

How Will Patient Centricity be Captured in the Japanese HTA and Healthcare Reform?

View from the Japanese Academia Side

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患者 中心

Kanja-chushin

Patient centricity

What is Patient Centricity?

- Putting the patient first in an open and sustained engagement of the patient to respectfully and compassionately achieve the best experience and outcome for that person and their family.

Guy Yeoman et al. *BMJ Innov* 2017;3:76-83

Overview on Patient Centricity in Cancer Care

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Successful implementation of treatment in cancer care partially depends on how patients' perspectives are taken into account, as preferences of health care professionals and patients may differ. Objectives of this exploratory research were (I) to identify patient preferences and values (PPVs) in cancer care as indicated by patient organizations (POs), (II) to determine how these PPVs are captured in cancer care guidelines and (III) to review how guidelines take into account these PPVs. Based on a survey developed and completed by 19 POs, a literature review was conducted to analyse how patient perspectives are incorporated in oncology treatment guidelines. Based on survey results traditional health technology assessment value propositions of oncology care, such as extended life, treatment-free remission and pain reduction, were also highly rated by POs. However, the heterogeneity of cancer PPVs were clearly reflected in the survey results.

[Narbutas et al., 2017]

Name of patient organization	Location	Name of respondent	Position of respondent
Europacolon	United Kingdom	Geoffrey Henning	Director of Policy
Norwegian Melanoma Patient Association	Norway	Roadt Nystad	Chairman
National association for CML Patients Aid	Poland	Euzebiusz Jan Dziwinski	Board member
National coalition of patient organizations	Spain	Ainhoa Garcia	Member of steering committee
Irish Haemophilia Society	Ireland	Lyndsey Oconelly	Outreach co-ordinator
Europa UOMO	Belgium	Erik Briers	Board member
Firefly Children with Cancer	Croatia	Ana Radunic	Project manager
Funcamama	Venezuela	Adriana Curiel	Member of steering committee
Romanian National Community of Young Cancer Survivors	Romania	Daniel Tomai	Member of steering committee
GIST and STS Alliance for Patients	Bulgaria	Yuliana Popova	President
Lithuanian Cancer Patient Coalition	Lithuania	Šarūnas Narbutas	President
Ovarian Cancer Canada	Canada	Elsabeth Baugh	Chief Executive Officer
Instituto Oncoguita	Brazil	Luciana Holz	President
Fundacion ACIAPO	Argentina	Ignacio Zervino	Board member
PAN Can Japan	Japan	Yoshi Majima	President
Colorectal Cancer Association of Canada	Canada	Barry Stein	President
Prevent Cancer Foundation	USA	Carolyn Aldige	President
ICANSERVE Foundation	Philippines	Kara Magsanoc – Alkपाल	Founding President
Women Against Lung Cancer in Europe	Italy	Stefania Vallone	President

[Narbutas et al., 2017]

TABLE 5 | Involvement of patient representatives to health technology assessment (HTA) (survey results).

Could you please list any examples from your country where patients and/or caregivers were involved in a health technology assessment (HTA) of cancer medicines, or other medications that cancer patients may need?	Frequency of mentioning by POs (n=19)
● Participation at reimbursement committee discussion or HTA meetings	9
● Limited use of HTA in the country	5
● Involvement of patients to surveys in the HTA process	3
● Patients can submit requests or dossiers for HTA committees or agencies	3
● Voting right to HTA recommendation or reimbursement decisions	1
✕ Patients are not involved or represented in the HTA process	2
● Patients are involved into the HTA process, but it is uncertain whether their opinion is taken into account in the final recommendation	3

[Narbutas et al., 2017]

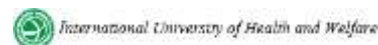
Pricing system for new drugs and medical devices

- New drugs and medical devices are approved by the Pharmaceutical and Medical Devices Agency (PMDA)
- The Ministry of Health, Labour and Welfare (MHLW) determines official reimbursement price, which are uniform throughout Japan.
- The official price is calculated by the detailed pricing rule by the Drug Pricing Organization of *Chuikyo*.
- The price suggested by the Organization is usually approved by the *Chuikyo* General Assembly without any revision.



