



# Inclusive HTAs overview

- Defining involvement
- Drivers for patient involvement
- Who should be involved
- Principles of involvement
- Mechanisms for patient involvement
- Issues



# Involvement?

# Engagement?

# What does it mean to you?



# Why has it emerged?

- Deepening democracy or growing mistrust
- Public scrutiny regarding determination (public accountability)
- Social scientists - HTA involves values & judgements



# Why?

‘No one knows better what it is like to live with an illness ...than those who are doing this – the patients and their family and friends who care for them. It is this unique insight that patients and patient groups can most usefully contribute to the HTA process.’

Patients and carers can provide experiential evidence to an HTA of the true benefits and extent of unwanted effects

HEE ‘Understanding HTA’ (A guide for patients, 2008)






# IAP2 spectrum of public participation

([www.iap2.org](http://www.iap2.org))

	Inform	Consult	Involve	Collaborate	Empower
Goal	Balanced & objective information to assist understanding	Gain public feedback on analysis, alternatives, decisions	Work directly with public throughout process so concerns understood & considered	Partner with public in each aspect, identify alternatives & preferred solution	Place final decision-making in hands of public
Promise	Informed	Informed, listen to you, provide feedback on influence	Concerns directly reflected, feedback	Look to public for advice & solutions & include to maximum	Implement what you decided
Example	fact sheets web sites	focus groups public meetings	workshops deliberative polling	citizens' advisory committees consensus building	ballot delegated decision citizens' jury



# Public engagement Rowe & Frewer (2005)

Type	Flow of information
<b>Communication</b>	Sponsor  Public
<b>Consultation</b>	Sponsor  Public
<b>Participation</b>	Sponsor  Public



