



# Socioeconomic Impact Analysis

«Towards A More Comprehensive Patient Perspective»

**Linking Research & Policy:**

*A Unique Opportunity for OECD*

*on behalf of the OECD Task Force on Socioeconomic Impact Research*

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[«A Cycle of Poverty»]

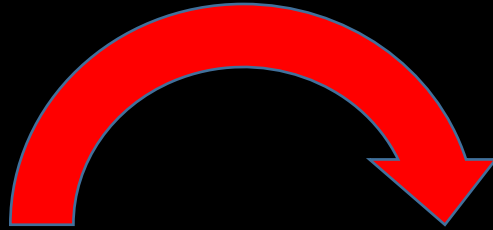
[always?]

Prof. Michael Schlander, MD, PhD, MBA

**OECI Oncology Days 2025**

Athens, Greece – June 12 – 13, 2025

«ex post»



**«Cancer and Poverty»**

[«A Cycle of Poverty»]

**[always?]**

Our Focus Today

Prof. Michael Schlander, MD, PhD, MBA

**OECI Oncology Days 2025**

Athens, Greece – June 12 – 13, 2025

# OECD Task Force Socioeconomic Impact Research

## Membership

### **Netherlands Cancer Institute**

(NKI-AVL), *The Netherlands*

**Wim van Harten** (*TF Co-Chair*), **Valesca Retèl**, Nora Franzen, Julie Vancoppenolle

Centre Henri Becquerel, *France*

Artus Paty, Thomas Vermeulin

Institut Curie Paris, *France*

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Humanitas Research Hospital (IRCCS),  
*Italy*

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Instituto Catalán de Oncología, *Spain*

Olaya Seoane, Agustín Escobedo, Sandra Foix

Hospital de Braga, *Portugal*

João Porfírio Oliveira

Klinika za tumore Klinicki bolnicki centar  
Sestre milosrdnice, *Croatia*

Iva Kirac

Former Minister of Health, *Croatia*

Sinisa Varga

University of Oslo, Institute of Health  
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Eline Aas

Oslo University Hospital, *Norway*

Sigbjørn Smeland

King's College London, *England*

Richard Sullivan

Arturo López Pérez Foundation, *Chile*

Camila Quirland Lazo, Felipe Maza,  
Jeanette Alejandra Fuentes

Haus der Krebshilfe, *Germany*

Bernd Crusius

**German Cancer Research Center  
(DKFZ) / Health Economics, *Germany***

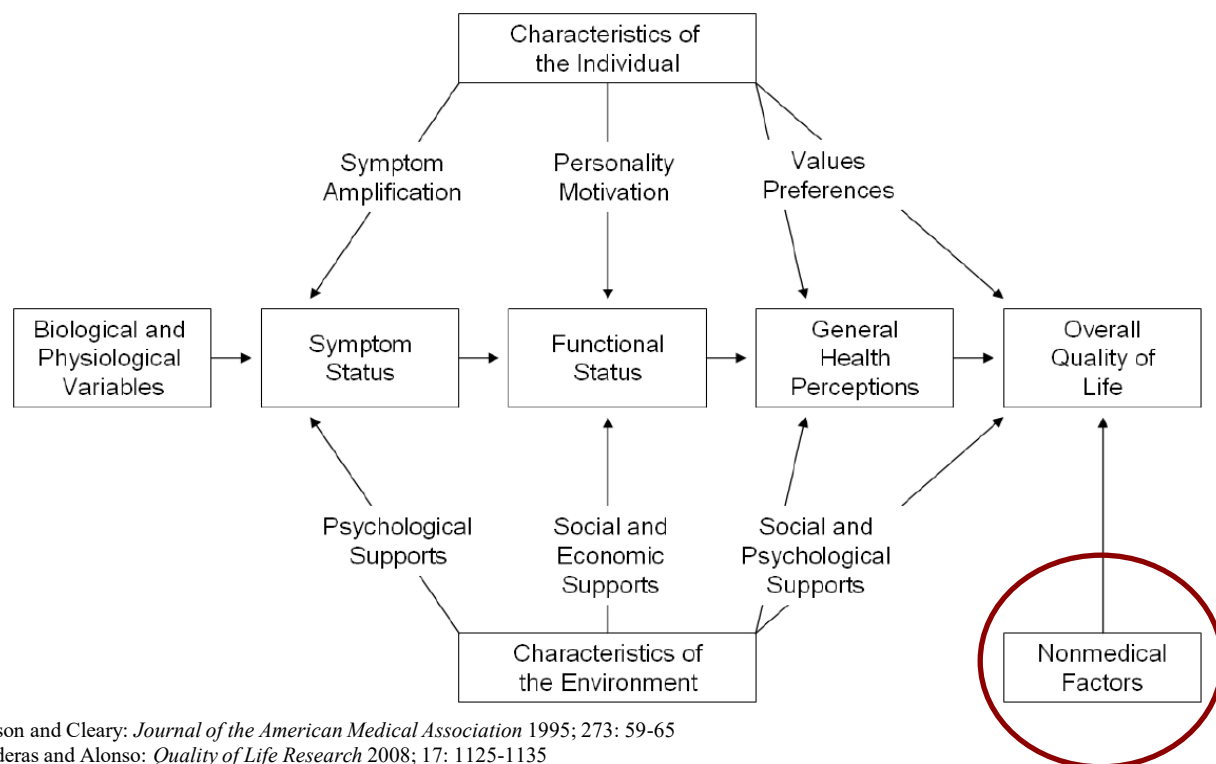
**Michael Schlander** (*TF Chair*), Karla Hernandez-Villafuerte, Diego Hernandez-Careno,  
**Rachel Eckford**, Phu Duy Pham, Jasper Ubels

## Narrow Focus: What About «Nonmedical Factors»?

### The Traditional Perspective on PROs

Wilson and Cleary (1995)<sup>1</sup>

=> *far-reaching de facto exclusion of non-health-related outcomes*



<sup>1</sup>Wilson and Cleary: *Journal of the American Medical Association* 1995; 273: 59-65

