Patient Values and Preferences in Health Technology Assessment

Barry D. Stein
Colorectal Cancer Canada
Global Action for Cancer Patients

World Cancer Congress
Kuala Lumpur, Malaysia
1—4 Oct 2018

Strengthen
Inspire
Deliver

uicc
global cancer control
WORLD CANCER CONGRESS

Background

Therapeutic innovation continues to grow as new therapies enter clinical practice.

Increased survivorship is transforming the approach from acute treatment to chronic disease management.

This has resulted in a change of focus to total patient care encompassing QoL issues and patient preferences and Values.

There is pressure for better access to affordable & effective cancer treatments and a growing call for *Value* in cancer drugs.

Cancer Drugs Present 3 Sustainability Challenges*

Growth in the cancer drug pipeline:

Over 150 new cancer therapies and 300 new drug indication pairs under investigation in clinical trials.

Increase in the number new cancer cases in Canada:

By 2030, cancer cases are expected to grow by 40%.

Survival rates continue to improve.

There is an increasing rate of recurrent and new primary cancer diagnoses.

Rising Provincial Oncology Drug Budgets:

Oncology drug budgets tripled in less than a decade. Increasing between 12-15% annually.

Expanding lines of treatment, simultaneous use of multiple cancer drugs, targeted therapies and immunotherapies.

*January 19, 2017 - Canadian Association of Provincial Cancer Agencies

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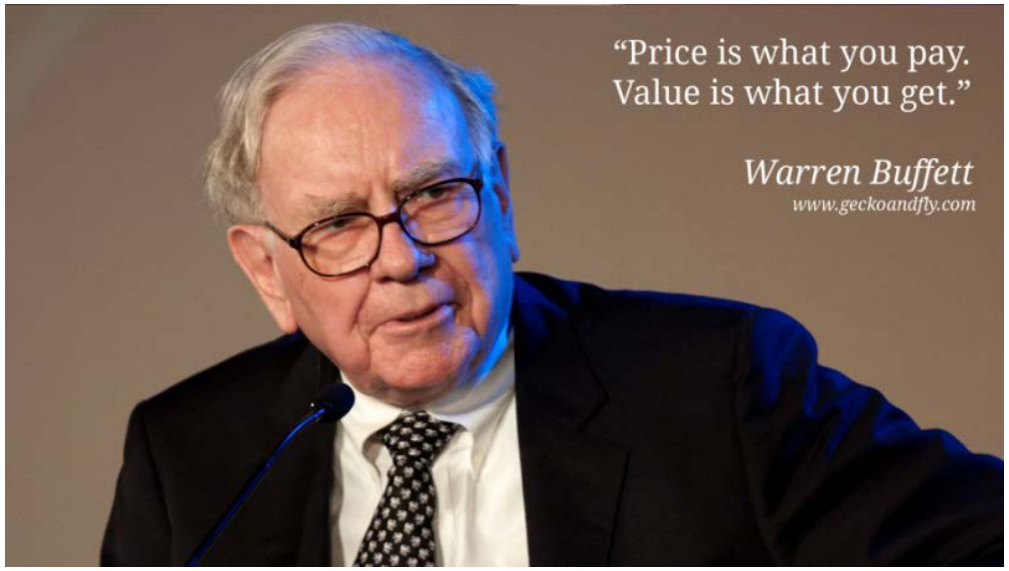
WHAT IS VALUE?



Value Based Medicine is more than managing drug costs, it is part of a broader debate on access to treatment that includes differing stakeholder expectations on value in cancer care in general.

There is also a shift from a product-oriented approach, rooted in science and efficacy, to a broader assessment that includes pharmacoeconomics, therapy management, compliance issues and patient QoL.

New approaches are developing to address this issue, but do they truly account for what patient’s value?

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Why Engage Patients & Caregivers In HTA? (Value?)

Patient and Citizen Involvement Interest Group. HTAi.org

RELEVANCE

Patients have knowledge, perspectives and experiences that are unique and contribute to essential evidence for HTA.

FAIRNESS

Patients have the same rights to contribute to the HTA process as other stakeholders and have access to processes that enable effective engagement.

EQUITY

Patient engagement in HTA contributes to equity by seeking to understand their diverse needs with a particular health issue, balanced against the requirements of a health system that seeks to distribute resources fairly among all users.

LEGITIMACY

Patient involvement facilitates those affected by the HTA recommendations to participate in the process; contributing to the transparency, accountability and credibility of the decision-making process.

CAPACITY BUILDING

Patient involvement processes address barriers to involving patients in HTA and build capacity for patients and HTA organizations to work together.

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The Challenge

Defining, Measuring & Weighing "Values" as they apply to new oncology drugs is a challenge faced by many stakeholders with different interests.

Patients: Have the most vested interest.

Advocacy groups: Equal and timely access to effective treatments to improve patient outcomes.

Physicians: Treatment options for best outcomes.

Healthcare providers: Best treatments within their system and budget.

Regulators: Fairness and diligence in assessing the risk/benefit ratio according to their methods of appraisal.

Government agencies: Policy and direction on best spending practices to ensure overall population good health.

Third-party payers: Best value from available funds when covering prescription choices.

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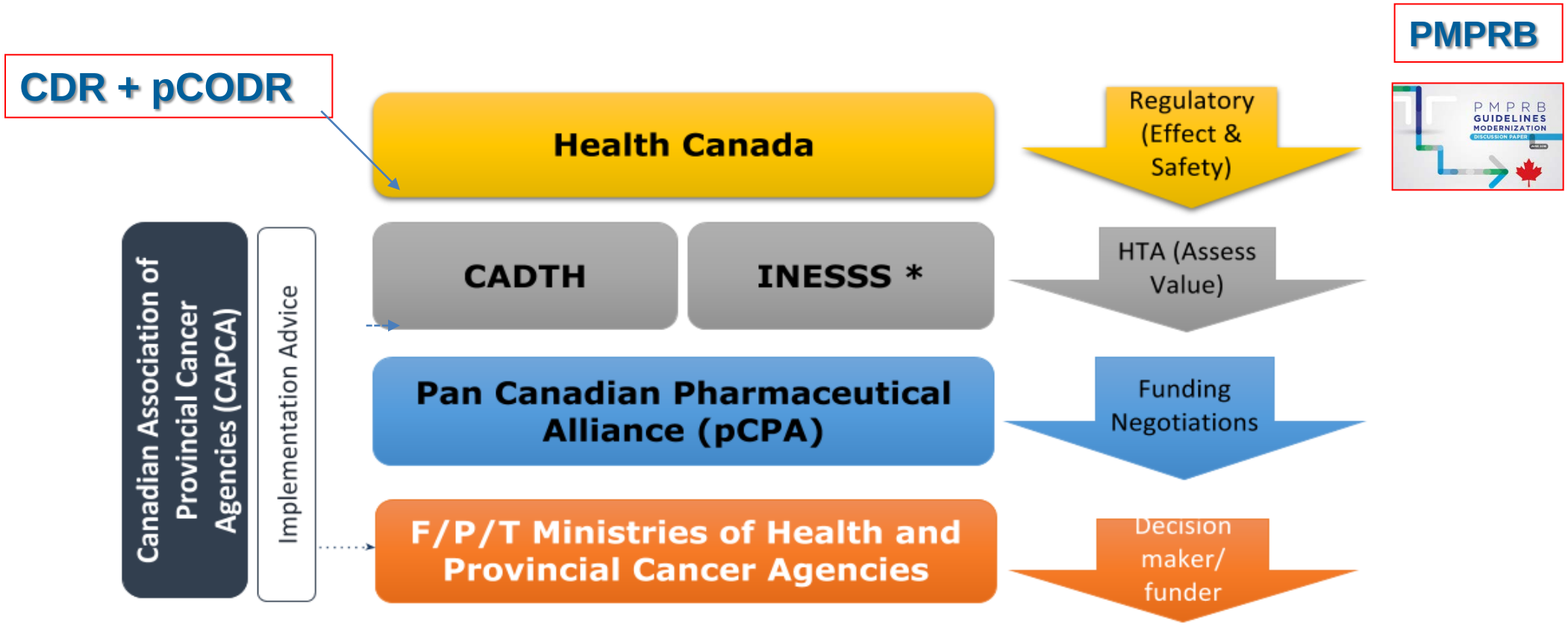
DRUG APPROVAL PROCESS IN CANADA

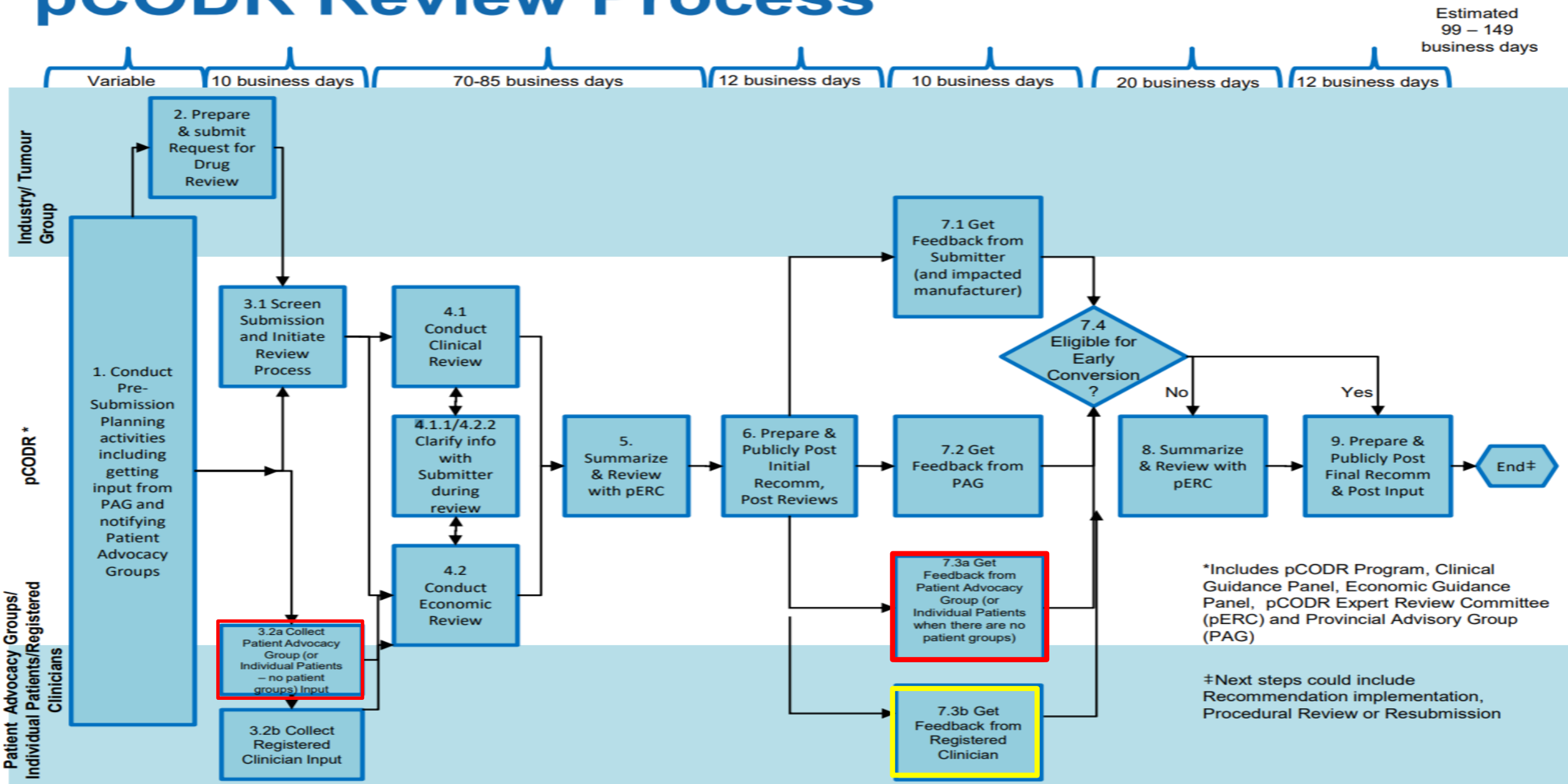
Supporting the provinces and aligning with pCODR and pCPA



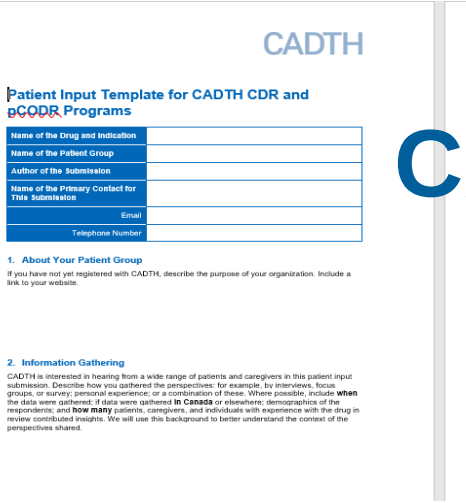
** INESSS is not directly linked to pCPA.*

CADTH | pCODR PAN-CANADIAN ONCOLOGY DRUG REVIEW

pCODR Review Process



©CADTH-pCODR August 2018


CADTH

Patient Input Template for CADTH CDR and pCODR Programs

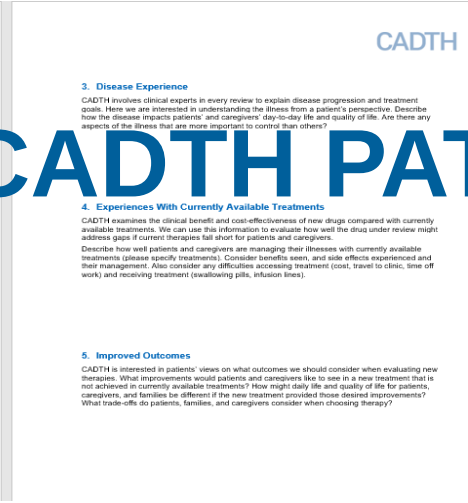
Name of the Drug and Indication	
Name of the Patient Group	
Author of the Submission	
Name of the Primary Contact for This Submission	
Email	
Telephone Number	

1. About Your Patient Group

If you have not yet registered with CADTH, describe the purpose of your organization. Include a link to your website.

