

Feedback from Patient Rapporteurs

Alexandra Wyke

**Actual developments in European
Regulatory and HTA Management:
What does this mean for oncology in Europe?**

BONN, GERMANY
9 MARCH 2011

SLIDE 1

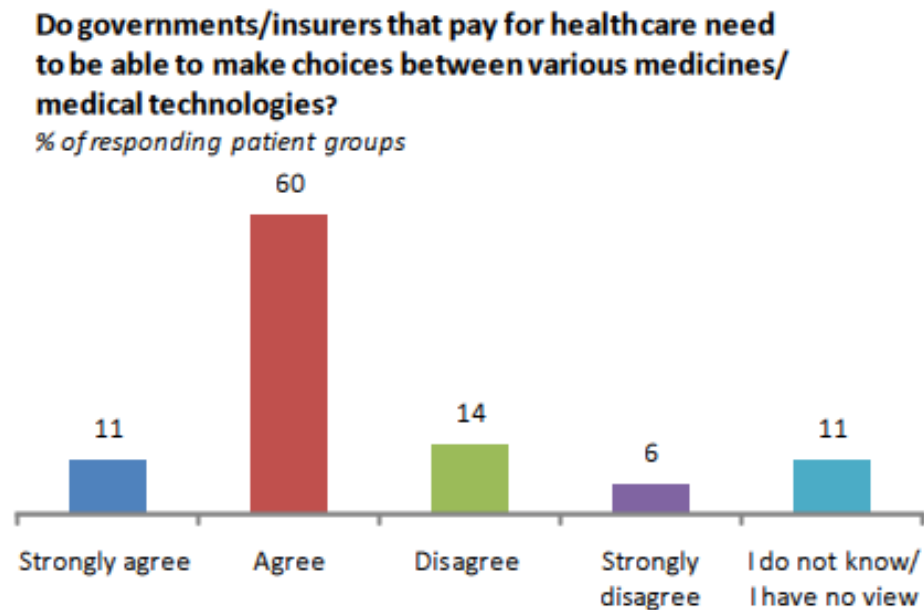
Feedback from the Patient Rapporteurs : *Alex Wyke and Jan Geissler*

Do patients embrace the concept of HTA?

“In medical oncology cost-effectiveness is considered essential used on evidence-based medicine” Lothar Bergmann

So it is with patients

Patients understand the need for rationing...



..but..

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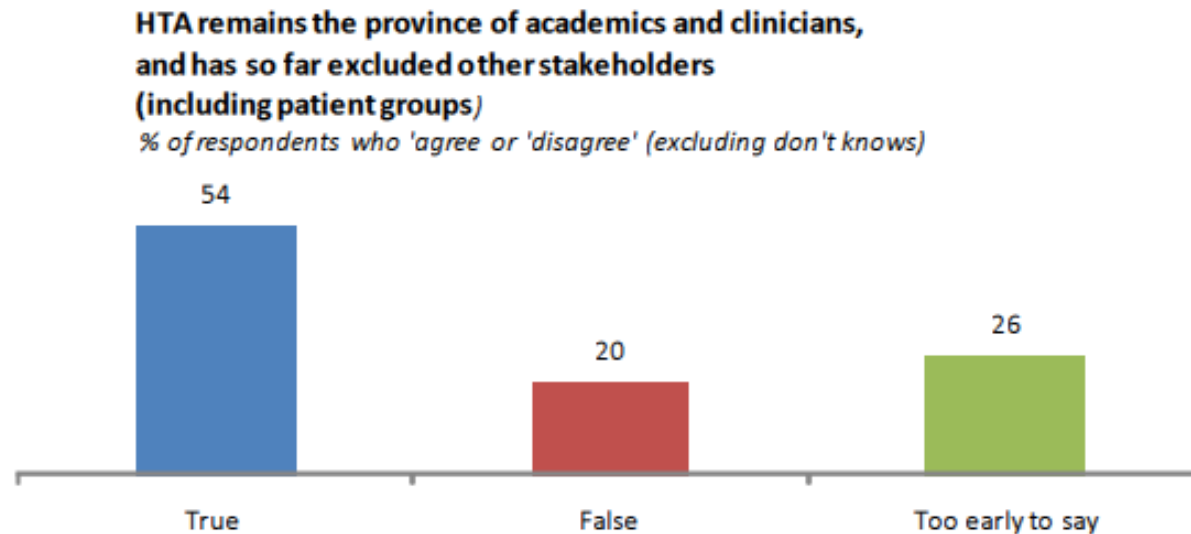
“Who has a say in health Technology Assessment”, published by Hill & Knowlton,

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But patients are largely excluded from the HTA process

“The Helsinki - based Syöpäjärjestöt [Cancer Society of Finland] has cancer - specific expertise which exceeds that of the HTA authority. Naturally, we have lobbied, been involved, and opposed their decisions.”