<sup>2</sup>Valderas and Alonso: *Quality of Life Research* 2008; 17: 1125-1135

# OECD Task Force Socioeconomic Impact Research

## Initial Working Hypothesis /

followed by a Best Fit Framework Synthesis Subproject

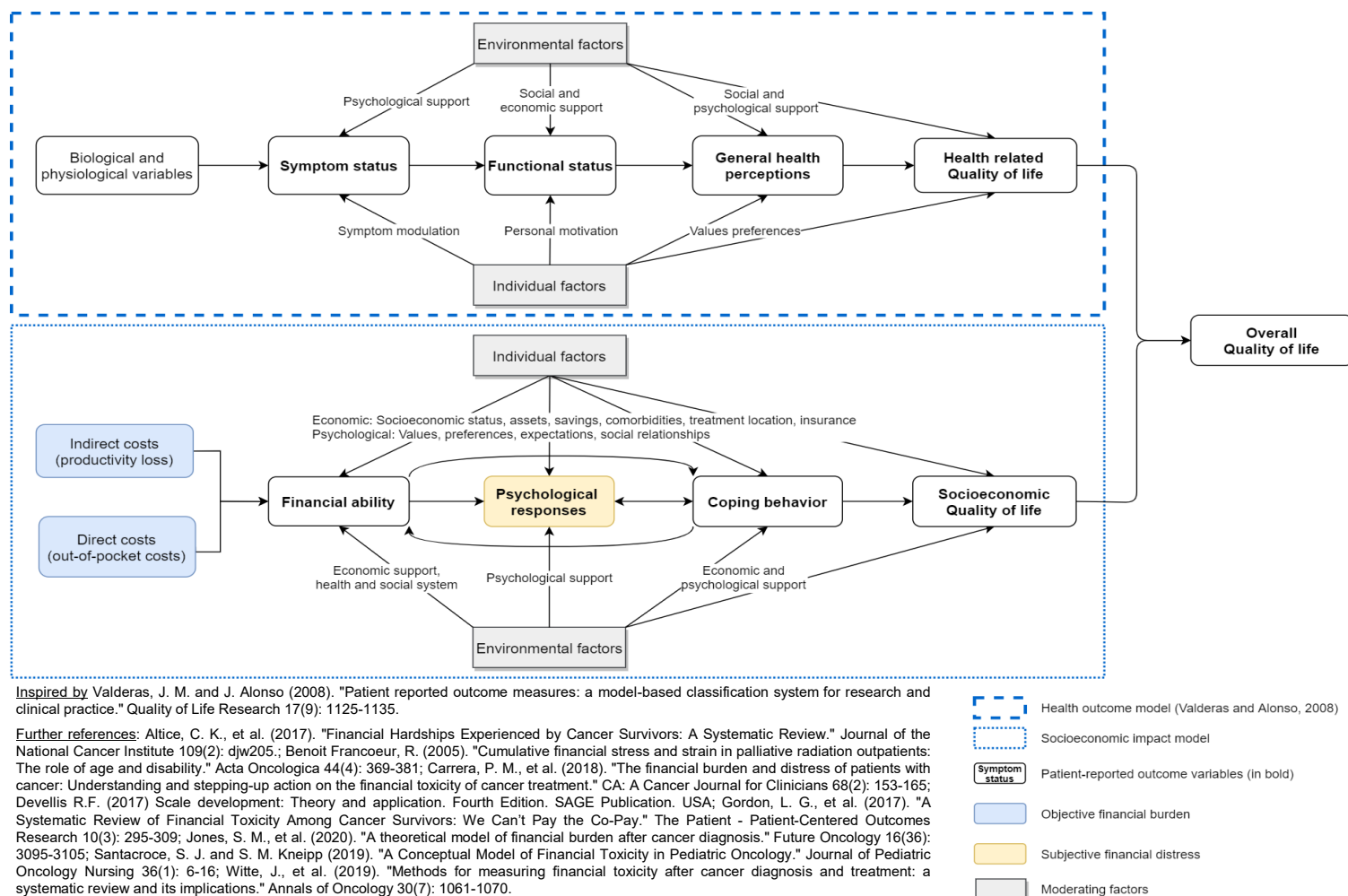
### Health-Related Outcomes

[e.g., Health-Related QoL in the extra-welfarist tradition of health economics]

### Socioeconomic Outcomes

[by design largely neglected by most traditional PRO measurement instruments]

Note role of *ex ante* socioeconomic status as a moderator of outcomes



# «Financial Toxicity»: A Narrow Definition<sup>1</sup>

## National Cancer Institute (NCI):

Problems a **patient** has related to the **cost of medical care** such as not having health insurance or having a lot of costs for medical care not covered by health insurance can cause financial problems and may lead to debt and bankruptcy.

Financial toxicity can also affect a patient's **quality of life** and access to medical care. For example, a patient may not take a prescription medicine or may avoid going to the doctor to save money.