2. Information Gathering

CADTH is interested in hearing from a wide range of patients and caregivers in this patient input submission. Describe how you gathered the perspectives: for example, by interviews, focus groups, or survey; personal experience; or a combination of these. Where possible, include **when** the data were gathered; if data were gathered **in Canada** or elsewhere; demographics of the respondents; and **how many** patients, caregivers, and individuals with experience with the drug in review contributed insights. We will use this background to better understand the context of the perspectives shared.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3. Disease Experience

CADTH involves clinical experts in every review to explain disease progression and treatment goals. Here we are interested in understanding the illness from a patient's perspective. Describe how the disease impacts patients' and caregivers' day-to-day life and quality of life. Are there any aspects of the illness that are more important to control than others?

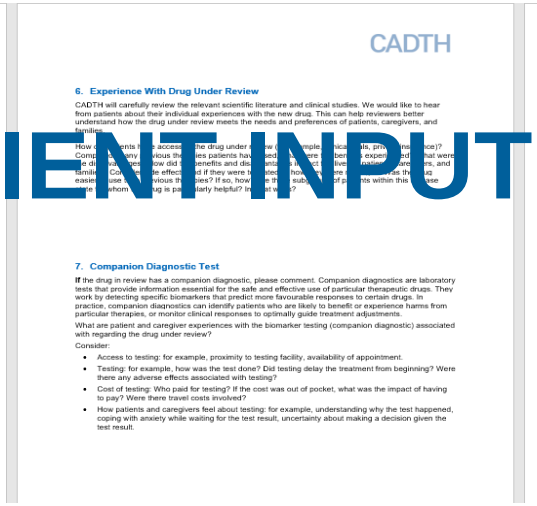
4. Experiences With Currently Available Treatments

CADTH examines the clinical benefit and cost-effectiveness of new drugs compared with currently available treatments. We can use this information to evaluate how well the drug under review might address gaps if current therapies fall short for patients and caregivers.

Describe how well patients and caregivers are managing their illnesses with currently available treatments (please specify treatments). Consider benefits seen, and side effects experienced and their management. Also consider any difficulties accessing treatment (cost, travel to clinic, time off work) and receiving treatment (swallowing pills, infusion lines).

5. Improved Outcomes

CADTH is interested in patients' views on what outcomes we should consider when evaluating new therapies. What improvements would patients and caregivers like to see in a new treatment that is not achieved in currently available treatments? How might daily life and quality of life for patients, caregivers, and families be different if the new treatment provided those desired improvements? What trade-offs do patients, families, and caregivers consider when choosing therapy?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6. Experience With Drug Under Review

CADTH will carefully review the relevant scientific literature and clinical studies. We would like to hear from patients about their individual experiences with the new drug. This can help reviewers better understand how the drug under review meets the needs and preferences of patients, caregivers, and families.

How c[illegible] access[illegible] the drug under review (for example, clinical trials, private insurance)? Compa[illegible]ny obvious the[illegible]ses patients have used[illegible]here's been the expert[illegible]d that were the dr[illegible]ow did the benefits and dis[illegible]ect their lives, caregivers, and families? Co[illegible]de effects and if they were t[illegible]ow[illegible]re[illegible]as they got easier[illegible]obvious th[illegible]es? If so, how[illegible]e th[illegible]suit[illegible]of patients within this phase [illegible]whom[illegible]g is particularly helpful? In[illegible]at was?

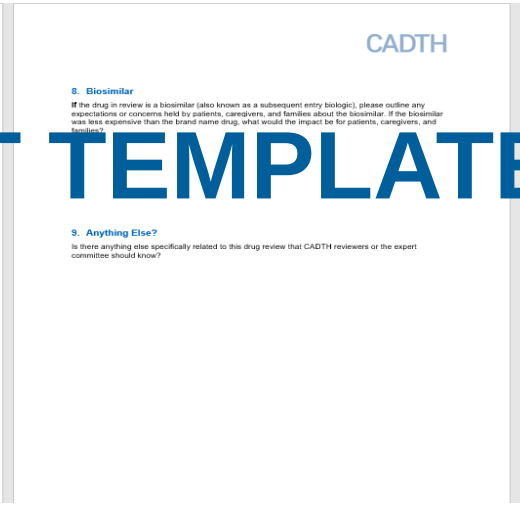
7. Companion Diagnostic Test

If the drug in review has a companion diagnostic, please comment. Companion diagnostics are laboratory tests that provide information essential for the safe and effective use of particular therapeutic drugs. They work by detecting specific biomarkers that predict more favourable responses to certain drugs. In practice, companion diagnostics can identify patients who are likely to benefit or experience harms from particular therapies, or monitor clinical responses to optimally guide treatment adjustments.

What are patient and caregiver experiences with the biomarker testing (companion diagnostic) associated with regarding the drug under review?

Consider:

- Access to testing: for example, proximity to testing facility, availability of appointment.
- Testing: for example, how was the test done? Did testing delay the treatment from beginning? Were there any adverse effects associated with testing?
- Cost of testing: Who paid for testing? If the cost was out of pocket, what was the impact of having to pay? Were there travel costs involved?
- How patients and caregivers feel about testing: for example, understanding why the test happened, coping with anxiety while waiting for the test result, uncertainty about making a decision given the test result.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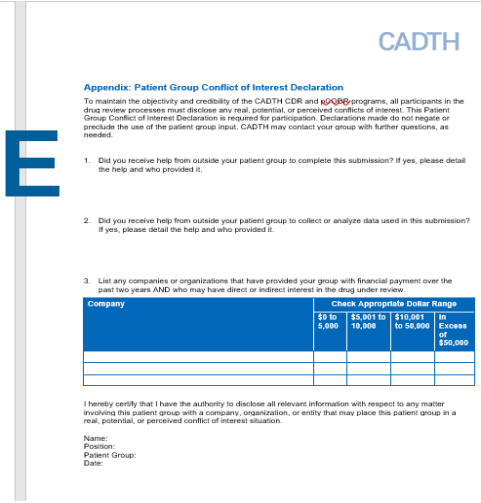
8. Biosimilar

If the drug in review is a biosimilar (also known as a subsequent entry biologic), please outline any expectations or concerns held by patients, caregivers, and families about the biosimilar. If the biosimilar was less expensive than the brand name drug, what would the impact be for patients, caregivers, and families?

9. Anything Else?

Is there anything else specifically related to this drug review that CADTH reviewers or the expert committee should know?


CADTH

Appendix: Patient Group Conflict of Interest Declaration

To maintain the objectivity and credibility of the CADTH CDR and pCODR programs, all participants in the drug review processes must disclose any real, potential, or perceived conflicts of interest. This Patient Group Conflict of Interest Declaration is required for participation. Declarations made do not negate or preclude the use of the patient group input. CADTH may contact your group with further questions, as needed.

1. Did you receive help from outside your patient group to complete this submission? If yes, please detail the help and who provided it.

2. Did you receive help from outside your patient group to collect or analyze data used in this submission? If yes, please detail the help and who provided it.

3. List any companies or organizations that have provided your group with financial payment over the past two years AND who may have direct or indirect interest in the drug under review.

Company	Check Appropriate Dollar Range			
	$0 to 5,000	$5,001 to 10,000	$10,001 to 50,000	In Excess of $50,000

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this patient group with a company, organization, or entity that may place this patient group in a real, potential, or perceived conflict of interest situation.

Name:
Position:
Patient Group:
Date:

CADTH PATIENT INPUT TEMPLATE

1. About your Patient Group.
2. Information Gathering (How, Who, What, Where, When, How many people).
3. Disease Experience.
4. Experience with Currently Available Treatments
5. Improved Outcomes.
6. Experience with the Drug Under Review.
7. Companion Diagnostic Test.
8. Biosimilar.
9. Anything Else?
10. Conflict of Interest declaration.

https://cadth.ca/pcodr-update-61

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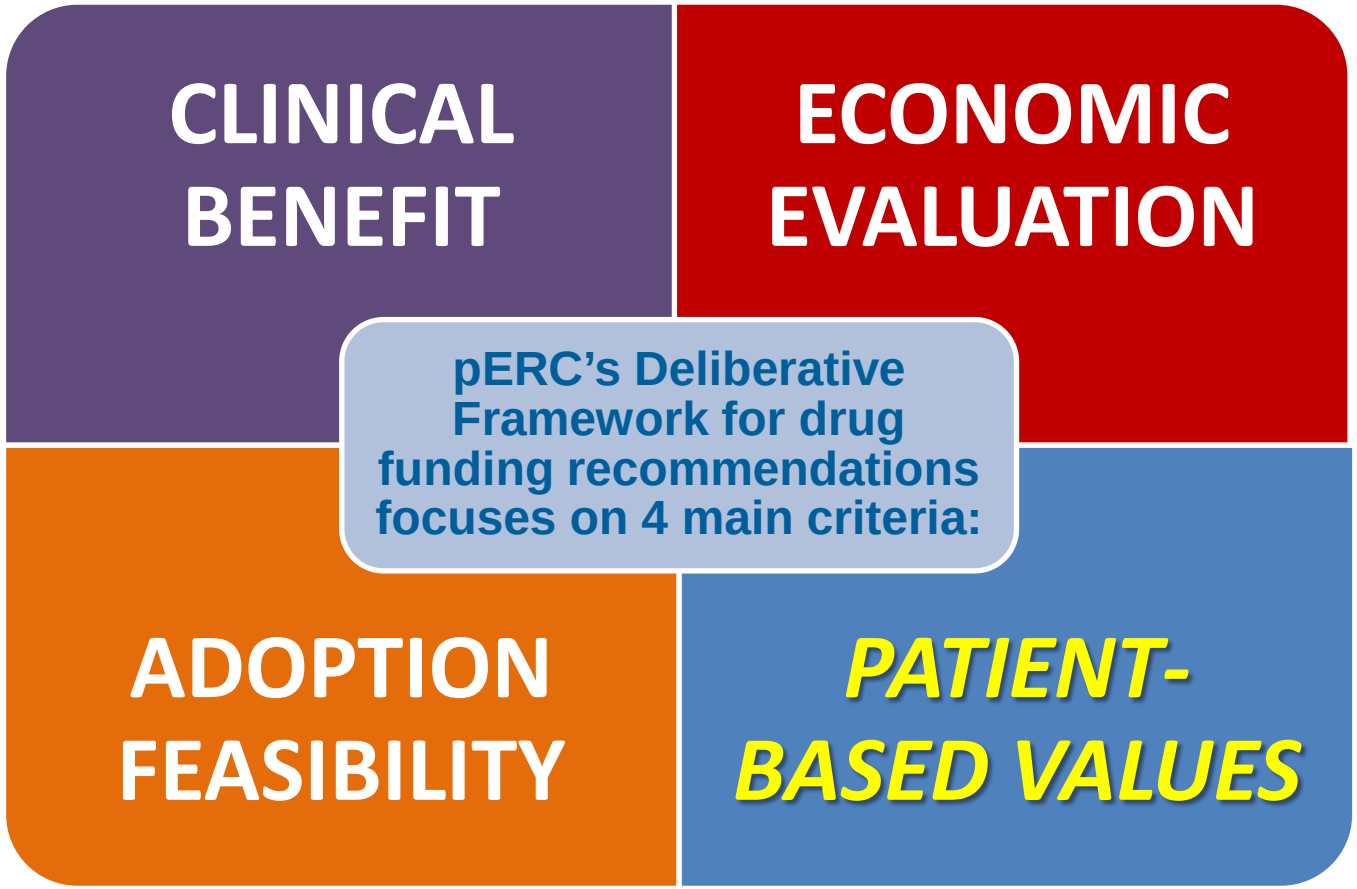
CANCER PATIENT GROUP INPUT IN CADTH

PATIENT GROUP INPUT is reviewed by pERC (pCODR Expert Review Committee) as part of the deliberative framework to assess a cancer drug for reimbursement.



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PATIENT EVIDENCE

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Framework Tool and Value Items

✓= included in algorithm/calculation

✓= shown for information or comparison purposes

✗= not included or shown

Table 2. Framework tools and value items

Value item	Framework tool						
	PASKWIL[5]	CDF Prioritisation Tool[6]	ESMO Magnitude of Clinical Benefit Scale[7]	ASCO Conceptual Framework[8]	NCCN Evidence Blocks[29]	MSKCC DrugAbacus[11]	ICER Value Assessment Project[13]
Efficacy (OS, PFS, response rate)	✓	✓	✓	✓	✓	✓	✓
Toxicity	✓	✓	✓	✓	✓	✓	✓
QoL/palliation	✓	✓	✓	✓	✗	✗	✓
Treatment-free interval	✗	✗	✗	✓	✗	✗	✗
Level of evidence	✓	✓	✗	✗	✓	✓	✗
Patient preferences	✗	✗	✗	✗	✗	✗	✗
Disease burden/ incidence	✗	✗	✗	✗	✗	✓	✓
Unmet need	✗	✓	✗	✗	✗	✓	✗
Novelty	✗	✗	✗	✗	✗	✓	✗
Research cost	✗	✗	✗	✗	✗	✓	✗
Drug costs	✓	✓	✗	✓	✓	✓	✗
Cost-effectiveness/ offsets	✗	✓	✗	✗	✓	✗	✓
Budget impact	✗	✗	✗	✗	✗	✓	✓

✓=included in algorithm/calculation ✓=shown for information or comparison purposes ✗=not included or shown.
ASCO=American Society of Clinical Oncology; CDF=Cancer Drugs Fund; ESMO=European Society for Medical Oncology; ICER=Institute for Clinical and Economic Review; MSKCC=Memorial Sloan Kettering Cancer Center; NCCN=National Comprehensive Cancer Network; OS=overall survival; PASKWIL=Palliative/Adjuvant effectiveness, Specific adverse events, (Kw) quality of life, Impact of treatment, and Level of evidence; PFS=progression-free survival; QoL=quality of life.

