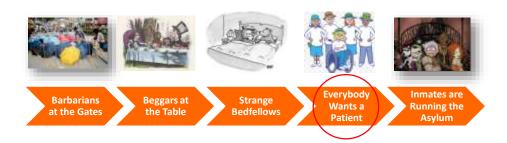
## Patient Centricity in Healthcare Decision Making (including HTA)



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Canadian Organization for Rare Disorders

# Patient Roles in Healthcare Decision Making Are Changing!



Multiple Roles for Engaged Patients

#### Inside Advisor, Reformer

- · Input: Council, Task Force,
- Collect Info: Survey, Focus Group
- · Form of Info: Consultation. Debate
- Impact: Advise, Discretionary
- Examples: NICE Citizens Council, **IQWiG**
- **Broker, Council Member**
- · Input: Committee, Board, Council
- · Collect Info: Experts, Deliberation
- · Form of Info: Analytical, Guidelines · Impact: Varied, Based on Guidelines
- · Examples: EMA, AU MASC, CADTH

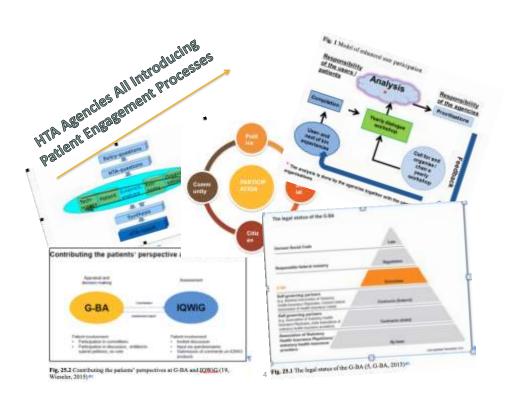
#### **Individual Patients**

- · Input thru Clinical Trials, Testimony
- · Collect Info: QoL, PROs, Impact Statement
- · Form of Info: Ratings, Qualitative
- · Impact: Varied, Emotional Suasion
- · Examples: FDA, SMC, IQWiG,

#### **Patient Groups**

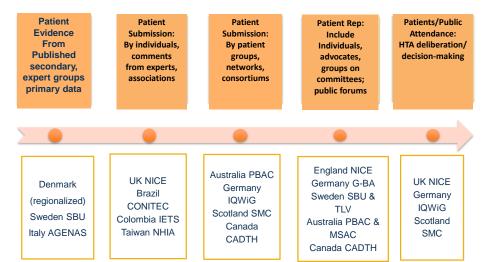
- · Input: Submission
- · Collect Info: Written, Oral, Meetings
- · Form of Info: Qualitative Statement
- · Impact: Participation, Informed
- · Examples: NICE, SMC AU MASC, **CADTH**

**Patient Representation** 



External – Internal Engagement

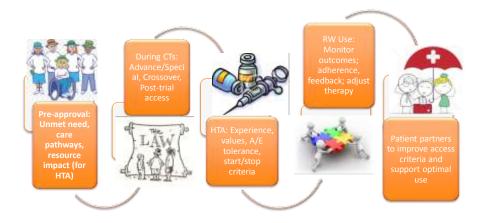
#### Patient Involvement in HTA: Country Differences



## Do Patient Goals Align with Other Stakeholders'?

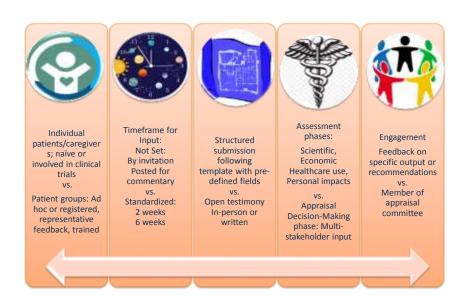


#### Patient-Based Evidence Supports Sustainable Access



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## **Training Patients for Participation**



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## Key Learning re: Patient Engagement

- Globally, patient centricity has evolved increasingly to patient engagement in all spheres of healthcare decision making, including HTA
- Emerging best practices for engaging patients in HTA process (and beyond) serve as useful tools but they must be customized to fit country-specific HTA process and country culture
- Benefits of patient engagement in healthcare decision making including HTA are real but need to be better documented to encourage more patient engagement
- Patients (including patient groups and advocates) require training and support to take full advantage of opportunities for engagement and adding value

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### Thank You!

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