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\* **Decision making in NICE single technological appraisals (STAs): How does NICE incorporate patient perspectives?**

Hashem F, Calnan M and Brown P

- \* Explicit rationing role performed by NICE : to assure the consistently equitable access of patients to drugs across the entire NHS /the efficient use of public finances by regulating NHS consumption of new /expensive drugs via cost-effectiveness criteria
- \* Based on rigorous appraisals of scientific evidence, NICE seeks to manage uncertainty through a calculative and evidence-based approach, as a reaction to “*the nature of modern culture, especially its technical and economic substructure, [which] requires precisely such ‘calculability’ of consequences*” (Weber 1978:351)
- \* Co-ordinated proceduralism to 'absorb' uncertainty and overcome associated arbitrary variations in pharmaceutical availability

## \* Regulating the provision of new drugs : the role of NICE (England)

- \* The decision-making within NICE technological appraisals appears neutral, objective and rational - yet there are number of ways in which mechanisms of decision-making might be influenced by social influences which are implicit in this process (i.e. patient perspectives)
- \* eg confidence is required in research paradigms and approaches - trust in weighing up the evidence presented by different expert patients, leading clinicians, or drug company representatives

\* **Rational decision making ?**

- \* Experience of having the condition, or caring for someone with the condition
- \* Experience of receiving care for the condition in the HS
- \* Experience of having specific treatments for the condition
- \* Outcomes of treatment that are important to patients & carers
- \* Acceptability of different treatments & modes of treatment
- \* Preferences for different treatments & modes of treatment
- \* Expectations about risks & benefits of the technology

NICE - Process & Methods  
Guide (2013)

# \* The Involvement of patient & carer groups in decision making

\* *“...in the context of technological appraisals the main purpose of qualitative research is to explore areas such as patients’ experiences of having a disease or condition, their experience of having treatment and their views on the acceptability of different types of treatments”*

**NICE - Process & Methods Guide (2013)**

\* ***epistemic uncertainty*** - the effectiveness of certain methods of investigation to provide knowledge about conditions and their treatment

\* ***interpersonal uncertainty***- regarding the competency and motives of those providing evidence and/or recommendations within the process. Focus here will be on

- how Committees incorporate evidence
- dealing with patient experts' views
- Committee members' personal experience and background

\* **Uncertainty in decision-making**

\*The study explores the decision-making process and more specifically the various ways in which different forms of uncertainty -epistemic procedural, relational and others were perceived, presented and tackled within these drug appraisals

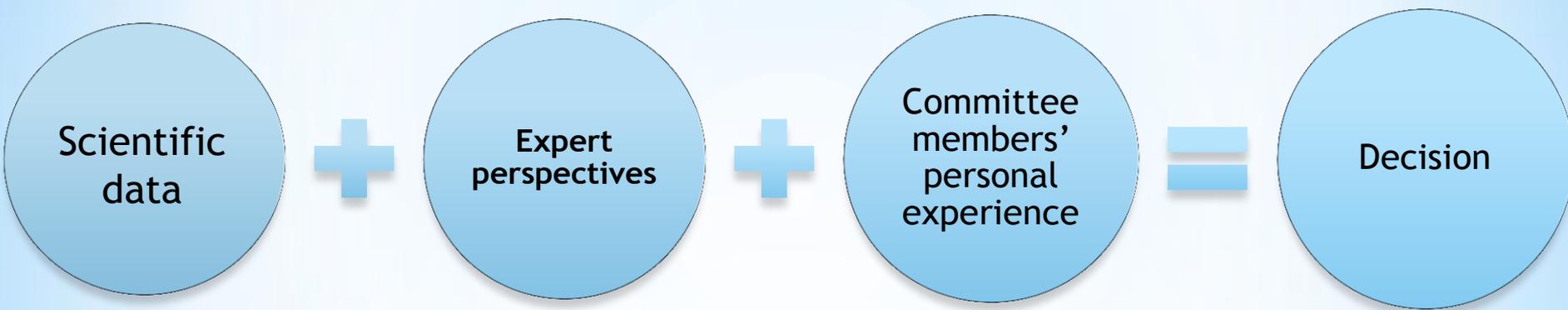
\*Aims

\* Qualitative, ethnographic research methods: data was collected through three different but complementary methods: analysis of documents; non participant, unstructured observation of meetings; and qualitative, informal interviews with key informants involved in the appraisal process.

\* **Methods**

	Telephone interview	Face to face	Sub-total
Case Study 1	9	5	14
Case Study 2	7	5	12
Case Study 3	10	2	12
Background interviews	0	3	Total = 41

# \* Data collection



Potential points of tension / conflict



\* How to incorporate the evidence?