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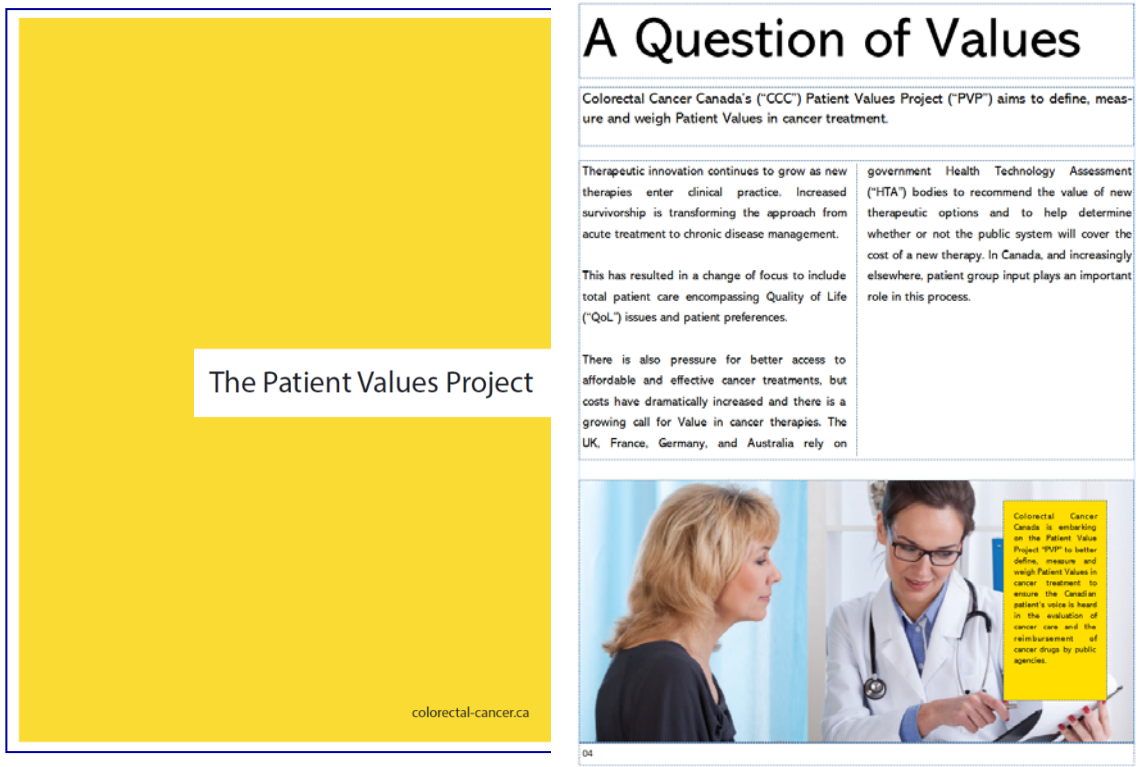
The Patient Values Project

The CCC is embarking on a Patient Values Project (“PVP”) to better define, measure and weigh patient Values in cancer treatment.



A Question of Values

Colorectal Cancer Canada's ("CCC") Patient Values Project ("PVP") aims to define, measure and weigh Patient Values in cancer treatment.

Therapeutic innovation continues to grow as new therapies enter clinical practice. Increased survivorship is transforming the approach from acute treatment to chronic disease management.

This has resulted in a change of focus to include total patient care encompassing Quality of Life ("QoL") issues and patient preferences.

There is also pressure for better access to affordable and effective cancer treatments, but costs have dramatically increased and there is a growing call for Value in cancer therapies. The UK, France, Germany, and Australia rely on government Health Technology Assessment ("HTA") bodies to recommend the value of new therapeutic options and to help determine whether or not the public system will cover the cost of a new therapy. In Canada, and increasingly elsewhere, patient group input plays an important role in this process.

04

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General Objectives

DEVELOP A BETTER DEFINITION OF PATIENT VALUES, DETERMINE THE APPROPRIATE METRICS TO MESUARE THESE VALUES, ASSIGN AN APPROPRIATE WEIGHT TO THESE VALUES THAT CAN BE USED BY THE EXPERT COMMITTEE IN THE HTA DECISION MAKING PROCESS.

- Empower Patient Groups to provide research based input to assist expert committees in the evaluation of a drug or treatment.
- Encourage better quality Patient Group submissions in HTA.
- Allow for a more reasoned and balanced rationale in the assessment of new cancer drugs by the expert HTA committees.
- Provide objective and quantifiable input on Patient Values based on validated research techniques.

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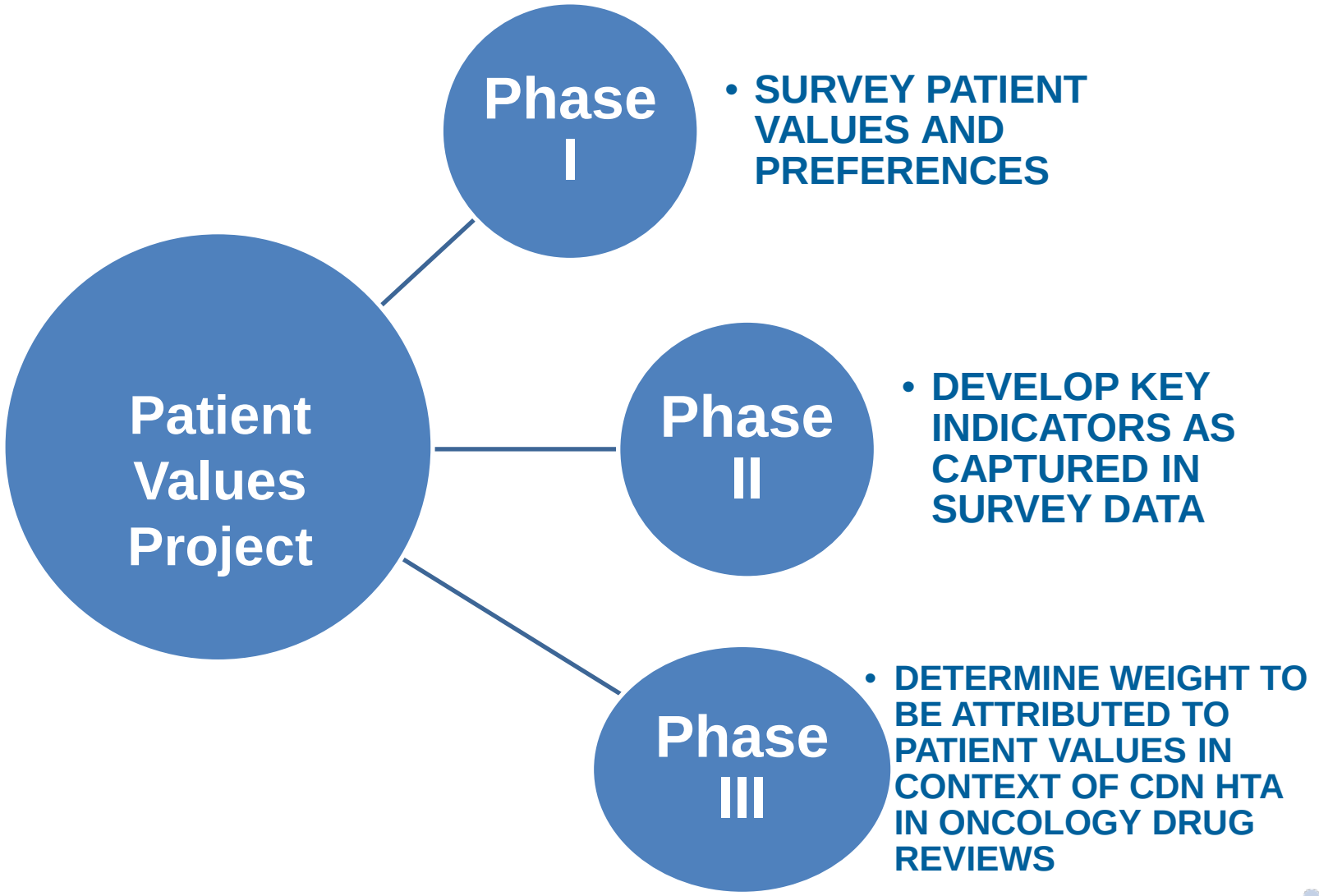
PATIENT VALUES PROJECT PHASES



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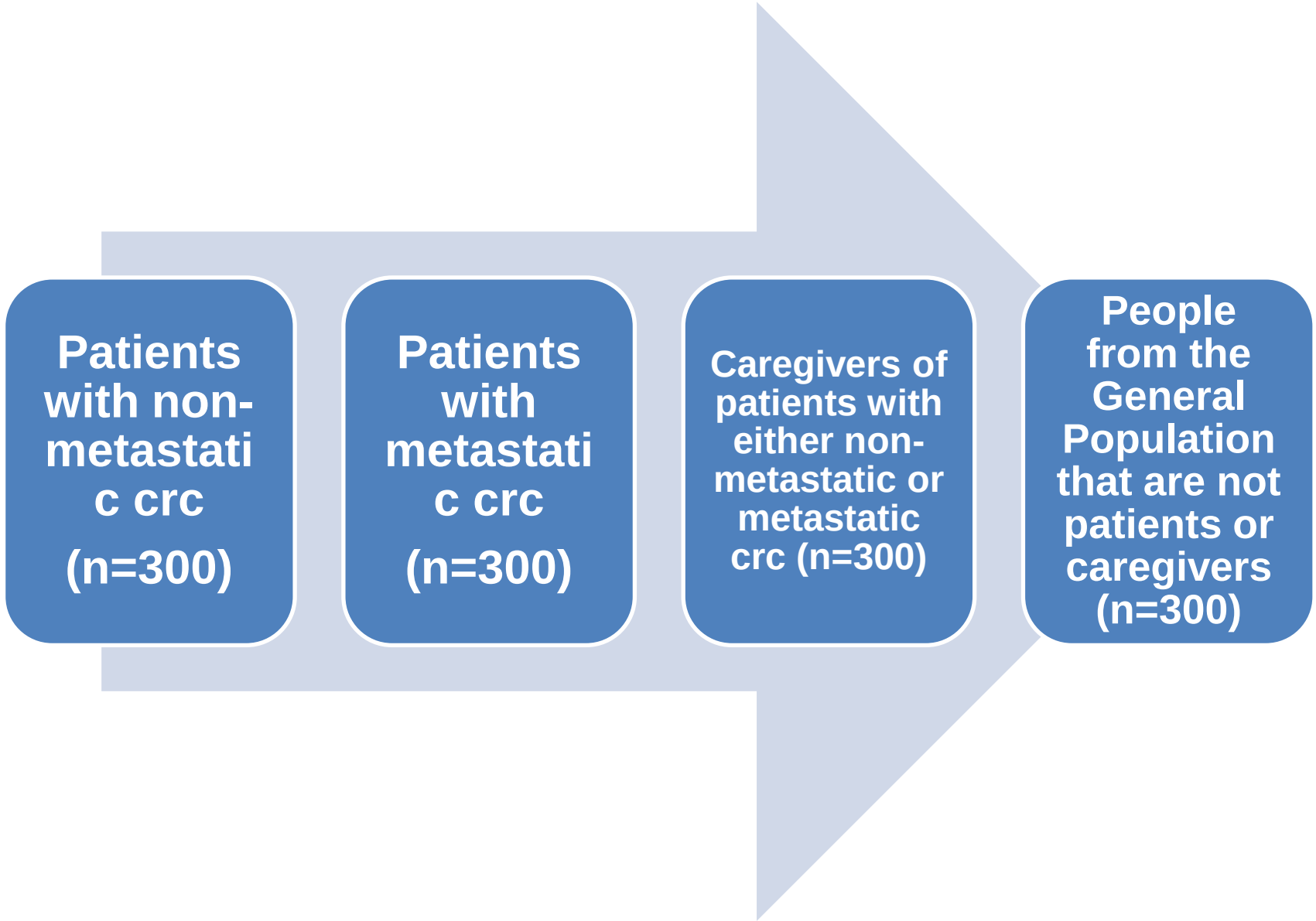
Survey Population to be Recruited

Survey population includes Canadian adults (18 years of age and older)



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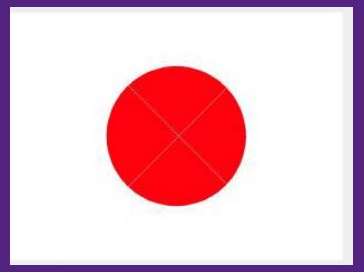
Thank You! Gracias! Obrigado!
Grazie! Merci! !תודה
ありがとうございました！
Ačiū! Salamat! Terima
Kasih!



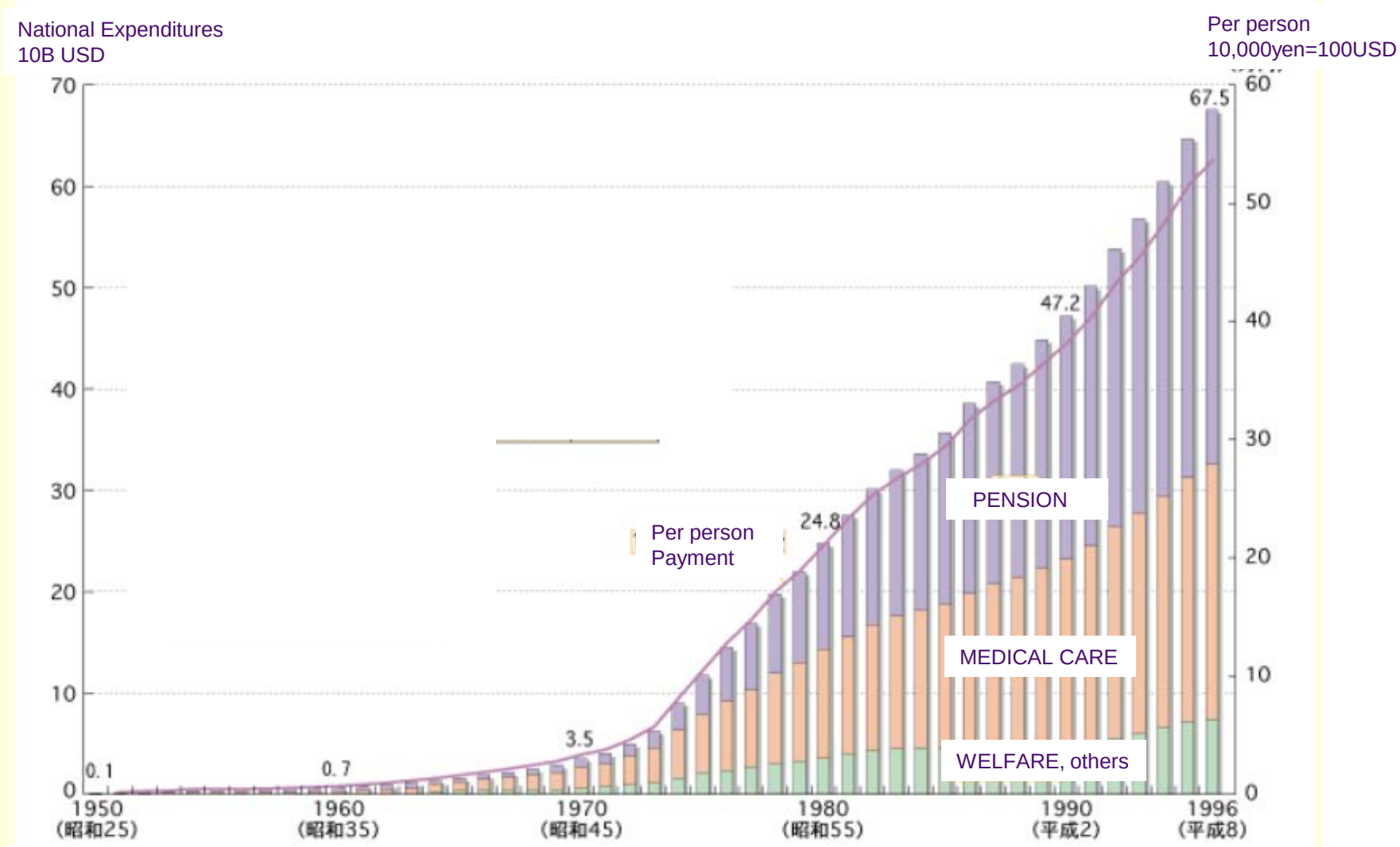
T3-51 : Towards global equity in cancer care
2018-10-02

Cross border efforts to improve patient care in Japan

Pancreatic Cancer Action Network Japan
President Yoshiyuki Majima

PANCREATIC CANCER ACTION NETWORK
ADVANCE RESEARCH. SUPPORT PATIENTS. CREATE HOPE.