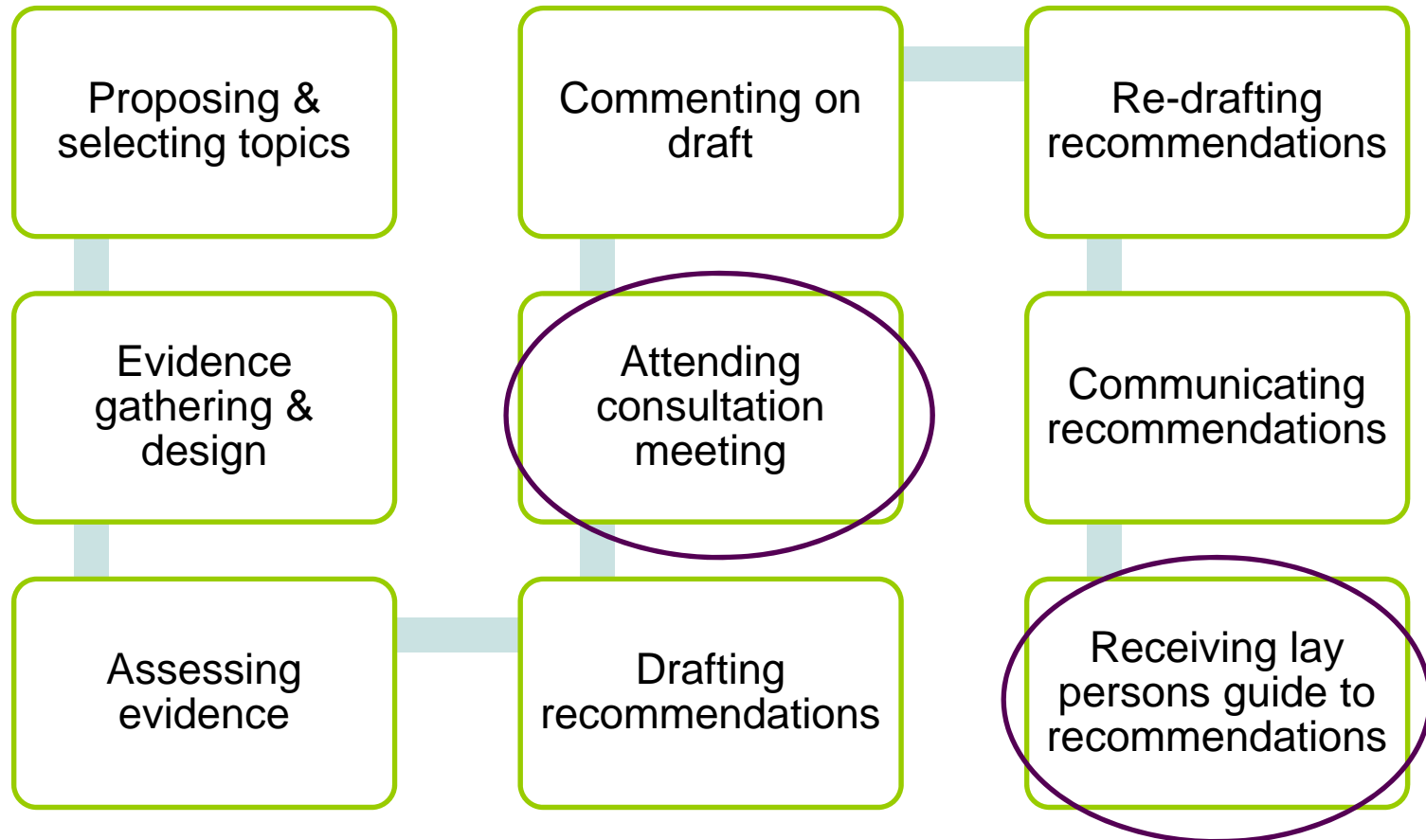
## Participation

Information is exchanged between the sponsor & the public . . . .  
rather than simple, raw opinions being conveyed to the sponsors, the act of **dialogue & negotiation** serves to transform opinions in the members of both parties.

Rowe G, Frewer LJ. A Typology of Public Engagement Mechanisms. Science Technology & Human Values. 2005;30:251-290

