledge and free online courses to follow, just don't miss out on opportunities!

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**Poll: In your opinion and experience,  
what aspects are missing in current HTA?**

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**Meaningful HTA engagement:  
including the voice of lived experience**

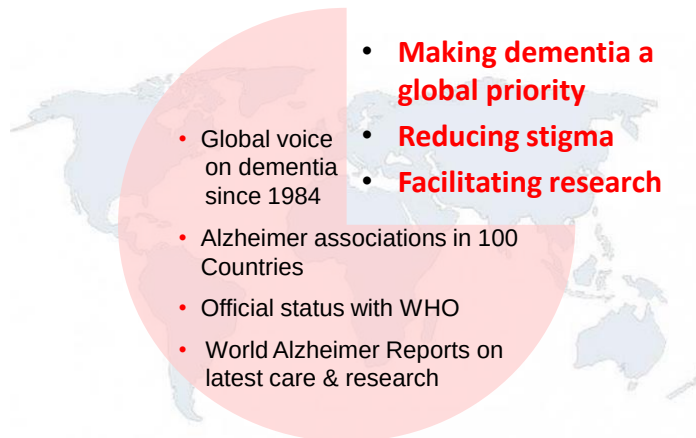
**Wendy Weidner, MA  
Alzheimer's Disease International  
(ADI)**

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## Alzheimer's Disease International

*Global voice on dementia in 100 countries*



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## HTA: listening, learning, changing

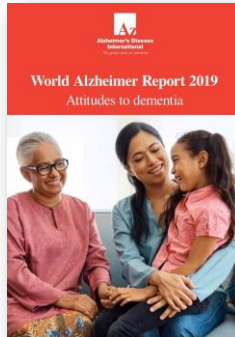


- ADI experience: successes & learning
- Key challenges
- Future considerations & impact

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## ADI Experience

- Dementia research webinar series
- World Alzheimer Report 2019
- STRiDE project



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## Key challenges

- **Nature of dementia**
  - Progressive illness
  - Ethical issues
  - Need to include carers
- **Stigma**
  - Need for timely diagnosis
  - Awareness, knowledge and attitudes
- **HTA in low- and middle-income countries**
  - Complex – issues of capacity, lack of evidence, stakeholder engagement, policy making process
  - Infrastructure – care pathways, rural vs urban
  - Policy and Regulatory issues
  - Costs – scarce resources, high need

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## Future considerations

- Increase awareness of HTA
  - Why and how
- Build capacity
  - Evidence to guide policies for efficient and equitable healthcare systems
- Use of technology
  - Need to start *now* to engage people living with dementia and their families



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**Poll: In your opinion, in what areas HTA is currently most underdeveloped and very needed**

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# Patients' organisations role in HTA: experiences, challenges and way forward

Kawaldip Sehmi, LLM  
International Alliance of Patients' Organisations  
(IAPO)

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## IAPO's involvement in research and HTA



- **IMI-PREFER:** To identify most effective methodologies to collect, analyse and take into account patient preferences in medicines development;
- **IMI-GETREAL2:** Follow-up project on how to use real world evidence in medicines development decision making (bringing the patient perspective)
- **ASPIRE:** 'One stop shop' for people living with diseases who want to share their expertise and insights, inspired by one of the World's most popular search engines

**prefer.**  
PATIENT PREFERENCES  
<http://www.imi-prefer.eu/>

**Get Real**  
<http://www.imi-getreal.eu/>

 **ASPIRE**

# Challenges of HTA

## Shortcomings in Recognizing Value

Most HTA systems do not fully consider patient preferences, societal impacts, or broader health system savings in their assessment frameworks, which has the effect of undervaluing innovation

## Lack of Objectivity

A focus on cost-containment can cloud the conduct of a scientific and objective assessment of clinical value

## Variability across Key Attributes

Certain HTA systems perform better on measures of transparency, flexibility, stakeholder engagement, and patient access

*(Source: Dr Ratna Devi, IAPO Chair, PRR Council presentation, 2019)*

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# Challenges for patient involvement in HTA

- Different approach at national level to selecting patient groups for representation
- Different patients' preference and willingness for participation dependent on wide number of factors
- Researchers' bias and dilemma regarding fundamental assumptions surrounding patient behavior
- Education remains a critical component for patient involvement
- Data remains most important tool for patients' organizations to present their case to decision-makers

What can patients provide to decision-makers to make HTA more useful?

How can decision makers better value the needs and preferences of patients?

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## **Poll: How do you evaluate patients' involvement in HTA and why?**

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## **Social Q&A**

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# Discussion...



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