SOCIAL SECURITY EXPENDITURE TREND



SOURCE: National Institute of Population and Social Security Research
100yen=1USD

Revolutionary new drugs with high price tag have arrived

WHO Resolution *A67/33*

- Many countries currently lack the capacity to assess the merit of HTA

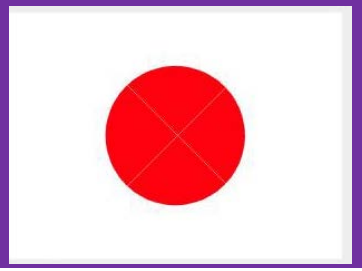
- HTA main purpose is to inform technology related policy making healthcare and thus improve the uptake of cost-effective new technologies and prevent the uptake of technologies that are of doubtful value in the healthcare system.

- Wasteful spending on medicines and other technologies has been identified as major cause of inefficiencies in the health service delivery

HTA in Asian Countries

Country	Agency	Type
CHINA	Various university centers	アカデミア
MALAYSIA	MaHTAS (HTA Section) and HTAU (HTA Unit)	厚生省/政府
PHILLIPPINES	National Center for Pharmaceutical Access and Management	健康局/政府
SINGAPORE	Research & Technology Assessment Department	厚生省/政府
ROK	Health Insurance Review & Assessment Agency / National Evidence-based Healthcare Collaboration Agency	厚生省/政府
TAIWAN	HTA Division – Center for Drug Evaluations	健康局/政府
THAILAND	HiTAP (Health Intervention & Technology Assessment Program)	厚生省/政府

Source: HTAWorkshop - Role of HTAin Asian Pacific Region, Madeleina Valeria



医薬品産業の総合情報サイト
日刊薬業
NIKKAN YAKUGYO WEB

TOP | 回覧板 | キーワード | myスクラップ
行政・政治 | 企 業 | 団 体 | 臨床・学会 | 眞島 喜幸 さん

日刊薬業WEBトップ ＞ 行政・政治 ＞ 記事詳細

【中医協】費用対効果、試行的導入の在り方を了承　品目指定は4月以降（2015年12月16日）

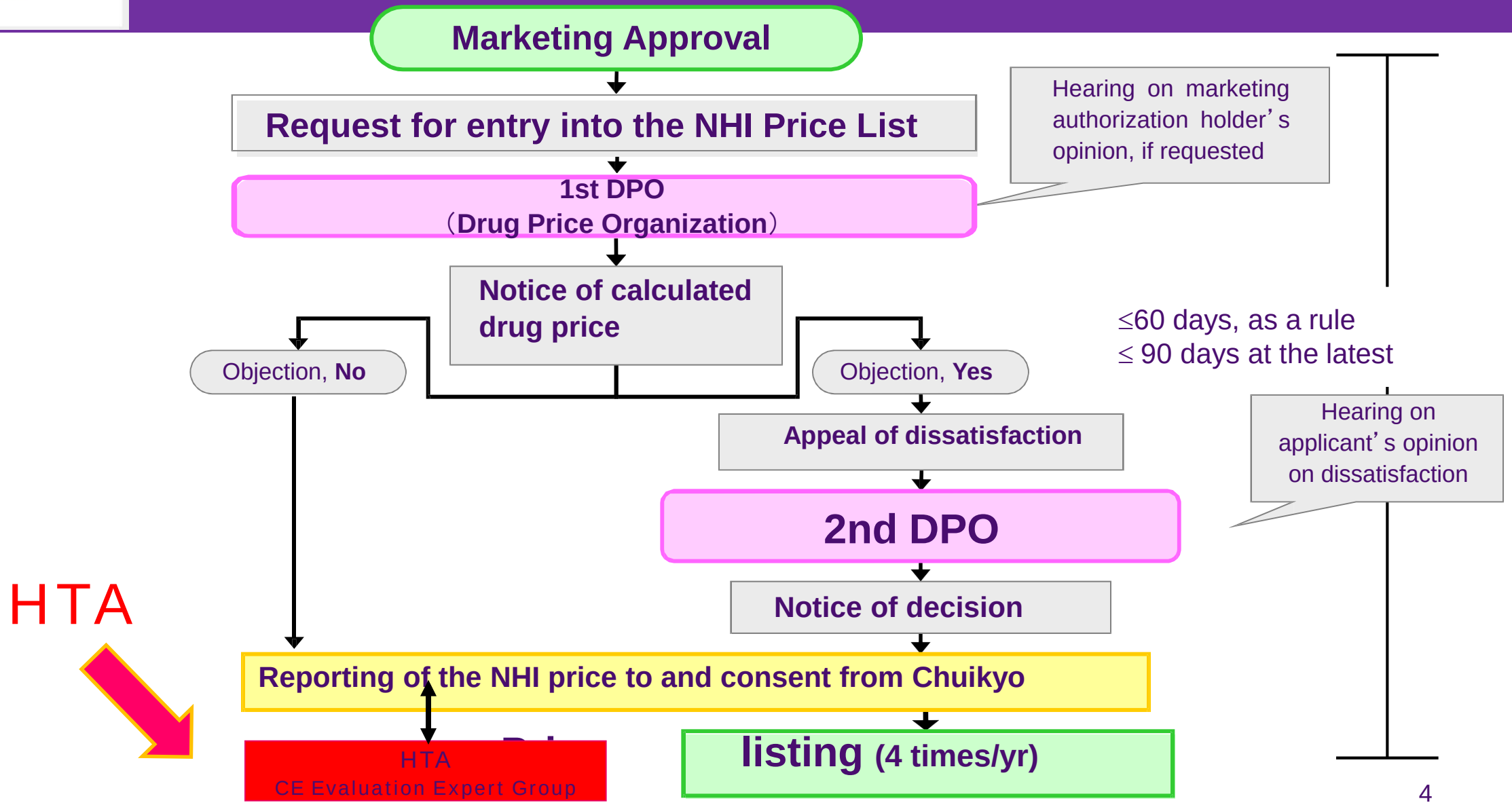
中医協総会は16日、2016年度診療報酬改定時における費用対効果評価の「試行的導入の在り方」を了承した。来年2月に対象品目の選定基準と制度の運用方法について結論を得て、4月以降、再算定の対象となる具体的な品目を指定する。対象品目を持つ企業は、16年度内に関連データを提出する。費用対効果の良しあしを判断する目安となる「ICER（アイサー、増分費用効果比）」の値は、試行導入では定めないこととした。

HTA is used not for drug approval, initial pricing, but for drug pricing adjustment using ICER

否の判断を行う場合の具体的な取り扱いなどを挙げた。

総会に先立って開かれた費用対効果評価専門部会では、土屋裕専門委員（エーザイ代表執行役）が、企業にとって新たな負担になると指摘した上で「薬価の調整では、引き上げも含めた評価をお願いしたい」と求めた。

New drug pricing process (2016)



Chuikyo Member List 2016

HTA special committee member

1．保険者、被保険者、事業主を代表する委員

矢内 邦夫	全国健康保険協会健
白川 修二	康保険組合連合会
花井 圭子	日本労働組合総連合会
花井 十伍	日本労働組合総連合会
石山　恵司	「患者本位の医療を確立する連絡会」委員 日本経済団体連合会
田中　伸一	全日本海員組合副組合長 愛知県津島市長
伊藤 文郎	

2．医師、歯科医師及び薬剤師を代表する委員

（氏　名）	（現役職名
）鈴木　邦彦	日本医師会常任理事
安 達 秀樹	日本医師会社会保険診療報酬検討委員会
中 川 俊男	日本医師会副会長
長瀬 輝諠	日本精神科病院協会副会長
万代 恭嗣	日本病院会常任理事
堀　　憲郎	日本歯科医師会常務理事 日
三浦 洋嗣	本薬剤師会副会長

3．公益を代表する委員

印南 一路	慶應義塾大学総合政策学部教授
牛 丸 聡	早稲田大学政治経済学術院教授
関原 健夫	日本対がん協会常務理事
西村 万里子	明治学院大学法学部教授
野口 晴子	早稲田大学政治経済学術院教授
◎ 森 田 朗	学習院大学法学部教授

4．専門委員

藤原 忠彦 福	長野県川上村長
井 トシ子 宮	日本看護協会常任理事
島 喜文 丹沢	日本臨床衛生検査技師会会長
秀樹	千葉大学医学部附属病院歯科・顎・口腔外科教授
加茂谷 佳明	塩野義製薬株式会社
土 屋 裕	エーザイ株式会社
吉村　恭彰	株式会社アステム 昌子 久仁子 テルモ株式会社
田村　誠	アボットジャパン
十 河 功二 ス	株式会社イノメディック

No Patient Advocates in the list

Mock HTA panel to discuss HTA Appraisal process (2016)

OVERVIEW:

- Appointing those with medical and economic backgrouds to panel members and discuss opinions about Appraisal Process of HTA.

Clinicians (2)　Health Economist(2)　Citizen (Graduate Student) (1)
Bioetheist (1)　Nurse (1)

DISCUSSION:

- Concept of "**Fair Inning Argument(FIA)"** to deny treatment to elderly when competing with younger patients for resource?

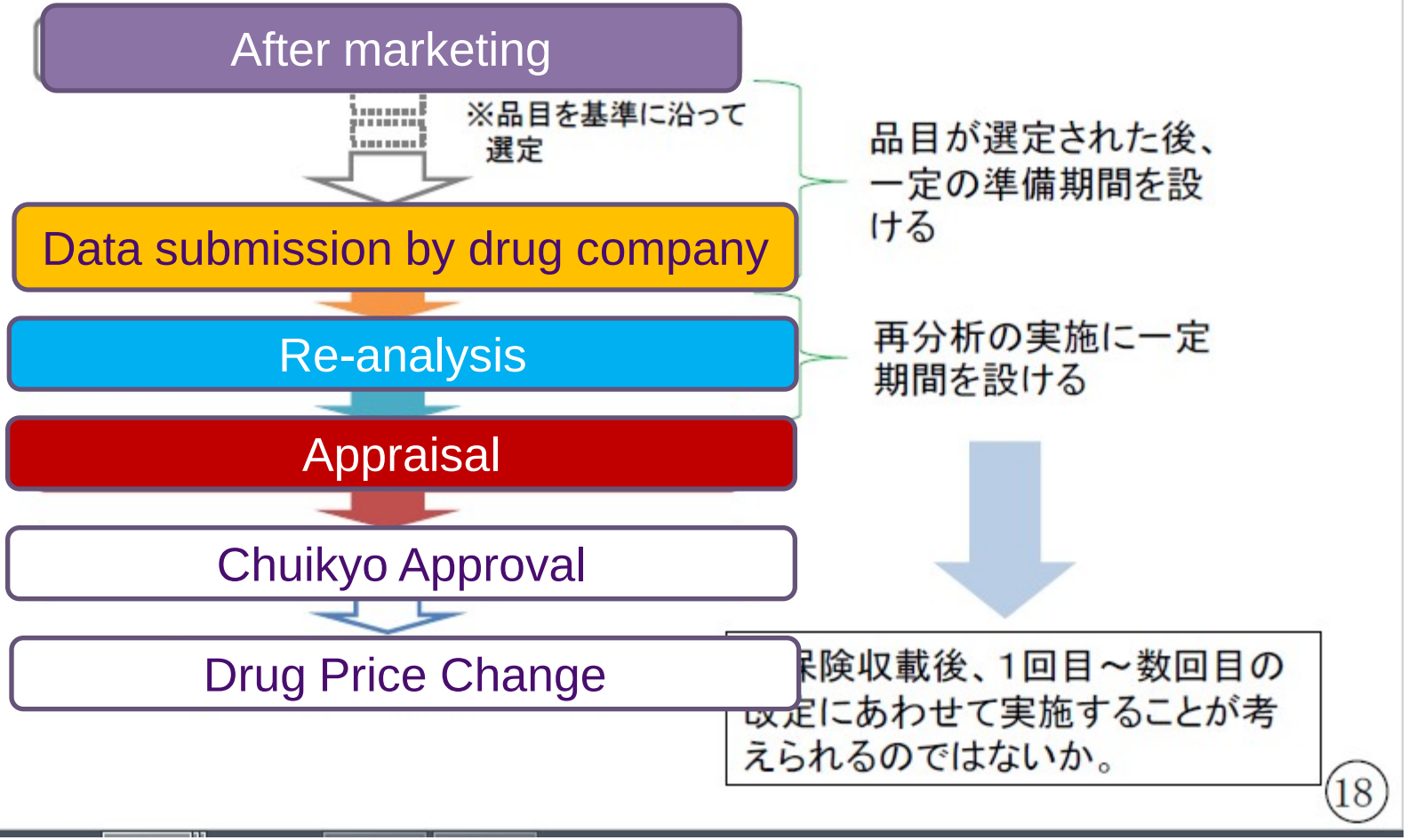
- Saving lives suffering from deadly disease is ethical thing to do?