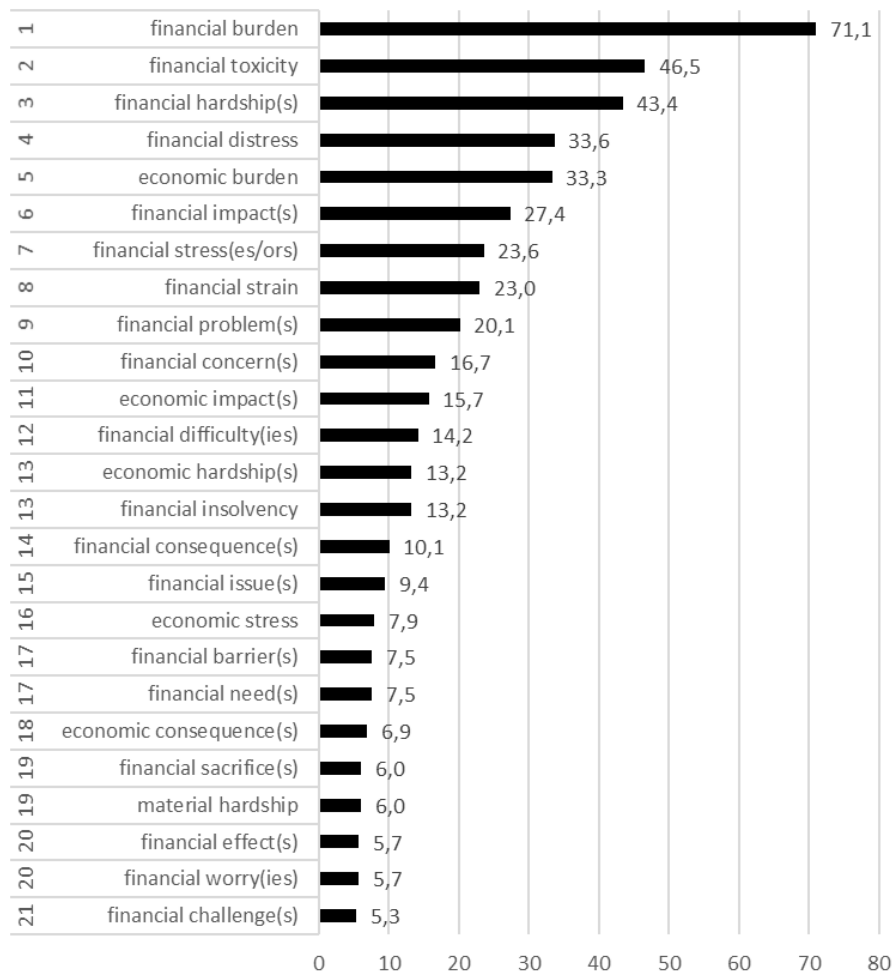
1. adopting the perspective of patients
2. what about impact of/on relatives (caregivers, dependents, etc.)

1. focus on “out-of-pocket” (oop) costs, i.e., direct medical & non-medical costs from the perspective of patients
2. what about income loss, i.e., indirect costs from the perspective of patients

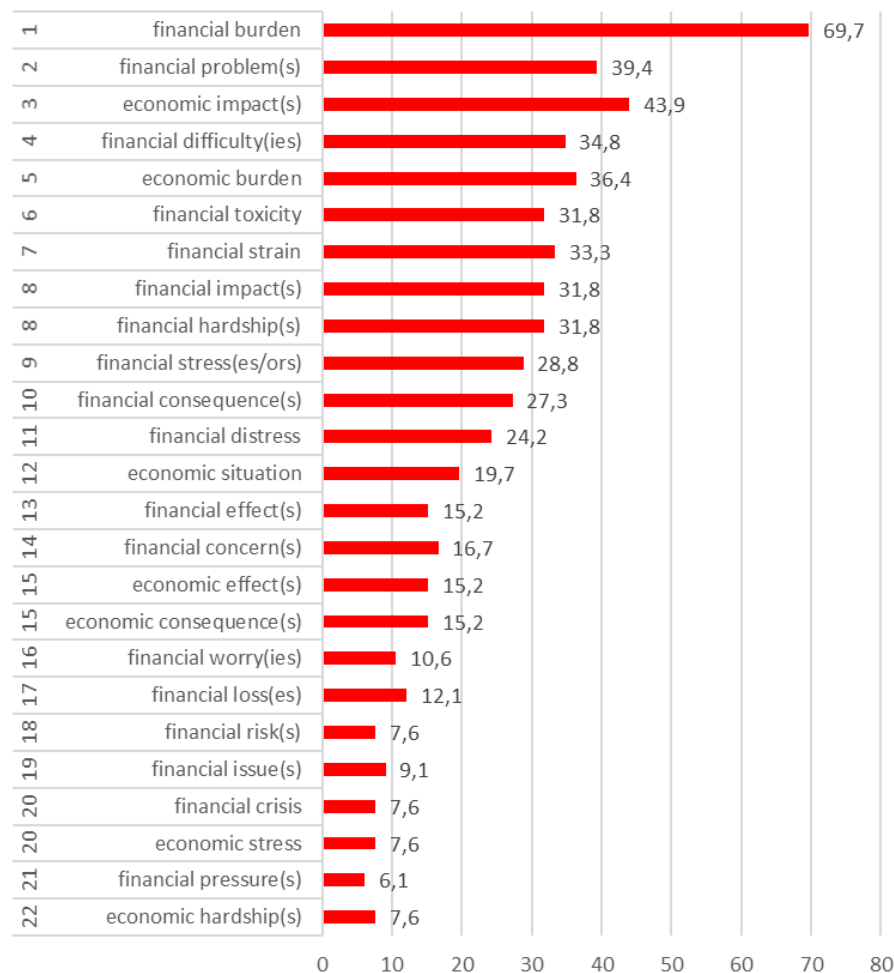
1. reflecting the traditional focus on (presumably “health-related”) quality of life
2. what about other constructs (and their valuation), capturing the full range of “intangible costs” incurred by patients (such as capabilities / functional status, health perceptions, psychological well-being / distress, social networks, life satisfaction, etc.)