薬価算定組織 Drug Pricing Organization

- Created in 2000 in order to increase the transparency of the pricing process for ethical drugs.
- The chairperson of the committee is Professor of Gerontology from the University of Tokyo
- Committee members consist of experts from the medical, dental, pharmaceutical, and economic fields.
- **No lay members !**



中医協総会 Chu-i-kyo General Assembly



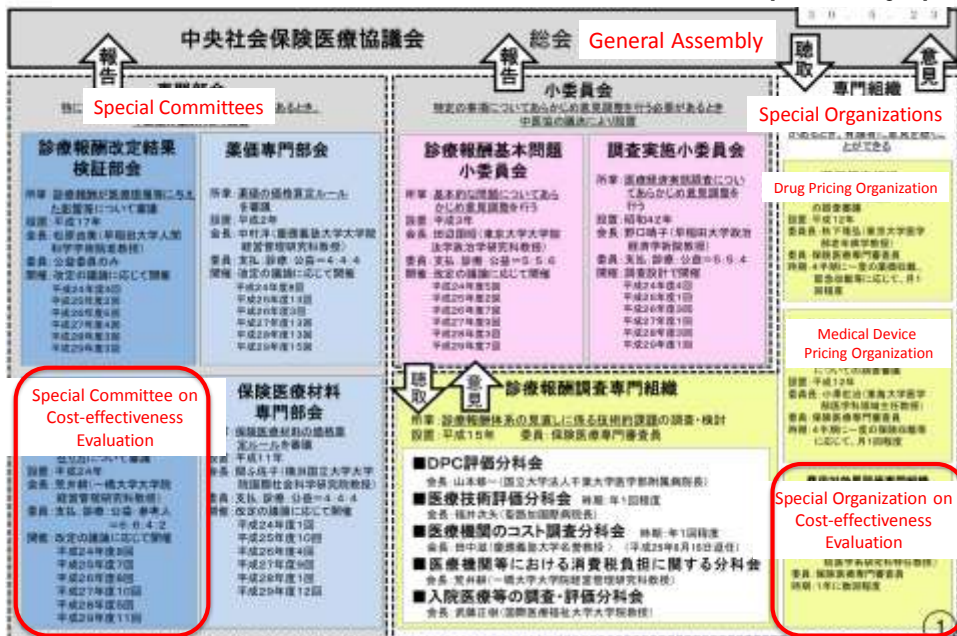
This board consists of 20 individuals

- 7: healthcare payers
- 7: healthcare providers
- 6: third parties

No lay members!



the Central Social Insurance Medical Council (Chu-i-kyo)



Source: MHLW

費用対効果評価専門部会 Special Committee on Cost-Effectiveness Evaluation

- Created in 2012 in order to implement HTA in policy decision making.
- 6 representatives of health care payers
- 6 health care professionals
- 4 public interest [e.g., academics]
- 4 industries and 3 health economists as nonvoting members.
- **No lay members !**



費用対効果評価専門組織 Special Organization on Cost-Effectiveness Evaluation

- Created in 2016 for the appraisal of cost-effectiveness analysis for re-pricing if selected products .
- The chairperson of the committee is Professor of Health Economics and Policy from the University of Tokyo
- Other members are not disclosed.
- **No lay members ?**

Issues to be considered

- Patients are diverse, preferences vary.
 - How do we integrate that opinion?
- There is no worthless treatment if patients need it.
 - How do we prioritize treatments?
- How quantitatively reflect the opinion of patients on the reimbursement decision and drug price?
- How are patients and their families/carers involved in HTA process in culturally-sensitive way?

BackUp

THE NATIONAL INSTITUTE FOR HEALTH AND
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Key Principles

1. NICE's approach to patient and public involvement is based on two key principles:
 - that lay people, and organisations representing their interests, have opportunities to contribute to developing NICE guidance, advice and quality standards, and support their implementation, and
 - that, because of this contribution, our guidance and other products have a greater focus and relevance for the people most directly affected by our recommendations.