- Conditions to allow expensive and low cost-effective treatment

>>> limit to certain expert doctors who may effectiveness of treatment

HTA used for price adjustment

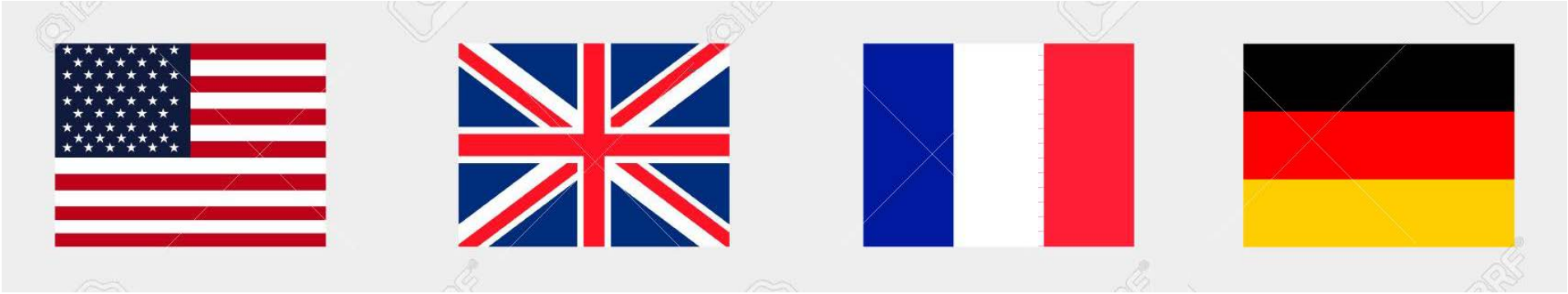
After listing of new drug, following process can be considered



出典　中医協　平成27年6月24日

Why patient (and caregiver) input to HTA is important

MHLW:
Decides Initial Drug Price by Referencing Oversea Average Price



NICE HAS DIMDI

Reference pricing has an impact on drug access

Thanks to Panos Kanavos, LSE

HTA Trial Evaluation of 7 Drugs

中医協　費薬材－１
３０．３．７

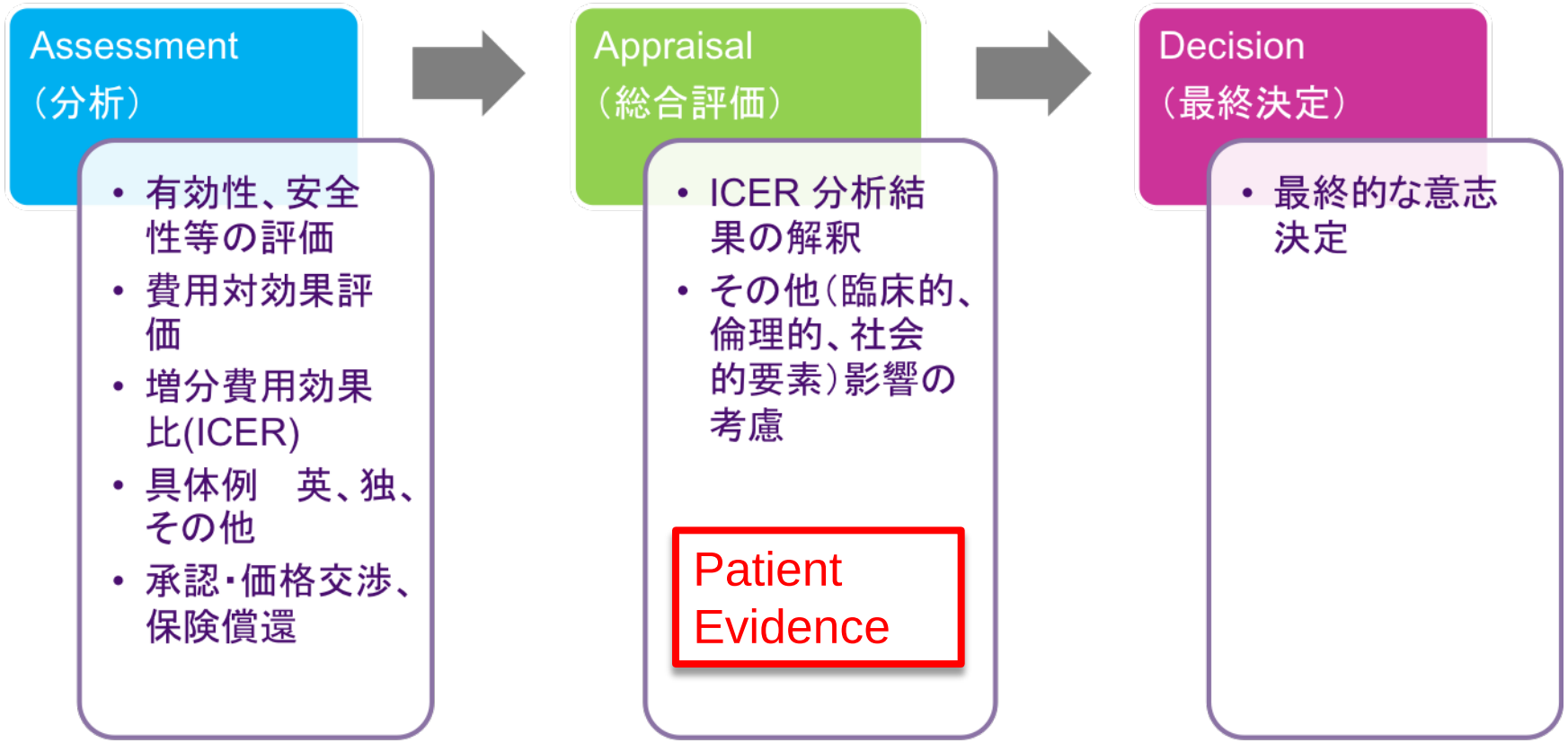
○医薬品（７品目）

Drug	Disease	Technology	ICER	Ethical/Social Factors	Reassessment Analysis
ソバルディ【ギリアド・				った公用性」	No Adj
ハーボニー【ギリアド・				った公用性」	○
ヴィキラッ【アッヴィ合				った公用性」	○
ダクルインスンベプラ【ブリストル（株）】				った公用性」	○
オプジーボ【小野薬品工				L は大生存期に該当	Price Adj
カドサイラ (KADCYLA) Kadcyla【中外製薬（株）】	HER2+ BC ら	ChemoTx	> \10M/QALY	「重篤な疾患の、QOL は大きく向上しないが生存期間が延長する治療」に該当	Price Adj

※１　費用対効果評価専門組織における評価結果（平成２９年１１月８日の合同部会（非公開）において提示済み）

Price of Opdivo and Kadcyla have been singled out for price cut adjustment

HTA process and Appraisal

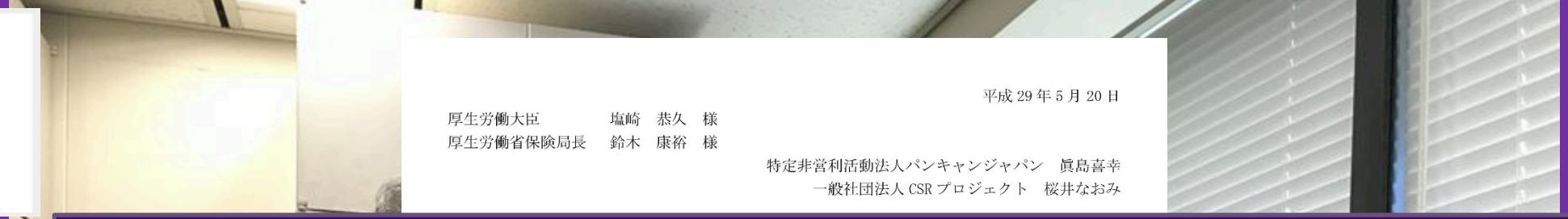


Source: ISPOR 2013 Consumer Advocate Network

An important difference

- Assessment
  - What benefit does it bring?
  - To which patients?
  - For how long?
  - With what unwanted/side effects?
  - What safety profile?
  - [At what cost?]

- Appraisal
  - Assessment in national/regional/local context
  - How would it fit into this healthcare system’s priorities?
  - Is it worth it?



平成 29 年 5 月 20 日

厚生労働大臣　　塩崎　恭久　様
厚生労働省保険局長　鈴木　康裕　様

特定非営利活動法人パンキャンジャパン　眞島喜幸
一般社団法人 CSR プロジェクト　桜井なおみ

REQUEST FOR PATIENT PARTICIPATION IN HTA PROCESS

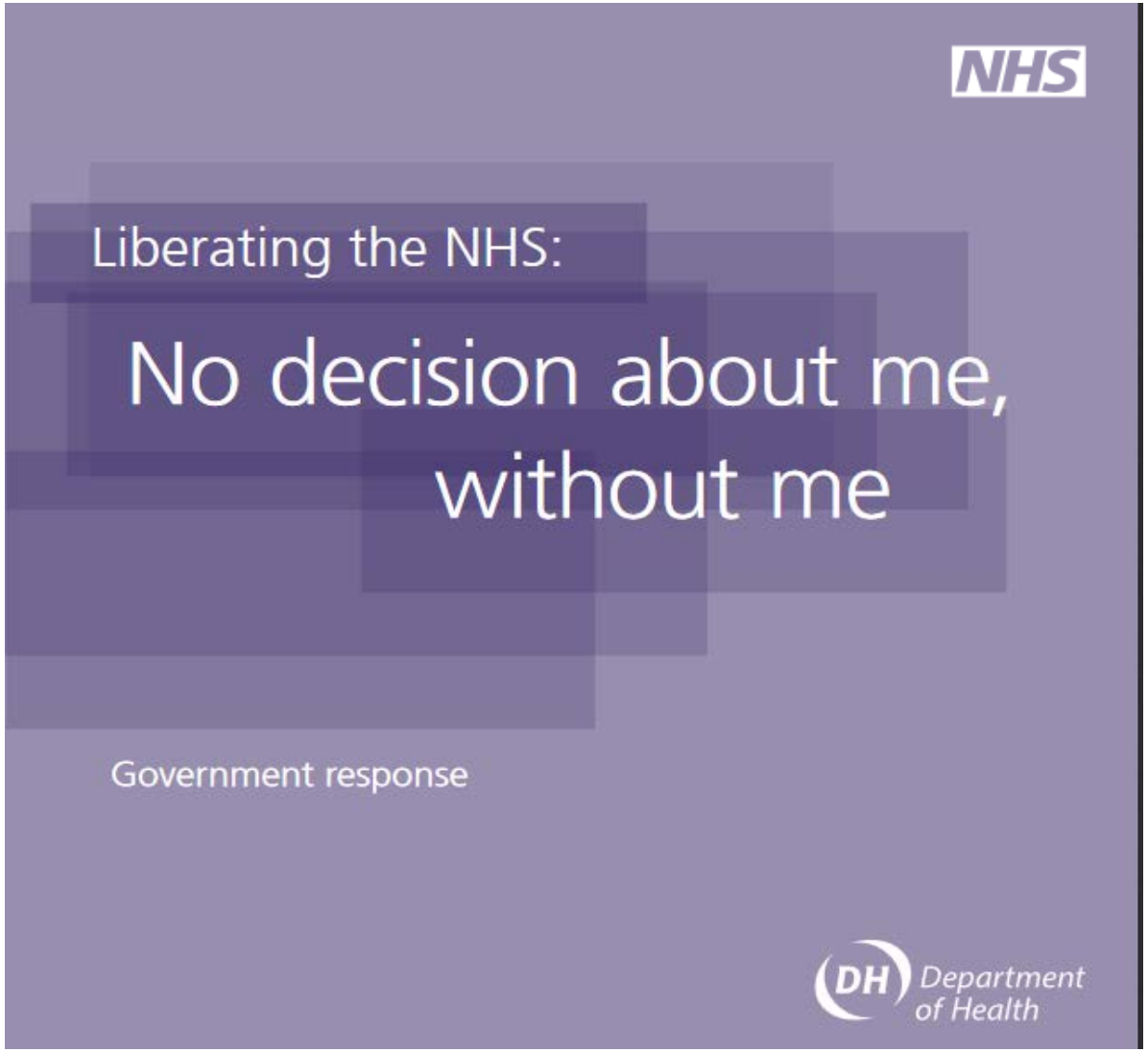
TO: Sakoi Masami, MD, MPH
MHLW Health Insurance Bureau Medical Economics Division

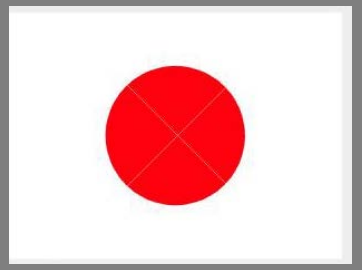
FROM: PanCAN Japan, CSR Project

1.Include patient advocates in HTA committee of Chuikyo
2.Include experienced patient advocates in Appraisal Mock Panel
3.Maintain transparency in setting ICER threshold
4.Provide and support patient education program for Appraisal participation

2017年5月29日提出

No decision about me, without me





Summary

- Patient involvement in HTA is a must, especially in Japan where advocates are not engaged at all in HTA setting.
- Clinical trial outcomes only provide a part of evidence. Understanding patient/caregivers experiences of the disease is critical, especially the use of PRO is very limited in Japan.
- Guaranteeing rapid “Access” to new drugs is more important than creating better “Value” through HTA given NHI pricing scheme.
- MHLW should provide more transparent approach to HTA and HTA training to patient advocates.