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Patients/patient advocates argue they should be involved. Why?

We heard why patients have vested interested and need protecting against false hype and hope ... But ..

- **44% of cancer patient advocates worldwide [sample size 160] are involved in providing practical services to their country's healthcare system:** Access to consultants **28%** / Monetary grants for patients **14%** / Palliative care **9%** / Screening for a medical condition **9%** / Equipment / furniture for patients **9%** / Diagnosis **8%** / Medical devices **8%** / Medication **8%** / We have our own nurses **8%** / Home help **6%** / Our own care home/s or hospice/s **3%** / Our own GPs **2%** / Our own hospital/s **1%**.
- **Today's physicians are led by financial budgets not the individual needs of patients.**

Reasons why patients do not see the doctor when they should: On the side of the doctor or of the healthcare system	Sample quote
Doctors do not meet patients' needs	"Medical practitioners are governed by the UK's National Health Service (NHS) policy, and not always by what is best for the patients (so, patients may have choose to pay for a treatment that is not available within their local or national NHS). Practitioners are financially driven."—Prostate Screening Trust. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

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Patients/patient advocates argue they should be involved. Why?

- If the barrier to getting drugs are to be made higher (tougher) ...patients need to understand why they cannot be prescribed a product within national health systems, to avoid causing extreme stress and distress among patients.
- *One of the hardest jobs facing oncologists today is explaining to patients why they cannot be prescribed a drug because of guidelines.*

Greek cancer patient group: “We aired our concerns about a cervical cancer vaccine. The vaccine was initially approved only for girls up to 16 years old, with partial coverage by the social insurance funds. When evidence - based research proved that the vaccine would be beneficial also for young women aged 16–25, we started to contact and exchange correspondence with the Ministry of Health (MoH) and main social insurance funds, requesting an extension of the administration of the vaccine to young women aged 16–25, and its coverage by the social insurance funds. After a year of effort by us, the MoH and the largest social insurance fund approved our request, and the other social insurance funds followed.”

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Metrics for drug regulators/HTA—deciding on what is ‘good value’

We heard about the need to find commonly agreed biomarkers, end-points and types of clinical evidence used in drug approvals and HTA

But in reaching those decisions, account should be taken that patients can have different values to that adopted in clinical trials eg on quality of life issues

What treatment goals should be:

Cancer patient groups identify two main priorities for patients’ treatment goals:

- Treatments that enable the patient to lead a normal (or near-normal) life—even if the patient may have a shorter life expectancy as a result.
- Treatments that broadly satisfy patient expectations.

Patients think health professionals should offer treatments ...

Goals of treatment

[Please tick only ONE option]

% of total

That enable the patient to lead a normal (or near-to-normal) life—even if the patient may have a shorter life expectancy as a result	50%
That broadly satisfy patient expectations	29%
That aim to modify the progression of disease and/or control the condition—even if the patient’s quality of life suffers as a result	12%
That are easy to administer, and not difficult for a patient to comply with	6%
That produce fewer or no side effects—even if the treatment provided is not the most effective	3%
That broadly satisfy the doctor’s expectations for their patient	1%

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Patients can have different values eg on acceptable risks v. benefits.

“If treatment is curative, then short-term suffering is acceptable. If palliative care is being given, then the patient should have the best quality of life possible”,

Cancer patient group PatientView survey 2011

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Problems with HTA fragmentation and nationalistic approach to

From the patient perspective this leads to

- Rising costs and delays in access

But as was pointed out because of increased mobilisation of workforce and move towards cross-border care patients seek greater harmonisation of drug reimbursement systems. The EU cross-border directive specifically states that patients have rights.

- Health inequities (not in accordance with EU goals, says Professor McCabe)

Thanks to patients seeing redress, the European Court of Justice has ruled that distortions in access to medicines from country to country goes prohibits free movement of goods (and people). Healthcare is subject to EU mandates on freedom of goods.

How can patients/patient advocates get involved?

- Greater clarity on the weighting given in patient evidence in HTA processes.
- More training for HTA authorities in communicating with patients, and patients.
- Greater transparency, including from NICE, as to how they can reach their decisions.
- Patients would like to share their experiences with the drug. But anecdotal evidence is given zero rating by HTA even when anecdotal evidence is in volume.
- More sophisticated public and patient involvement procedures.
- Patients want the right to challenge decisions (right of redress), which only is possible on a limited basis or not all.

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