# «Financial Toxicity» / Inconsistent Use of Terminology

A. United States



B. Europe





## «Financial Toxicity» / Inconsistent Use of Terminology

- **Cancer patients from European countries report different levels of the financial burden**
  - Co-payments, sickness benefits, work flexibility, public provision of caregiving
  - There is a need for a better understanding of coping behaviors
- **No consensus on a “financial burden threshold”**
  - A consensus on when a family should be considered to be suffering from a worrying level of financial burden is required to establish effective policies
- **Methodology, terminology, and definitions vary considerably**
  - Variations hinder policy-makers and stakeholders from using the vast amount of information available to inform policies and actions
  - There is a need for a tool that allows classification of the current and future literature and that brings order to the topic
  - Such a tool should be based on a conceptual framework that reflects present knowledge and can be adapted to the needs of the health systems

## Task Force Objectives

### To Support Future Socioeconomic Impact Research in Europe

#### – Rationale:

- Need to better understand the extent of the problem, including predictors and moderators of **vulnerability** of patients (and their relatives), such as
  - Individual factors (e.g., personal values, preferences, general perceptions)
  - Environmental and social factors (e.g., psychological and economic support)
  - Characteristics of the respective health and social security system
  - Access to, as well as organization, location, and modality of medical care
- Research to date in Europe has been heterogeneous,
  - characterized by inconsistent use of terminology
  - impaired by a shortage of validated instruments
  - lacking a coherent and comprehensive conceptual framework

### Rationale, Objectives, and Anticipated Outcomes

#### — Objectives:

- To fill the gap in standards and guidance for studies exploring the socioeconomic impact of cancer and cancer care on patients and their relatives;
- To reduce or eliminate the risk of wasted research efforts due to redundant, overlapping, and incomparable work owing to unnecessarily heterogeneous use of terms and definitions, and
- To support and facilitate further research in the field, including a potential platform for future collaborative projects by members of the Task Force,
- such as, but not limited to, the pan-European OECD / NKI SEC Trial

### «Socioeconomic Impact» – An Integrated Framework

#### *Defining Output of Task Force:*

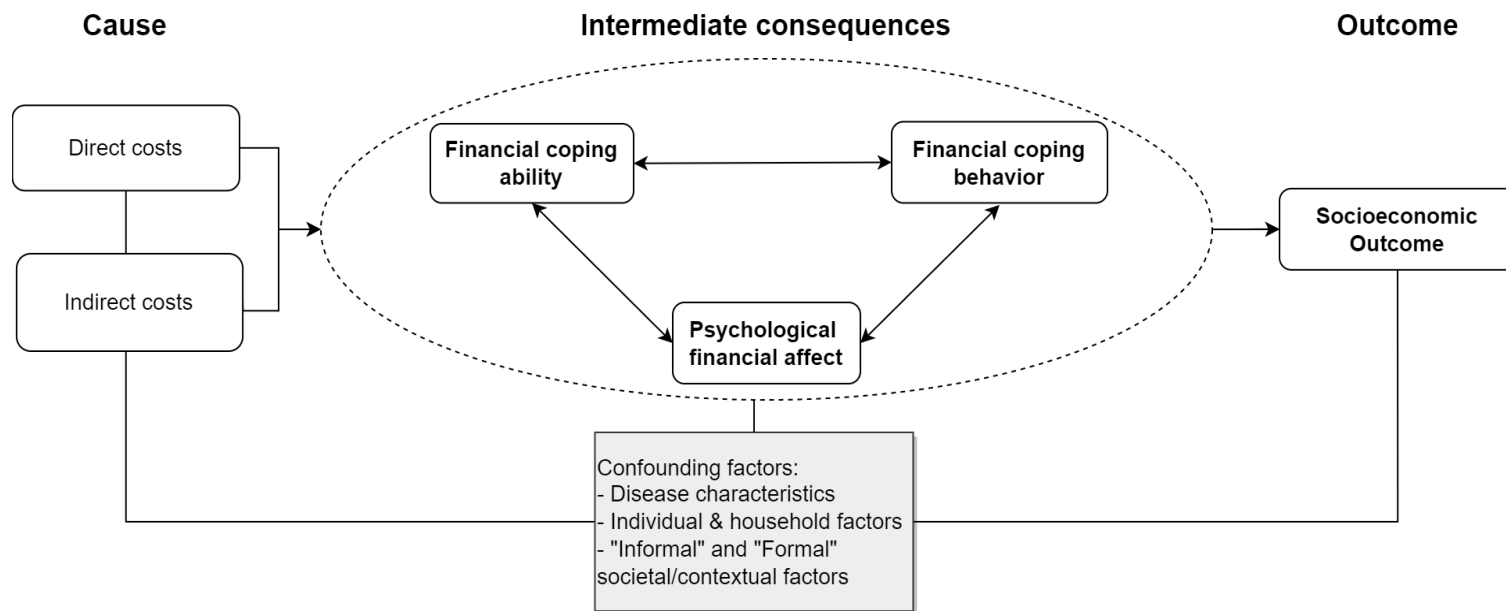
**The socioeconomic impact of cancer on patients and their relatives: Organisation of European Cancer Institutes task force consensus recommendations on conceptual framework, taxonomy, and research directions**

*Michael Schlander\*, Wim van Harten†, Valesca P Retèl, Phu Duy Pham, Julie M Vancoppenolle, Jasper Ubels, Olaya Seoane López, Camila Quirland, Felipe Maza, Eline Aas, Bernd Crusius, Agustín Escobedo, Nora Franzen, Jeanette Fuentes-Cid, Diego Hernandez, Karla Hernandez-Villafuerte, Iva Kirac, Artus Paty, Thierry Philip, Sigbjørn Smeland, Richard Sullivan, Elena Vanni, Sinisa Varga, Thomas Vermeulin, Rachel D Eckford*