Our fight: Get the Seat at the HTA Table

HARVARD T.H. CHAN SCHOOL OF PUBLIC HEALTH
Powerful ideas for a healthier world

UNIVERSITY OF MIAMI
MIAMI INSTITUTE for the AMERICAS

Value of Cancer Care and Caring about Cancer

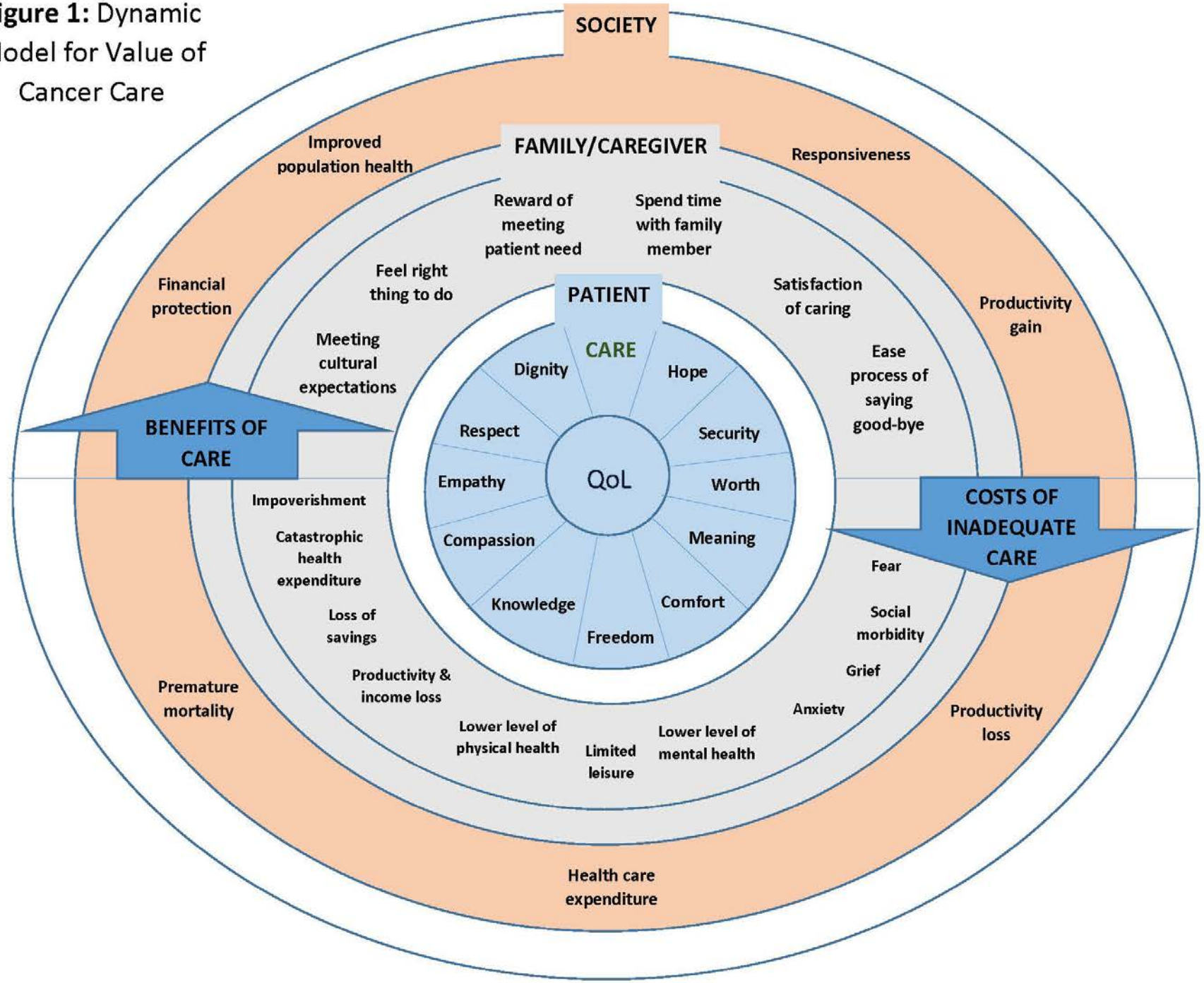
World Cancer Congress
October 2, 2018

Afsan Bhadelia, Research Associate
Harvard T.H. Chan School of Public Health

Research Objectives

- Contribute to improving understanding of the **multidimensionality of the value of health**
- Promote inclusion of patient perspective into **normative views of value of care**
- Develop a **dynamic model of the value of cancer care and control**, considering accrual of costs and benefits over time, across trajectories of care and from perspective of diverse stakeholders, including family/care givers, as well as society more broadly
- Provide **recommendations on patient engagement** for improving cancer care and caring about cancer, and health systems strengthening

Figure 1: Dynamic Model for Value of Cancer Care



Recommendations for Policy and Practice

- Promote **development of metrics** to capture patient value of care (cancer and beyond) to strengthen priority-setting frameworks
- Gather **evidence from diverse contexts**, particularly low and middle-income countries, to understand complexity of cultural norms, attitudes and perceptions around value of care
- Advance **advocacy agenda for civil society** to address gaps in knowledge
- **Engage patients/patient-advocates/patient advocacy groups**, care givers, and related associations
- Promote **network to undertake coordinated action**
- **Mobilize a movement**

Enabling Actions

- **Conduct global mapping of stakeholders around value of cancer care** and identify strengths, weaknesses, opportunities, and threats
- Garner **funding** for research, advocacy, and programmatic activities **to advance efforts on value of care**
- Develop a **committed space** for policy-oriented research focused on **patient-centered care**
- **Train patient/care giver groups** on effectively engaging in advocacy, as well as research and policy efforts more directly
- Organize opportunities for diverse stakeholders to conduct **shared learning**

Next Steps

- Validate framework through **comprehensive consultation and review by patient groups**
- **Conduct qualitative research on range of expressed values around care** from different cultures, health systems, and/or stakeholders to fill gap in knowledge
- Focus on **neglected areas** (e.g. palliative care)

Global Action for Cancer Patients

Towards global equity in cancer care

Carolyn Aldigé, Chair, GACP

2 October 2018

World Cancer Congress
Kuala Lumpur, Malaysia
1—4 Oct 2018

Strengthen
Inspire
Deliver

uicc global cancer control WORLD CANCER CONGRESS

Track 3 - Improved and sustainable healthcare systems for better outcomes

Disclosure of interest: None declared

GACP CURRENT MEMBERS

Steering Committee
Carolyn Aldigé, USA (Chair)
Yoshi Majima, Japan
Šarūnas Narbutas, Lithuania
Ignacio Zervino, Argentina
Stefania Vallone, Italy (Treasurer)

Elisabeth Baugh, Ovarian Cancer Canada

Barry Stein, Colorectal Cancer Assoc. of Canada

Šarūnas Narbutas, Lithuanian Cancer Patient Coalition

Linda House Cancer Support Community, USA

Carolyn Aldigé Prevent Cancer Foundation, USA

Oscar Prieto Martínez, Assoc. of Patients with Brain Tumours, Spain

Stefania Vallone, Women Against Lung Cancer in Europe, Italy

Yoshiyuki Majima, NPO Pan CAN, Japan

Kara Magsanoc-Alikpala, ICANSERVE,

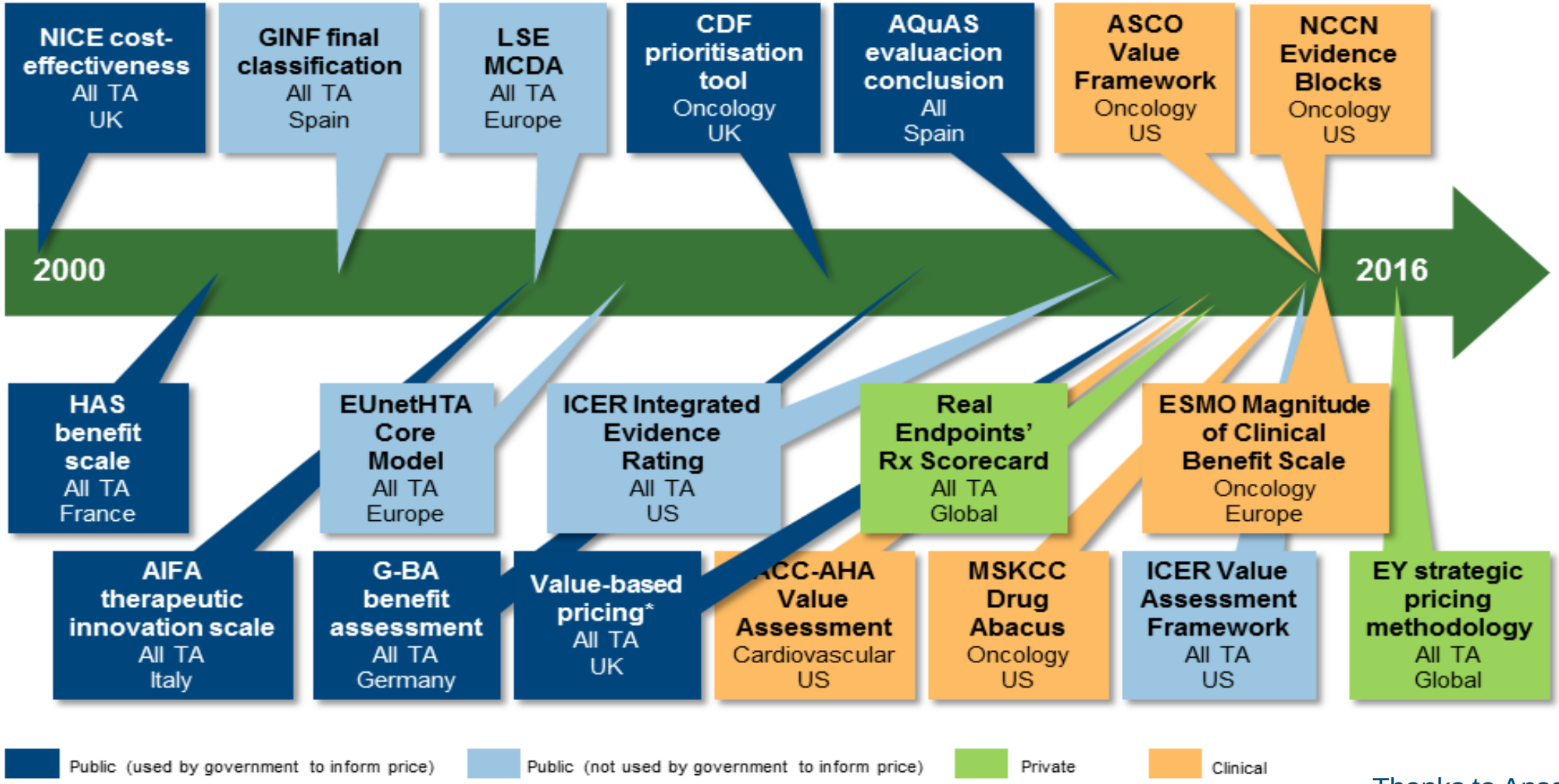
Luciana Holtz Instituto Oncoguia, Brasil

Ignatio Zervino Indp. Civic & Social Org. Professional,

Simone Leyden Unicorn Foundation Australia

Global Action for Cancer Patients

HTA and Value Frameworks



*Scheduled for 2014; abandoned in 2013
Source: website & publications from NICE, HAS, AIFA, GENESIS, LSE, EUnetHTA, AMNOG, ICER, ACC/AHA, RealEndpoints, MSKCC, ASCO, NCCN, ESMO, & Skrip; A.T. Kearney

Thanks to Ansgar Hebborn

HTA and value frameworks

- Most of these frameworks were developed without active involvement of patients or patient organisations

- Frameworks often do not include the patient perspective as a component of value estimations

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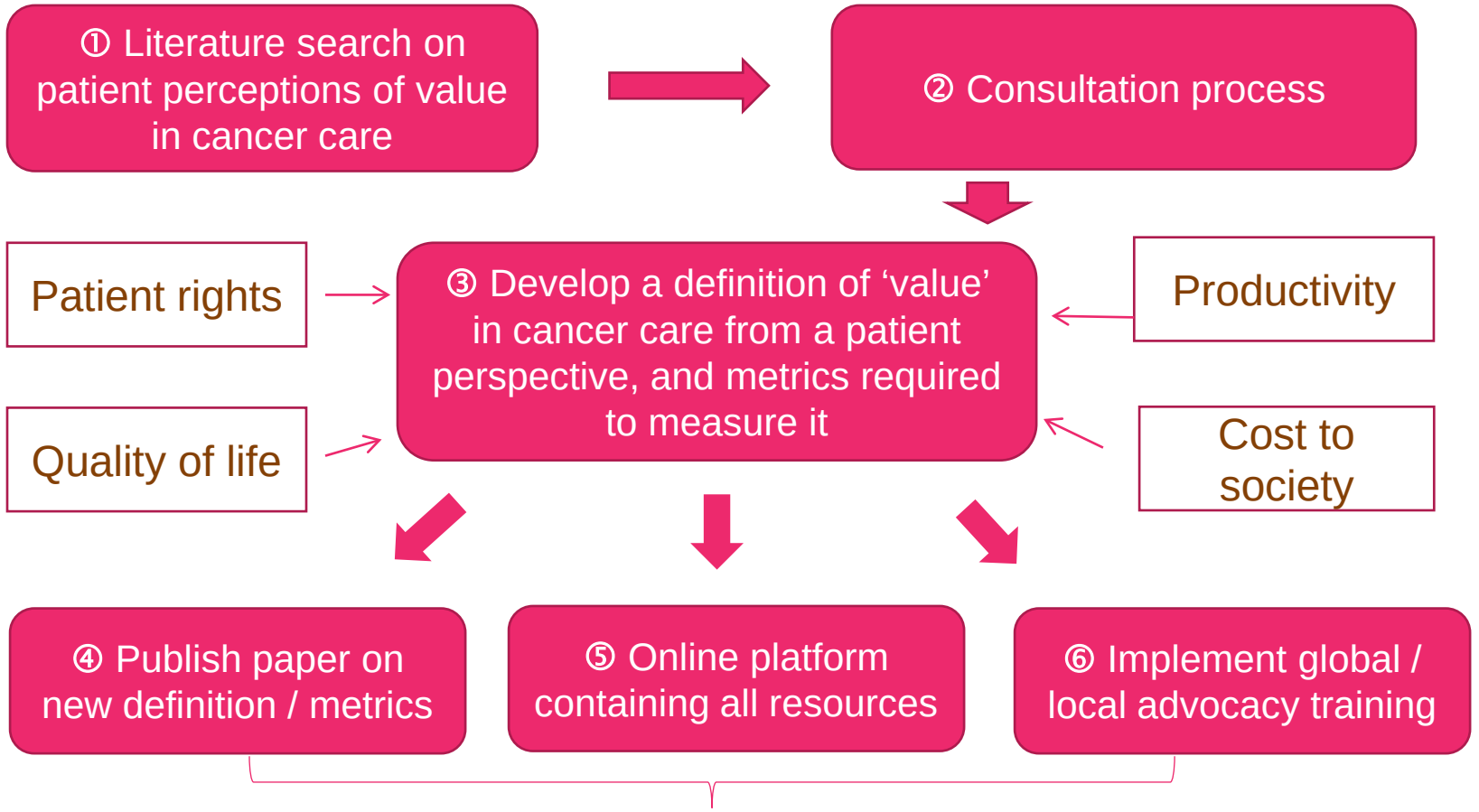
In 2014 GACP defined a plan to change this