\* *“And I think this is one of the challenges and why it’s so amazingly helpful to have people with all different perspectives because everybody will have their own, not just perspective but their own strengths in interpreting the evidence and some people will come from, for example lay people, with a sort of common sense lay perspective of what do they think patients would view their informed, fully informed patients in a way”*

Committee Member Clinician

\* **Contextualizing the  
disease & benefits of  
the technology**

\* *“Yeah. So basically around the issues and this was a person who clearly benefitted from the drug. She said, “This is my quality of life so...” and she seemed quite energetic and so NICE were kind of quite... quite... quite... Yeah, they were quite taken by how she presented herself etc. because, you know, she was a patient...”*

**Committee Member Clinician & Academic**

\* **Discerning of  
patients' views**

\* *“I think the committee members deal with it in two ways; one... one is completely dismiss the emotional arguments and give me the data, you know, or completely dominated by do we really understand, you know, the burden of this and the need for... the unmet need of the treatment and that’s kind of, you know, of, you know, the lens by which you view the case. So... so it’s a tricky one. You know, it’s not directly part of the QALY or the ICER or anything like that but it... but it... you know, it does have a role clearly”*

Committee Member Health Economist

\* **Tensions in evidence  
in decision-making**

\* *“Because, you know, they’re the people who are actually suffering and they’re telling you what a huge difference it can make to their lives or the... the length of time they have left so that’s sometimes quite a struggle...So it’s hard... it’s hard to keep... to stay neutral, I think, at times”*

Committee Member NHS Management

\* **Being objective vs being persuaded by patients in decision-making?**

\* *“So I can easily imagine that everyone takes their own personal background, experience into the deliberations so... The moment that your father has exactly that kind of cancer might colour your opinions, it’s quite difficult then to stay completely objective or, yeah, sometimes I feel that even the fact that a certain manufacturer has sort of built themselves a reputation for trying to manipulate things and not being very straightforward etc. can already... they already start in the negative basically. So these kind of things can play a role somewhere but it will never be acknowledged anywhere...”*

**Independent Evidence Reviewer**

\* **Bringing in personal views and experience**

\*"I've seen impassioned pleas for drugs that are completely ludicrous because the person didn't have the drug that anyway the combination has been discussed, secondly they've got a particularly difficult case and they've been selected for that reason so... But I mean... So I don't... I don't think that the patient representative is necessarily ever very illuminating. I think what it is sometimes it's a condition you don't know about and not in this one and the patient just says what the... is telling the committee what the disease means. And in that respect that can be quite a useful thing"

Committee Member Clinician

\* Interpersonal  
uncertainty : trust in the  
patient expert

\* *“It appears that many of these companies support these support groups and help groups and at the beginning of every meeting everyone declares a conflict of interest and things like that.. I’ve certainly been aware of it once where it was quite clear that a company was heavily supportive of the particular sort of patient support group and I found that quite difficult to be completely objective about... because sometimes the drug companies might take... or maybe the patients might be a bit naïve about some of the motivation but I think it is something you can’t really ignore... And that has crossed my mind a few times that, you know, that there may be a tighter relationship than is evident and it’s partly because sometimes on their way into the building, you know, we go into the building and up the stairs and the public and the others are all clustered down the stairs and they’re brought in and they sit, you know, up at the back and everything and you can’t help but notice engagement, you know, at that kind of social level”*

Committee Member Clinician

\* **Interpersonal uncertainty :  
conflicted interests of patient  
experts**

*“Also the chair felt it was not innovative although felt the need to mention that one of the charities saw it as ‘ground breaking’ as the CM did not want to be accused of not taking the patient experts seriously...”*

Observation notes Case study 2

\*Tokenism

\* *“No. I... I really felt that second time I interrupted about the XXXXX surgery, the patient experts really you could have almost said we... we weren't needed there”*  
Patient Expert

\* The second meeting I... No, I didn't feel that... I didn't... I think it was slightly unusual circumstances that I was invited back to the second meeting because you wouldn't normally be invited back...And I felt that I wasn't asked many questions, which was fine but I didn't really feel I needed to be there...I don't think I really... me being there really added anything to proceedings”  
Patient Expert

# \* Tokenism vs representation

- \* NICE Committee members grapple with assessing clinical / cost effectiveness data while incorporating patient perspectives in STAs
- \* Decision-making in STAs is far from an objective & neutral process - layers of social influences from patient perspectives, personal interpretations / views from Committee members
- \* Question arises around how much Committee members take on board the views of patients/carers in decision making

## \* Summary