*The Lancet Oncology 25 (2024) e152-e163*

## Proposed General Framework

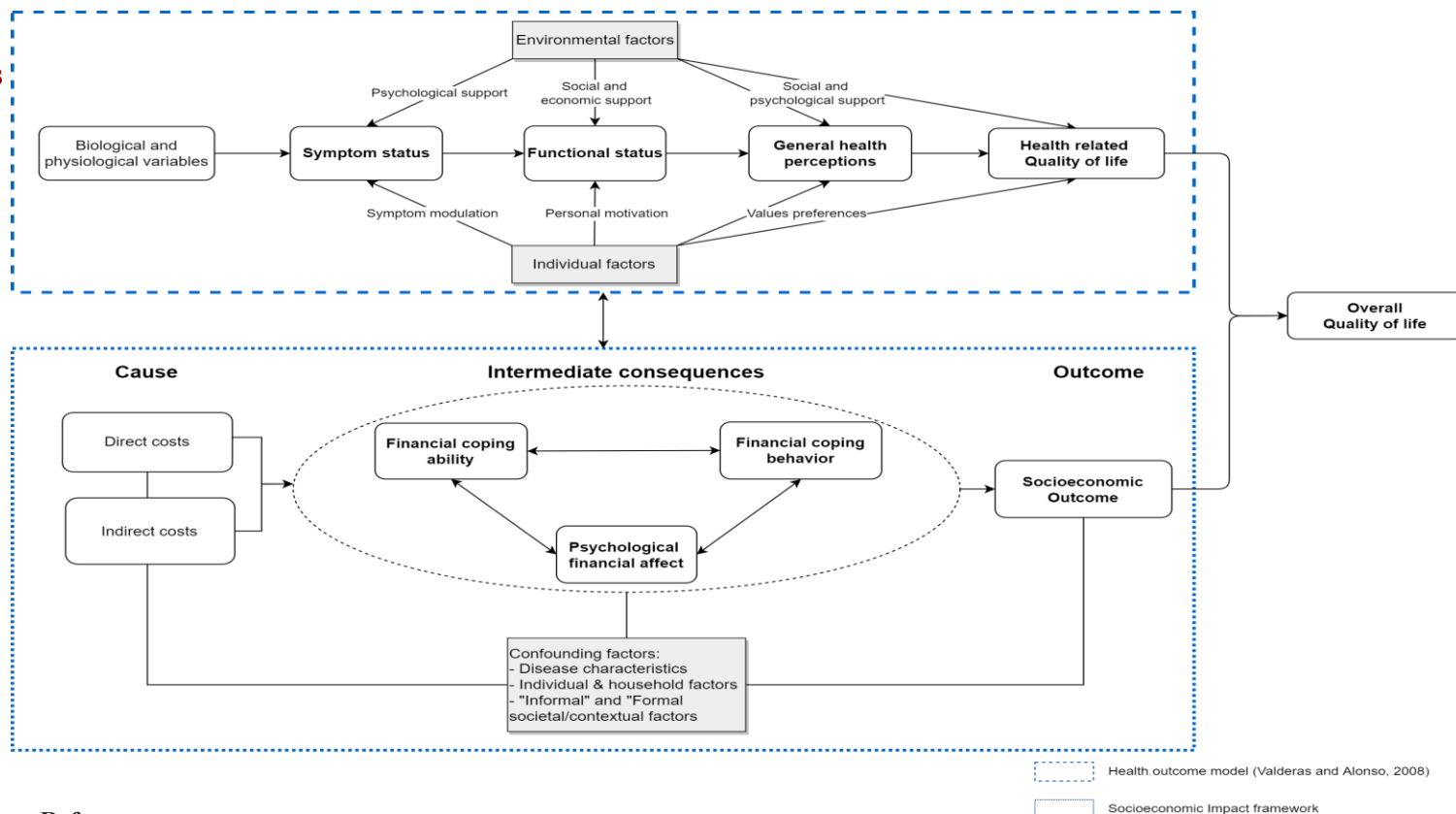
### Causes and Outcomes



## Integration Framework

### Health-Related Outcomes

[e.g., Health-Related QoL in the extra-welfarist tradition of health economics]



### Reference:

Valderas JM, Alonso J. Patient reported outcome measures: a model-based classification system for research and clinical practice. Qual Life Res. 2008 Nov; 17 (9): 1125-35. doi: 10.1007/s11136-008-9396-4. Epub 2008 Oct 3. PMID: 18836850.

## The European SEC Study<sup>1</sup>

### – Primary Objective

- To explore the socio-economic consequences for patients resulting from cancer diagnosis in European countries

### – Secondary Objectives

- To measure the relation between the FIT (& subscales) score per residence country
- To measure the relation between the FIT (& subscales) score and cancer category
- To measure the relation of the FIT (& subscales) score to socio-economic demographics of the patients

<sup>1</sup>J. Vancoppenolle, N. Franzen, L. Azarang, T. Juslin, M. Krini, T. Lubbers, J. Mattson, D. Mayeur, R. Menezes, J. Schmitt, F. Scotte, O. Seoane Lopez, T. Skaali, J. Ubels, M. Schlander, V. Retel, W. van Harten, OECD Working Group Health Economics

## The European SEC Study<sup>1</sup>

### – The Financial Index of Toxicity («FIT») Instrument

- Initially believed to be the most suitable instrument in the European setting
- Focus on psychological and practical elements of financial toxicity
- Score between 0 (lowest toxicity) and 100 (highest toxicity)
- Measuring **three domains**:

Financial stress score
<ul style="list-style-type: none"> <li>• Inability to pay for <b>food, housing of medication</b></li> </ul>

Financial strain score
<ul style="list-style-type: none"> <li>• <b>Satisfaction</b> of financial situation</li> <li>• <b>Worrying</b> about financial situation</li> <li>• Financial situation when young</li> <li>• <b>Borrowing</b> money for treatment related expenses</li> </ul>

Lost productivity score
<ul style="list-style-type: none"> <li>• <b>Quitting of job</b> patient</li> <li>• Quitting of job <b>caregiver</b></li> </ul>

<sup>1</sup>J. Vancoppenolle, N. Franzen, L. Azarang, T. Juslin, M. Krini, T. Lubbers, J. Mattson, D. Mayeur, R. Menezes, J. Schmitt, F. Scotte, O. Seoane Lopez, T. Skaali, J. Ubels, M. Schlender, V. Retel, W. van Harten, OECD Working Group Health Economics



## The European SEC Study<sup>1</sup>

### – Survey Design

- **41 items**
- **Topics covered**
  - Sociodemographic variables
    - Age, country, education, type of cancer & treatment
  - Financial Index of Toxicity (FIT score) & consequences
    - General and subscale scores
    - Loss of income & household income
    - Additional treatment related expenses
    - Employment status before & after diagnosis
- **Coping behaviors among patients**
  - Delay in doctor visits, not or partly fill prescriptions
- **Health-related quality of life**
  - EQ-5D questionnaire
- **Translated in 16 languages**