Advocate for the new definition to be incorporated into policy (e.g. HTA) in practice

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GACP MISSION

‘We want to ensure that patient values drive decision making in cancer care’

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GACP Achievements

Contributed to session at 2016 World Cancer Congress

Paper published in Frontiers in Pharmacology, October 2017

Overview on Patient Centricity in Cancer Care, Narbutas et al

Patient Values in HTA: preliminary research concluded in Canada to support standardised method of presenting evidence-based patient values

Harvard Global Equity Group developed '*Dynamic model of cancer care*' (*in press*)

Life worth living: Communicating the value of treatment in visual narrative form

Session at Health Technology Assessment International meeting

Multiple funders: Roche, BMS & Novartis

Global Action for Cancer Patients

GACP Current & Future Plans

Strategic plan in place 2018-2019

Secretariat established in UK

Website in development

Three more narrative videos in progress

Advocacy toolkit to support their use

Session at Health Technology Assessment International meeting

Future projects on the theme of patient value in cancer care in development

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GOAL: Global Oncology Advocacy Leaders

Global Oncology Advocacy Leaders

COLLABORATE | INNOVATE | ADVOCATE

BONNIE J. ADDARIO LUNG CANCER FOUNDATION

CML AdvocatesNetwork

EuropaColon
united against digestive cancers

GLOBAL LUNG CANCER COALITION

IBTA INTERNATIONAL BRAIN TUMOUR ALLIANCE

IKCC International Kidney Cancer Coalition

MHN Men's Health Network
www.menshealthnetwork.org

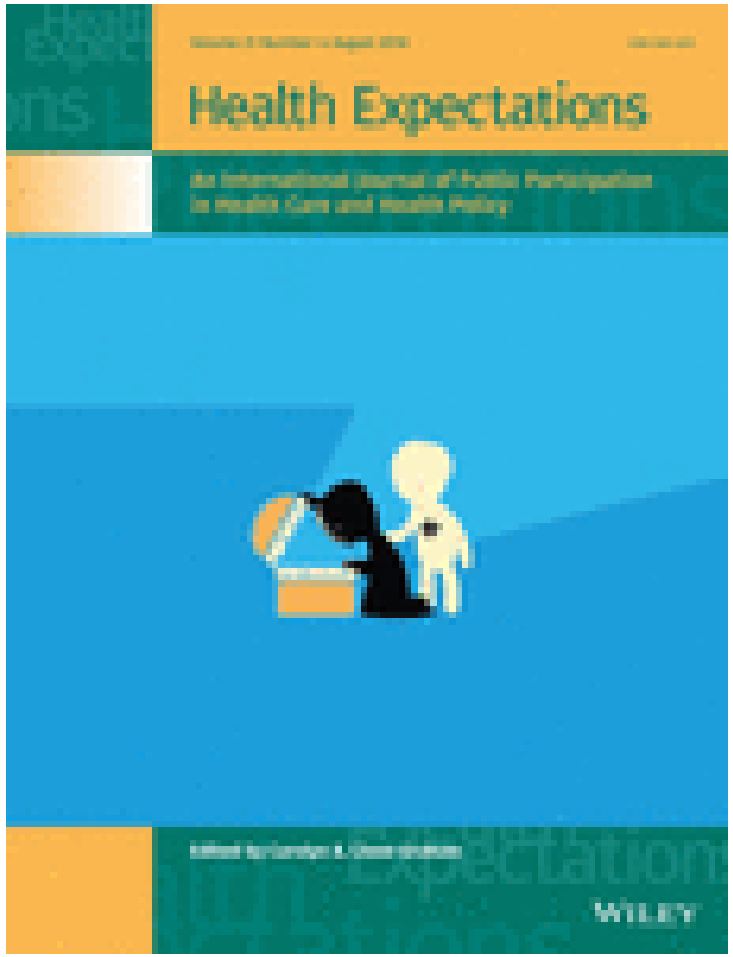
Melanoma Research Alliance

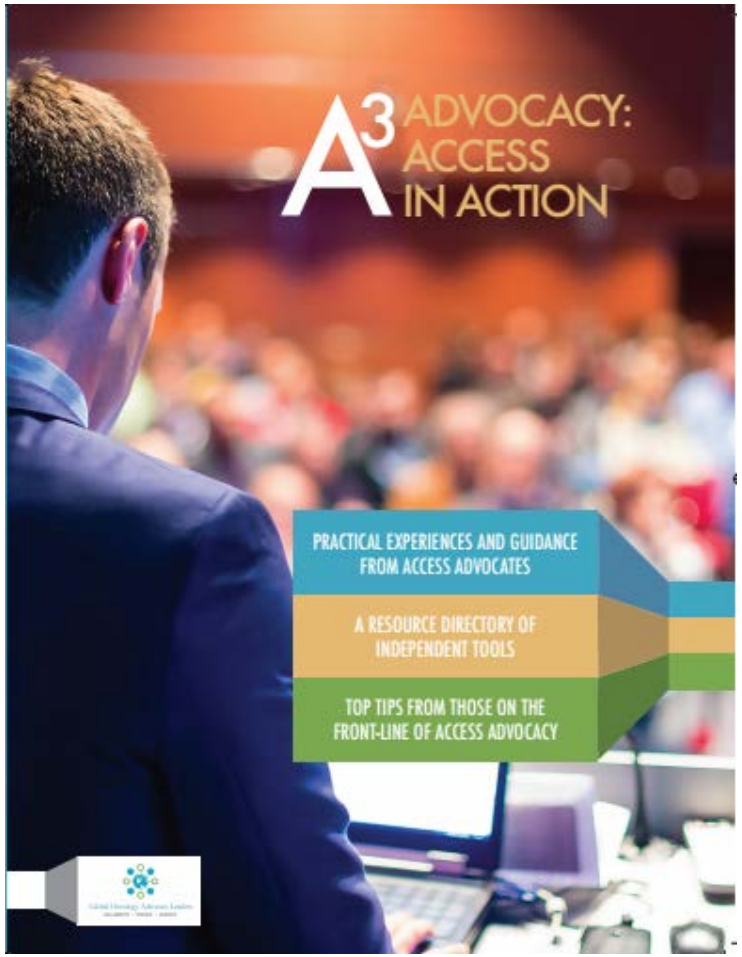
MRF MELANOMA RESEARCH FOUNDATION

MPe Myeloma Patients Europe

Meetings and outputs funded by BMS

GOAL Achievements





Summary

- Patients and patient groups believe that the patient perspective is the basis of good decision making about access to high quality cancer care
- A global approach is needed to ensure equity of access
- GACP is leading the efforts to make this happen

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for Cancer Patients

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for Cancer Patients

The Max Foundation

Global equity in cancer care

Erin Schwartz, VP of Global Engagement

Access to treatment is
access to life!

Global perspective on value

No frameworks about us without us!

- ✓Depends on many individual factors *(age, country, education, family)*
- ✓Changes over time *(prognosis, co-morbidities)*
- ✓About more than just treatment *(quality of life, social support, nursing care)*
- ✓We are not cost-agnostic *(outcomes, out of pocket expenses)*

Listening to patients results in better decision making & outcomes for all

"Patient Value: Perspectives from the Advocacy Community"
Published in Health Expectations, August 2017
Authors: Bonnie Addario, Ana Fadich, Jesme Fox, Linda Krebs, Deborah Maskens, Kathy Oliver, Erin Schwartz, Gilliosa Spurrier-Bernard, Timothy Turnham

Calls to action from global advocates

- **Framework developers:** Broader representation of patient voices
- **Advocacy community:** Strengthen OUR OWN body of evidence
- **Healthcare industry:** Advance methodologies for determining value
- **Decision makers:** Higher value on the patient perspective

It's a big world! How does all this apply to a global organization?

Beyond value frameworks

Patients value…

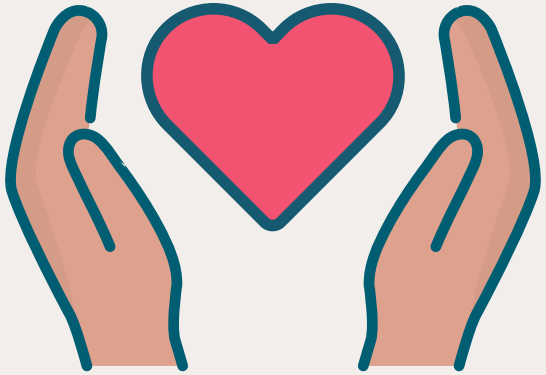
….access to treatment!

Max’s approach, a bridge to treatment

Assist when health systems are unable to by:

treating those who can be treated today

preventing avoidable cancer deaths through



humanitarian access to treatment, care and support

The Max Access Solution (MAS) Model

A patient-centered system of humanitarian access to oncology treatment

WRAPAROUND SUPPORT
A support system around the patient

SHIPPING & DISTRIBUTION
End-to-end validated supply chain

NETWORK OF DOCTORS
An approved network of cancer specialists

DONATED MEDICINE
Procurement of quality targeted treatment

Actions to increase health equity

- ✓ Identify patient leaders & form patient organizations
- ✓ Create opportunities for patient leaders to build capacity
- ✓ Empower physicians to collect data & publish research
- ✓ Gather better data ourselves and publish our own findings
- ✓ **Speak in global forums to represent ALL patients & make our voices heard!**

Together,
let's close
the cancer divide

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Capturing what patients report as important for their cancer care

Jean Mossman

Kuala Lumpur 2 October 2018

EQ-5D-5L

- EQ-5D-5L is a standardised instrument for use as a measure of health outcome
- 5 domains, 5 levels per domain
  - Mobility
  - Self-care
  - Usual activities
  - Pain/discomfort
  - Anxiety/depression
- EQ-5D-5L is used as the basis of cost/QALY calculations
- Sample is the general population

Sample 5 levels: Mobility characteristics

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

Advance HTA Work Package 4: Core research objectives

- To determine whether the preferences towards health related quality of life differ between the general population and defined patient groups, including those benefiting from personalised treatments
- Web-based survey of wide set of patients& caregivers across several countries
- Distribution list built through London School of Economics patient training courses and personal connections
  - 360 Patients, 73 caregivers
  - 257 organisations at national level
  - 24 organisations at European level

Research protocol

- EQ-5D-5L
- Supplementary question asked
  - Are there any aspects of your illness which have had a big impact on your health that were not covered in the interview?
    - If yes, please tell us what they were

Results – Response rate

- Patients
  Surveys started: 1031
  Surveys completed: 767
  Response rate: 74%
- 48 countries

- 11 countries with >10
-

Belgium (1%)
Croatia (2%)
Cyprus (4%)
Denmark (5%)
France (5%)
Germany (1%)
Greece (7%)
Netherlands(4%)
Romania (5%)
Slovenia (2%)
UK (52%)

Methods – Questionnaire design

1. Demographics; age, country of residence, marital status , education and employment status, relationship to the patient

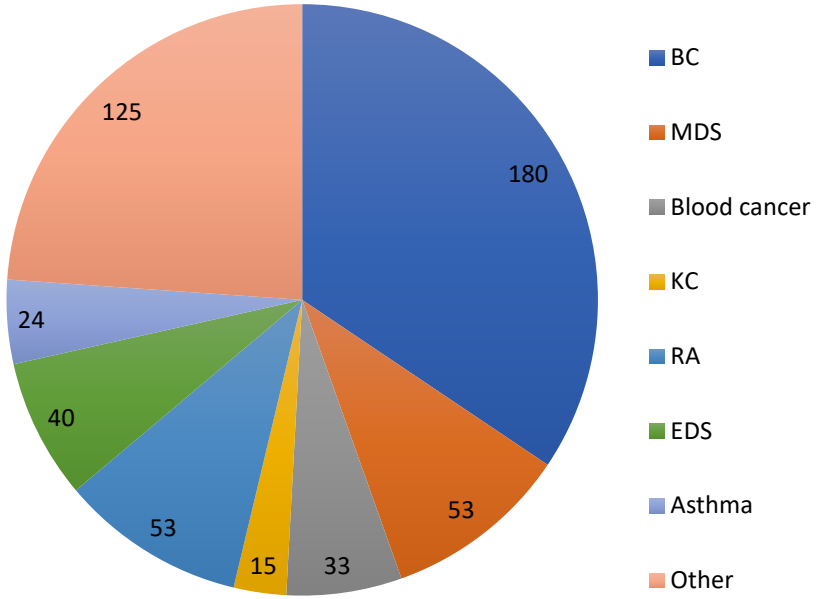
2. Clinical characteristics; disease area, years since diagnosis/provision of care, satisfaction with treatment received