NICE commitment to patient, service user, carer and public involvement

10. NICE will:

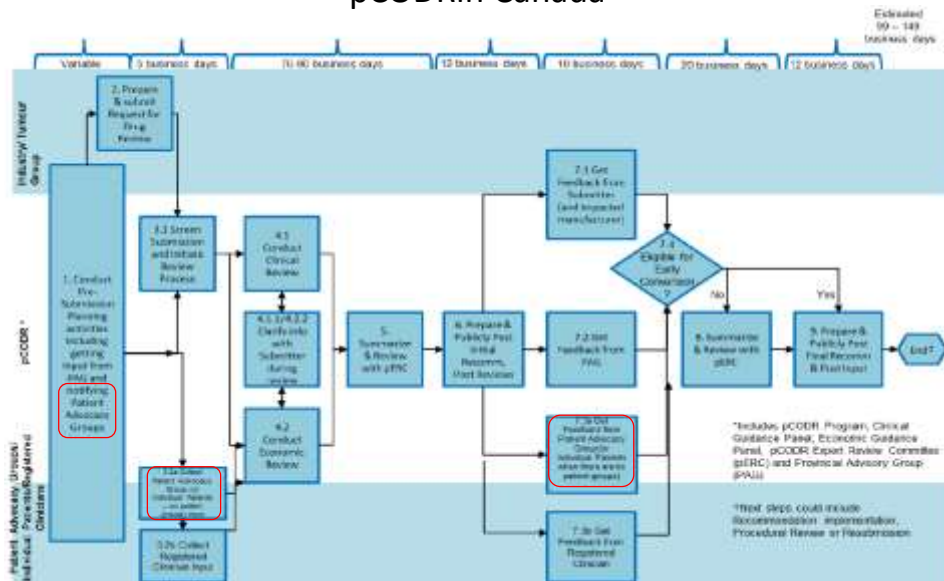
- produce clinical guidance for the NHS that focuses on the patient, service user and carer
 - produce public health guidance that focuses on the public's needs or the needs of specific groups or communities
 - produce social care guidance and quality standards which focus on the needs of service users, their carers and families
 - ensure other activities, such as quality standards and the Quality and Outcomes Framework, involve and focus on patients, service users, carers and the public
 - ensure that all NICE advisory committees and working groups have at least **two lay members** (patients, service users, carers or members of the public)
-
- provide opportunities for patients, service users, carers and the public to give evidence and testimony that can inform the development of our guidance and quality standards
 - involve lay people in its corporate decisions
 - offer support and training to lay people who contribute to NICE's work
 - [offer payment](#) to lay members of NICE advisory committees and working groups in recognition of their contribution
 - make its guidance available in language and formats suitable for patients, service users, carers and the public
 - work with patients, service users, carers, communities, voluntary and charitable organisations to promote our guidance and to help people access the services, care and treatment NICE has recommended
 - engage with groups protected by equality legislation to ensure their views are heard, and that issues of equality are considered in developing its guidance
 - review the processes and methods used to involve lay people in its work.

6.2.7 The Appraisal Committee's judgements on clinical effectiveness take account of the following factors:

- The nature and quality of the evidence derived from:
 - the analysis of the independent academic groups
 - the written submissions of the consultees
 - the views expressed by the clinical specialists, particularly their experience of the technology in clinical practice
 - the views of the patient experts and carers on the experiences of patients who have used the technology.
- Uncertainty generated by the evidence and differences between the evidence submitted for licensing and that relating to effectiveness in clinical practice.
- The possible differential benefits or adverse outcomes in different groups of patients.
- The impact of benefits and adverse outcomes associated with the technology as seen from the patient's perspective.
- The position of the technology in the overall pathway of care and the alternative treatments that are established in clinical practice.