<sup>1</sup>J. Vancoppenolle, N. Franzen, L. Azarang, T. Juslin, M. Krini, T. Lubbers, J. Mattson, D. Mayeur, R. Menezes, J. Schmitt, F. Scotte, O. Seoane Lopez, T. Skaali, J. Ubels, M. Schlander, V. Retel, W. van Harten, OECD Working Group Health Economics

## The European SEC Study<sup>1</sup>

### – Respondents

#### – Inclusion criteria

- All cancer patients that have been/are treated with systemic therapy and/or invasive surgery
- Max. 2 years after treatment
- Living in European country

#### – Distribution of questionnaire

- Hospitals
  - Pseudo-anonymous or Anonymous pathway
  - Ethical committee approval
- Patient organizations
  - Anonymous pathway

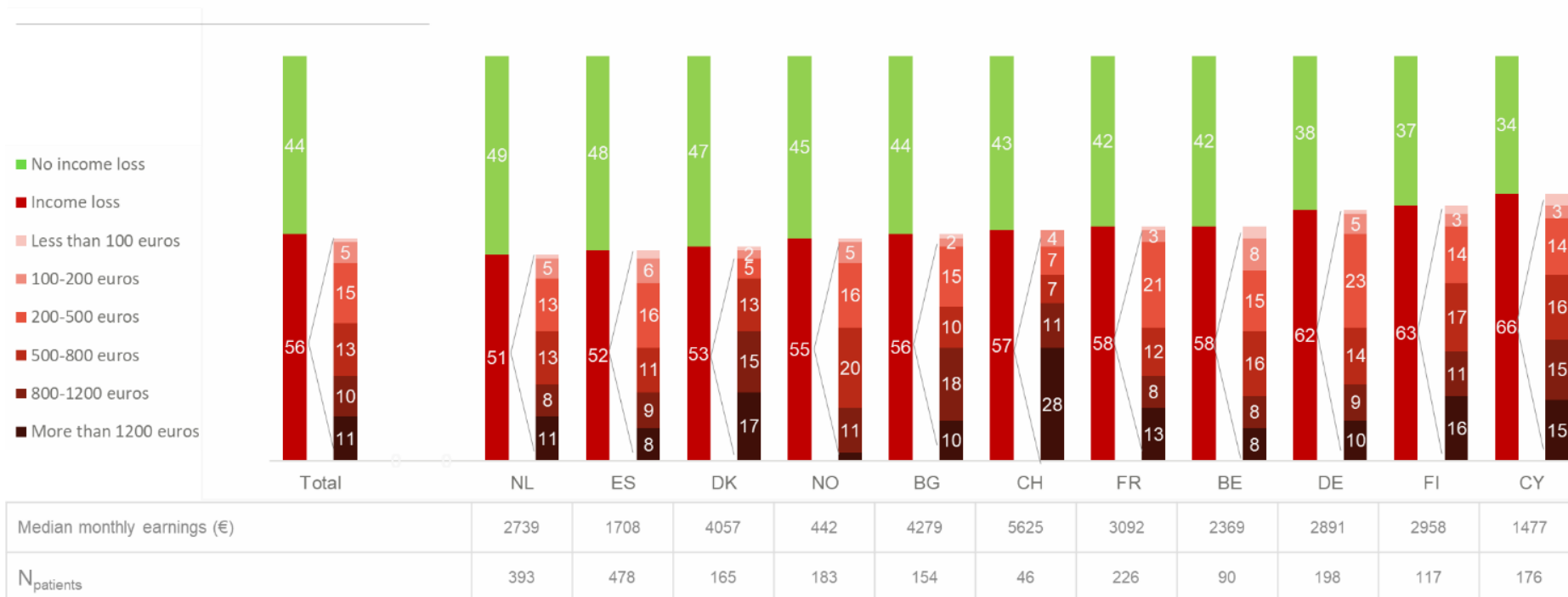
#### – Participation / evaluable questionnaires

- N=2507 (ES, 520; NL, 413; F, 241; D, 208; BG, 201;...)
- hereof, female 1832 (73.1%); breast cancer, 1181 (47.1%)

<sup>1</sup>J. Vancoppenolle, N. Franzen, L. Azarang, T. Juslin, M. Krini, T. Lubbers, J. Mattson, D. Mayeur, R. Menezes, J. Schmitt, F. Scotte, O. Seoane Lopez, T. Skaali, J. Ubels, M. Schlender, V. Retel, W. van Harten, OECD Working Group Health Economics

## The European SEC Study<sup>1</sup>

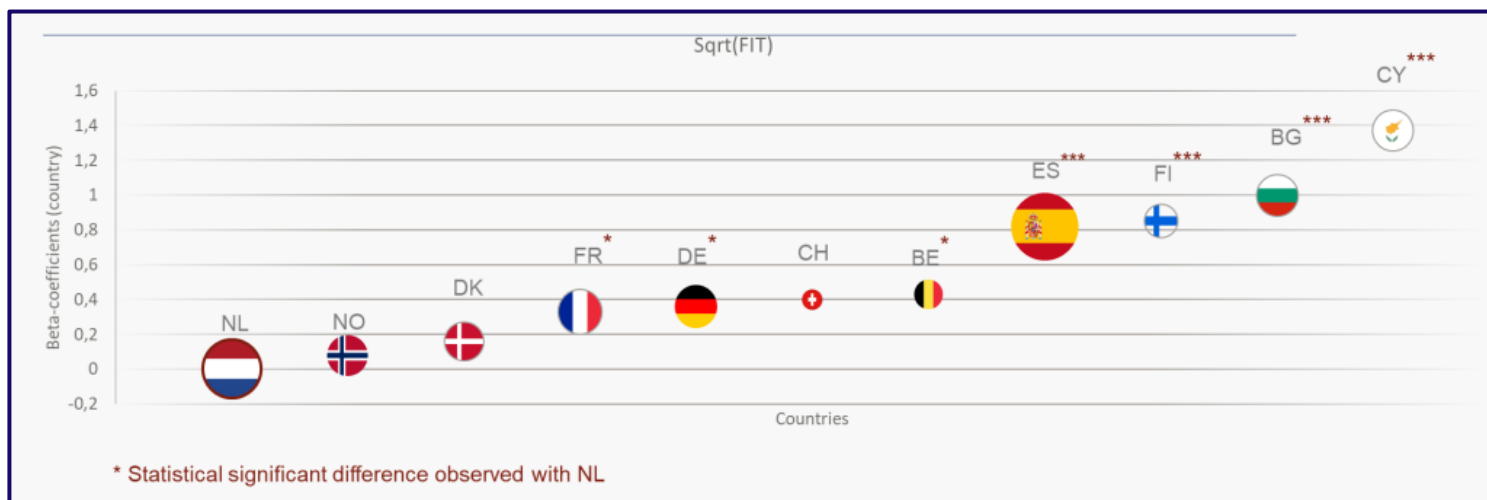
Income loss and its severity (%), total N=2281