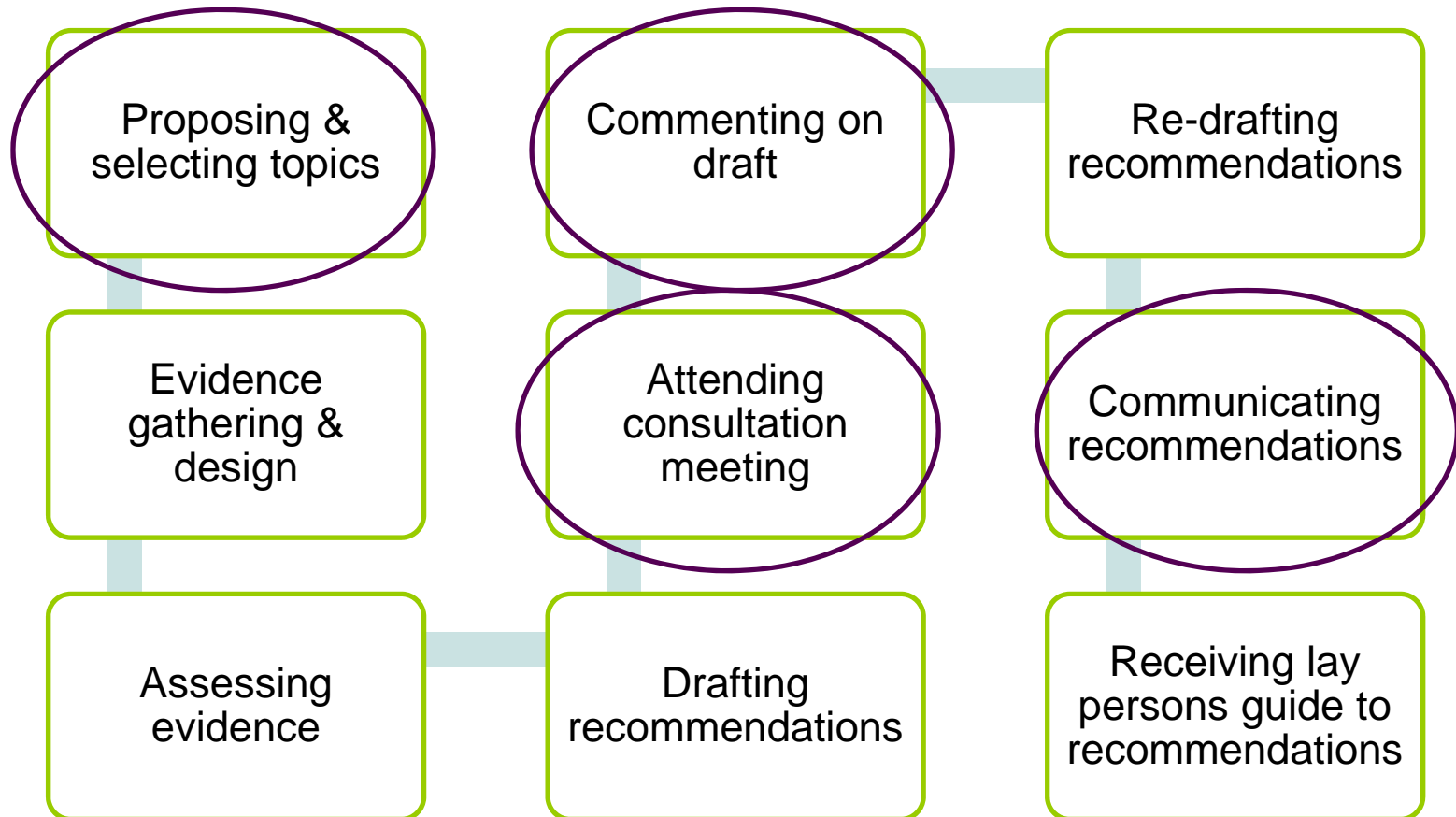


# When? Information



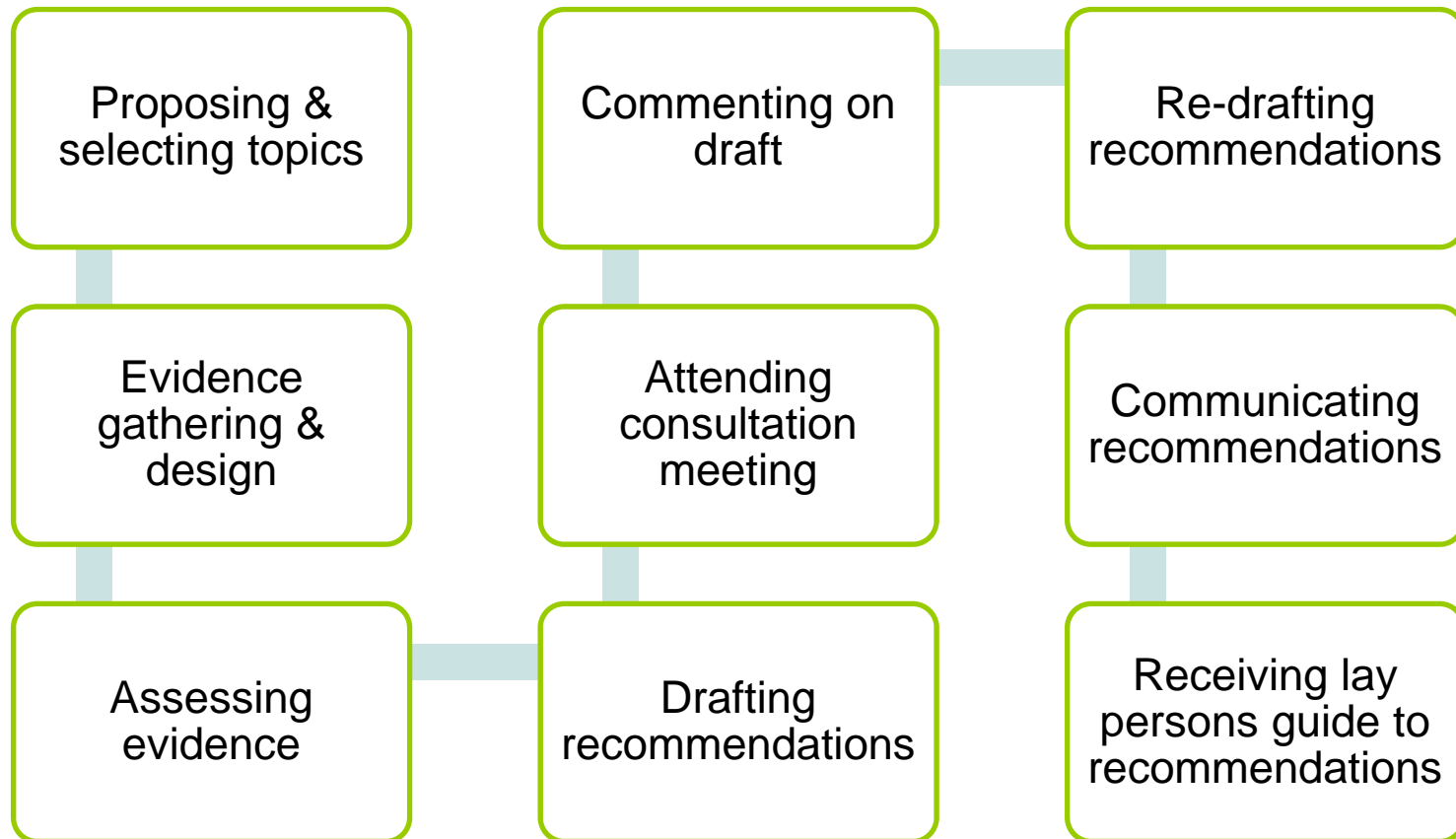


# When? Consultation





# When? Participation





# Who?

Patients with the  
condition

Family & carers

Patients with  
experience of the  
technology

Organisations  
that represent or  
support patients

Actively interested  
public



# How?

Citizen's jury

Consensus conference

World cafe

Scenario workshop

Lay representation

Focus group

Deliberative dialogues



# UN Brisbane Declaration (2005)

**Integrity:** openness & honesty about scope & purpose of engagement;

**Inclusion:** opportunity for a diverse range of values & perspectives to be freely & fairly expressed & heard

**Deliberation:** sufficient & credible information for dialogue, choice & decisions, & space to weigh options, develop common understanding & to appreciate respective roles & responsibilities

**Influence:** people have input in designing how they participate, policies & services reflect their involvement & their impact is apparent.



# Principles: Telford

1. Roles of consumers agreed between researchers & consumers involved
2. Researchers budget appropriately for costs
3. Researchers respect the differing skills, knowledge & experience of consumers
4. Consumers offered training & personal support



# Telford

5. Researchers ensure they have necessary skills to involve consumers
6. Consumers involved in decisions about how participants recruited & kept informed about research progress
7. Consumer involvement is described in research reports
8. Research findings available to consumers, in formats & language they can easily understand