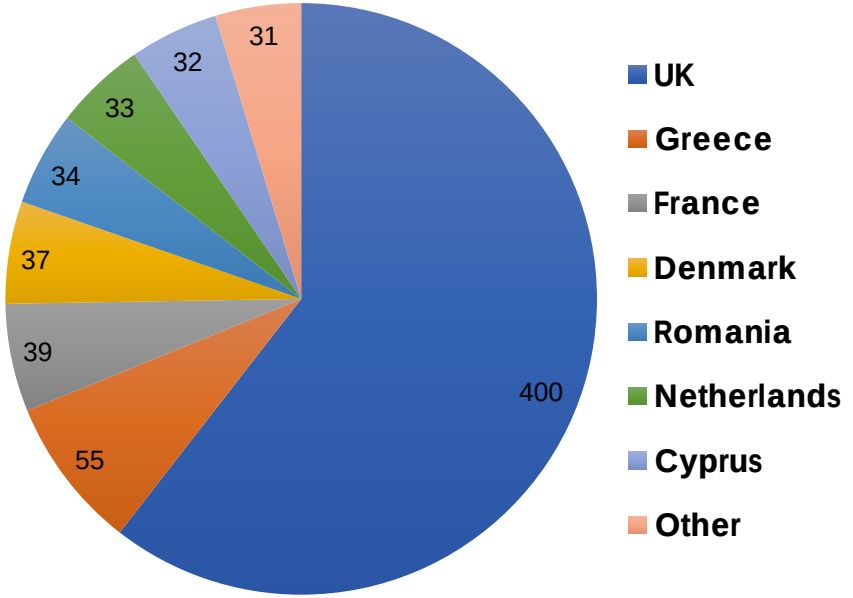
3. EQ-5D-5L Health state utility (EQ-5D-5L), self-perceived health (EQ-5D-5L VAS)

4. Views about important QoL aspects not captured by EQ-5D-5L

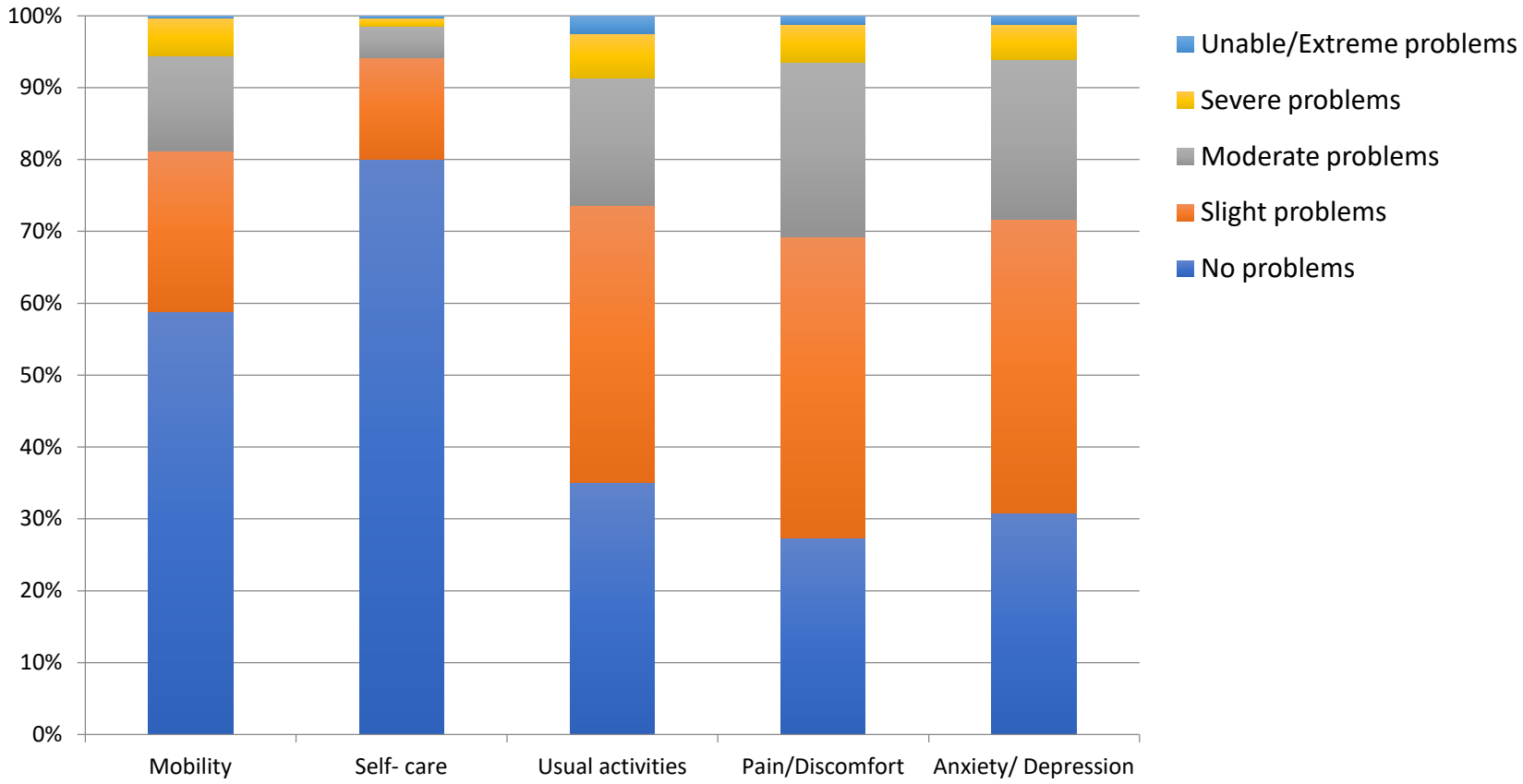
5.Additional QoL dimensions; patients' disability (Barthel Index) and caregivers' emotional burden (Zarit Burden Interview)

Results – Responses





EQ-5D-5L domains

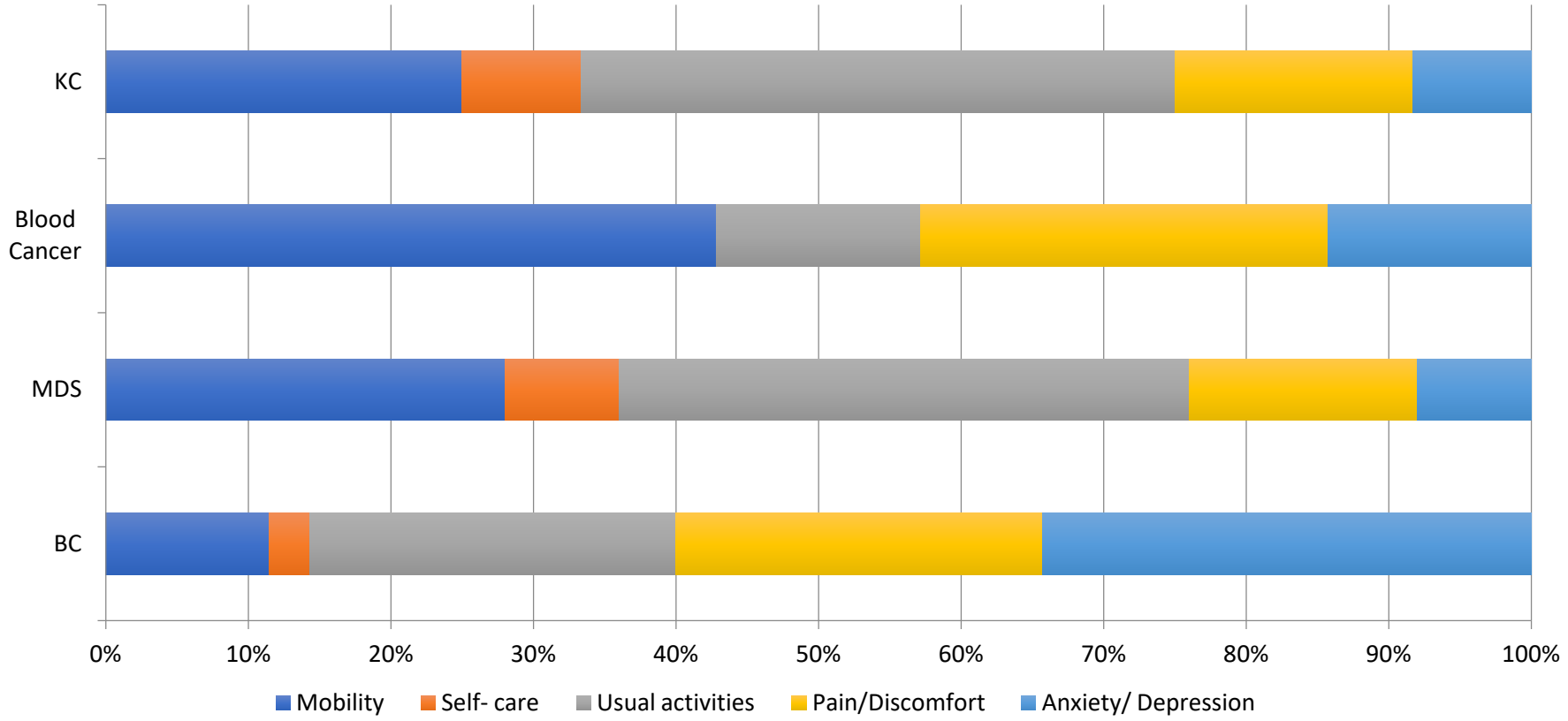


n= 326 (all cancer patients)

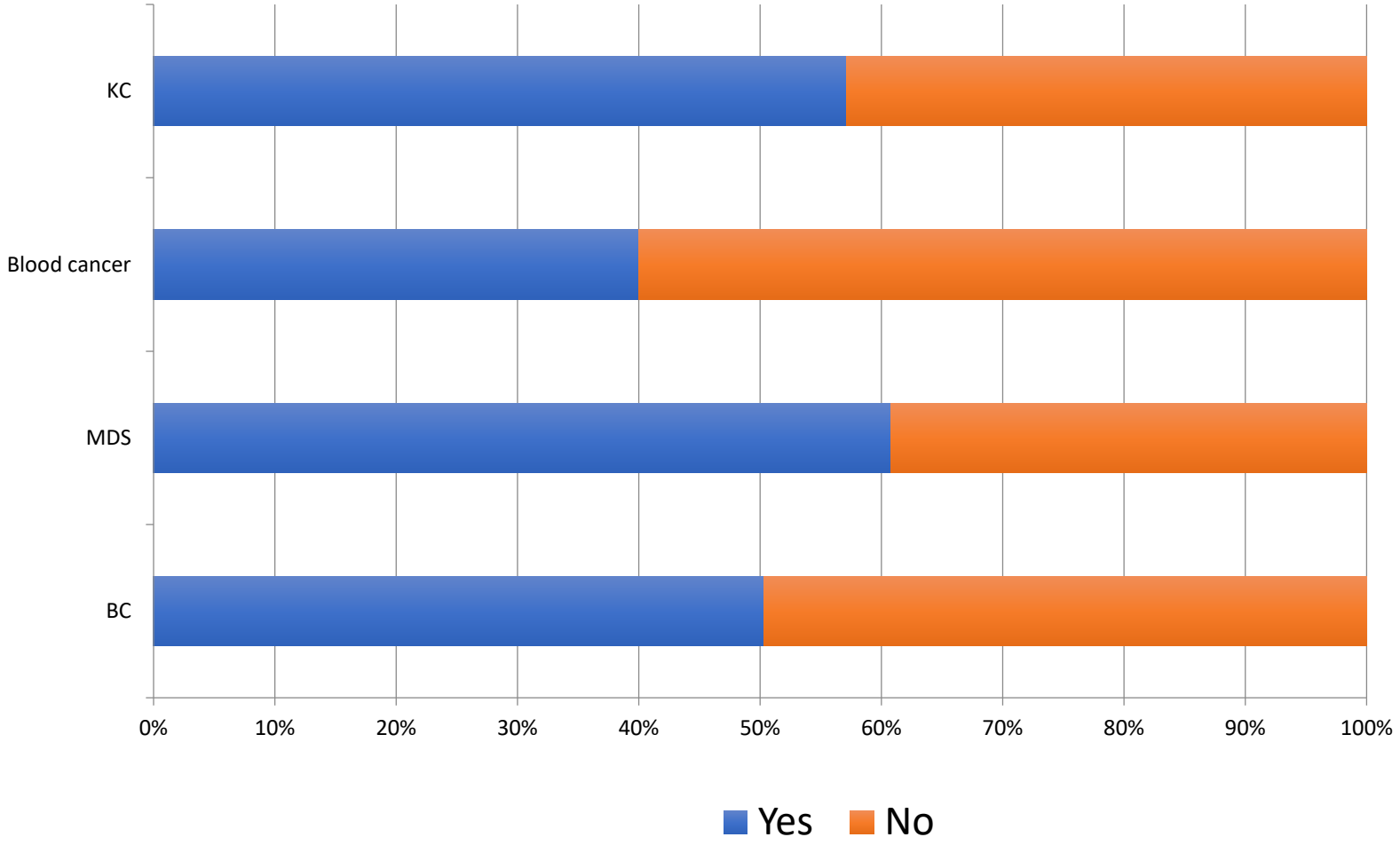
Perfect health scores mostly reported by BC (5.5%) and MDS (12.7%) patients

EQ-5D-5L domains

Proportion of individuals reporting extreme and/or severe problems in each EQ-5D-5L domain:



EQ-5D-5L limitations



"Are there any aspects of your illness, which have had a big impact on your health, that were not captured by the EQ-5D-5L?"

Conclusion

- EQ-5D-5L does not capture everything that patients say is important
  - Only for blood cancers did more than 50% of patients say it captured everything that matters
- If we base cost/QALY calculations on generic measures, may not reflect patient priorities
- Need to extend the research to get robust evidence of the limitations of EQ-5D-5L

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EQ-5D-5L limitations: domains omitted

	Fatigue /Insomnia	Medication SEs	Work limitation & financial issues	Maintenance of relationships /social life	Cognitive problems	Co-morbidities
BC	20%	22.6%	4.8%	4.8%	9.5%	-
MDS	39%	13%	-	3.2%	3.25	-
Blood cancer	20%	10%	-	10%	10%	20%
KC	50%	12.5%	-	12.5%	-	-

Aspects not captured by EQ-5D-5L: Sample Responses

- *“Comorbidities”*
- *“Cost of medication and other treatment. Difficulty with arranging doctor's appointments and appropriate onward referrals”*
- *“Financial stress”*
- *“Concentration”*
- *“Social isolation” “Stigma-Exclusion from Social Life”*
- *“Looking after my children”*
- *“Energy levels, making a contribution to family life, exercise”*
- *“Effects of long term medication, not of initial illness”*
- *“Uncertainty about the future. No distinction between discomfort due to disease and that due to treatment”*
- *“Partnerships and the possibility of raising children”*
- *“Each day is different so taking it for just one day is not indicative of the overall effects”*
- *“Lower self-esteem and self-image related with disabilities, social life, personal relationships”*
- *“Fatigue, and it only measures one day whereas many conditions result in varying abilities across different days”*

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