Guides to the methods of technology appraisal 2013

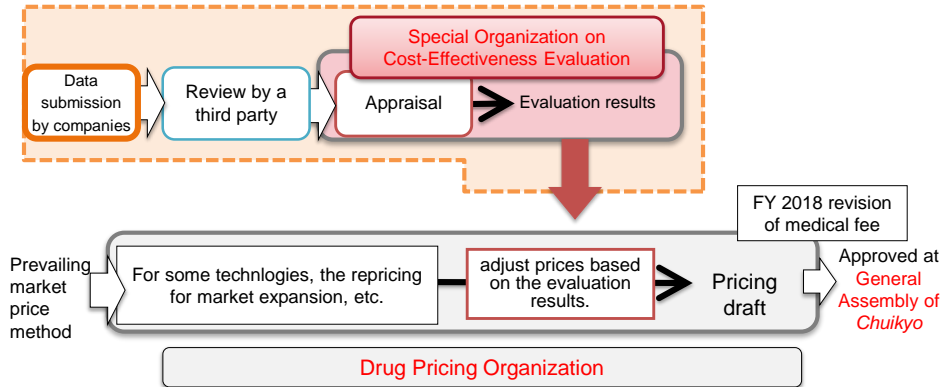
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Process of the trial introduction of HTA

- The results of evaluation by the **Special Organization on Cost-Effectiveness Evaluation** is used for price adjustments after the application of existing pricing (re-pricing) rule of drugs and medical materials/devices.

<Process in the trial introduction of HTA>



Patient centricity—definition evolution.

Europe	North America
Every person is included ¹ for the benefit of the individual patient ²	Educate patients and caregivers ² in a culturally-sensitive way ³ to access the health and care system. Implement a standard of excellence for all stakeholders ² in the health and care system which provides respectful, accountable and transparent ⁴ care that meets individual's rights and needs ²
Where empathetic, responsible, sustained ⁵ and innovative partnership ⁶ leads to where everyone matters ¹ for the ongoing benefit of the patient ²	Open ⁸ and continued engagement ⁸ among patients, caregivers, healthcare providers, payers and the biopharmaceutical industry ¹ to share knowledge ⁹ with respect and compassion ⁴ to offer the best possible outcome for that person and their family ²

In all cases, the definitions were shaped by the values that participants had originally identified as being most important to patients. ¹Inclusiveness; ²Sharing goals that are patient and family-centred; ³Empowering patients to take control of their own health; ⁴Working in a way that shows respect, compassion and openness; ⁵Working in partnership.

Putting the patient first in an open and sustained engagement of the patient to respectfully and compassionately achieve the best experience and outcome for that person and their family

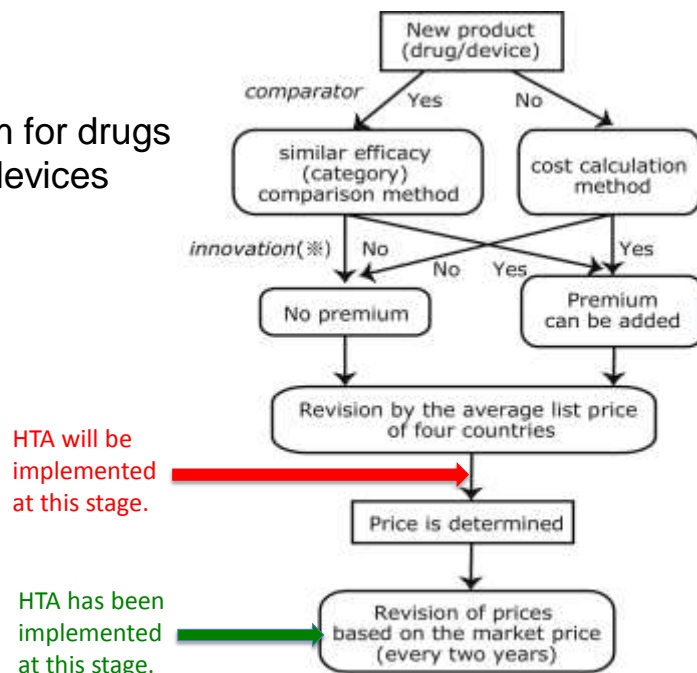
Guy Yeoman et al. *BMJ Innov* 2017;3:76-83

How Will Patient Centricity be Captured?

- Use of QALY
 - Patient’s “Quality of Life” can be explicitly considered.
- Patient Involvement in HTA process
 - The value from the viewpoint of patients will influence the policy decision.



Pricing system for drugs and medical devices



(*) Other types of premium are omitted.