# IAP2 core values of public participation

- based on the belief that those who are **affected** by a decision have a right to be involved in the decision-making process
- includes the **promise** that the public's contribution will influence the decision.
- promotes sustainable decisions by recognizing & communicating the needs and interests of all participants, including decision makers.
- seeks out & facilitates the involvement of those potentially affected by or interested in a decision.



# IAP2 core values of public participation

- seeks input from participants in designing how they participate.
- provides participants with the information they need to participate in a meaningful way.
- communicates to participants how their input affected the decision.



# Deliberative dialogues

- Based on providing information & providing time for thinking before forming a view.
- Suitable for complexity, uncertainty, conflicting values, trade-off
- Example: scenario workshops



# IAP2 core values

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# Patient representation (lay)

- Patient or patient organisation
- At the table
- Advisory or assessment committee
- Networks
- Support



# Citizens' jury

- Members of public (jury) cross examine expert witnesses
- Arrive at a verdict which is given to decision makers
- Priority setting or decision's about allocation



# Scenarios

- What are the potential benefits?
- What are the risks?
- What are the implications for members of the public taking part?
- What are the implications for the organisations?



# Useful resources

- NICE Citizen's Council reports ([www.nice.org.uk](http://www.nice.org.uk))
- INVOLVE ([www.invo.org.uk](http://www.invo.org.uk))
- Telford
- Rowe & Frewer
- More