<sup>1</sup>J. Vancoppenolle, N. Franzen, L. Azarang, T. Juslin, M. Krini, T. Lubbers, J. Mattson, D. Mayeur, R. Menezes, J. Schmitt, F. Scotte, O. Seoane Lopez, T. Skaali, J. Ubels, M. Schlender, V. Retel, W. van Harten, OECD Working Group Health Economics

## The European SEC Study<sup>1</sup>

Association between the patients' country of residence  
and the overall Financial Index of Toxicity (FIT) scores:



<sup>1</sup>J. Vancoppenolle, N. Franzen, L. Azarang, T. Juslin, M. Krini, T. Lubbers, J. Mattson, D. Mayeur, R. Menezes, J. Schmitt, F. Scotte, O. Seoane Lopez, T. Skaali, J. Ubels, M. Schlander, V. Retel, W. van Harten, OECD Working Group Health Economics

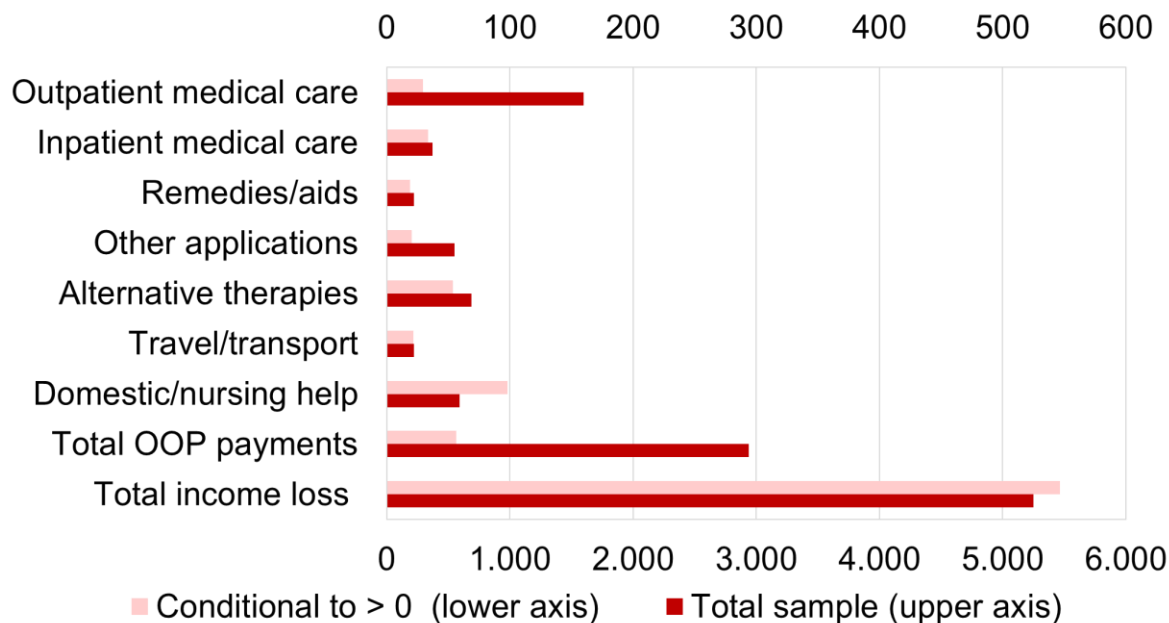
## Primary Results at a Glance: The European SEC Study<sup>1</sup>

- A multinational study to explore the socio-economic impact and financial toxicity among patients with cancer across Europe.
- 56% of patients suffered from income loss and 86% reported additional treatment-related expenses.
- 16% of patients delayed or avoided medical visits, buying medication, surgery or other health services.
- Divorced, self-employed, younger patients and patients with children are especially vulnerable for financial toxicity after a cancer diagnosis.
- In every EU country, a substantial number of patients with cancer report serious financial consequences and stress.

<sup>1</sup>J. Vancoppenolle, N. Franzen, L. Azarang, T. Juslin, M. Krini, T. Lubbers, J. Mattson, D. Mayeur, R. Menezes, J. Schmitt, F. Scotte, O. Seoane Lopez, T. Skaali, J. Ubels, M. Schlander, V. Retel, W. van Harten, OECD Working Group Health Economics

## Income Loss and Out-of-Pocket Expenditures<sup>1</sup> [Breast Cancer Survivors]

For the study, we used data from 2,654 long-term breast cancer survivors in Germany that participated in the population-based CAESAR study and who were at least five years post-diagnosis.<sup>1</sup>



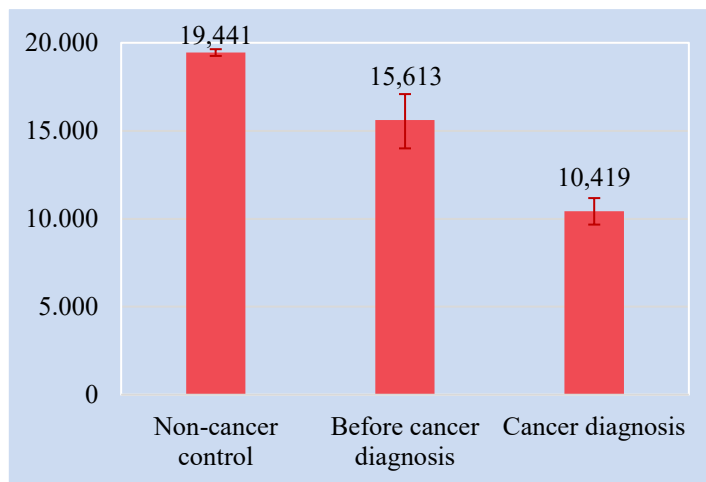
<sup>1</sup>J. Schneider; D. Hernandez; CAESAR Study Group; M. Schlander; V. Arndt. Out-of-pocket payments and loss of income among long-term breast cancer survivors in Germany: A multi-regional population-based study. *Journal of Cancer Survivorship* 2023; 17 (6): 1639-1659.

# Socioeconomic Impact of Cancer: German Data (II)

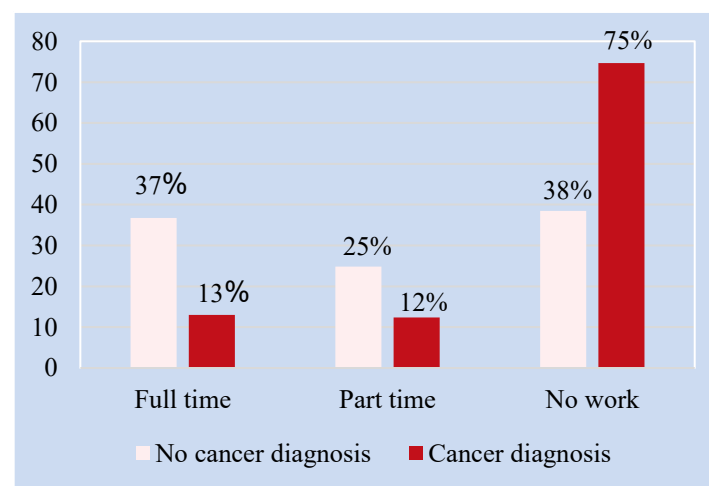
## Income Loss Associated with a Cancer Diagnosis<sup>1</sup>

For the study, we analyzed data from the **Socio-Economic Panel (SOEP)**, consisting of approximately 20,000 individuals, who are traced annually.<sup>1</sup>

**Job Income Average [€ 2016]**



**Work Status (Period from 2009 – 2015)**



<sup>1</sup>D. Hernandez and M. Schlander. Income loss after a cancer diagnosis in Germany: An analysis based on the socio-economic panel survey. *Cancer Medicine* 2021; 10 (11): 3726-3740.

## Validity of SEI Measurement Instruments (Analysis)<sup>1</sup>

### — Background

- Multiple patient-reported outcome (PRO) instruments—e.g., COST, FIT, PROFFIT—have been developed to measure SEI; a standardized comparison of their quality and alignment with comprehensive SEI frameworks is lacking.

### — Objectives

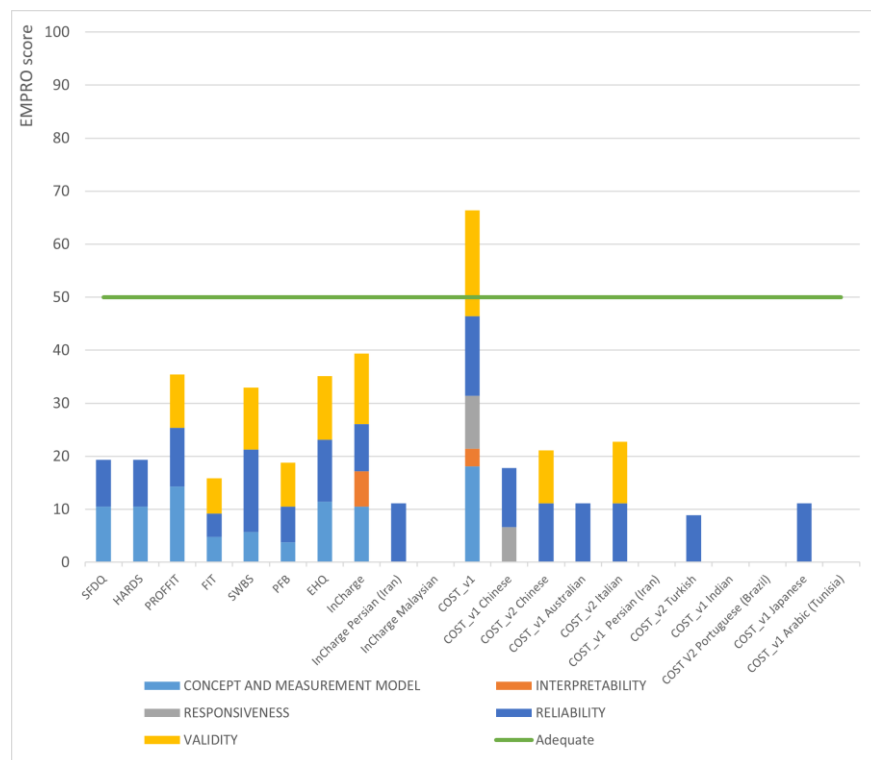
- To evaluate the quality of existing PRO instruments measuring the SEI of cancer using the EMPRO tool.
- To assess the content validity of these instruments by mapping their items to the OECD conceptual framework<sup>2</sup> for SEI analysis.

<sup>1</sup>P.D. Pham, J. Ubels, R. Eckford, M. Schlander: Measuring the Socioeconomic Impact of Cancer: A Systematic Review and Standardized Assessment of Patient-Reported Outcomes (PRO) Instruments. *PharmacoEconomics Open* (2025)

<sup>2</sup>M. Schlander, et al. (2024). The socioeconomic impact of cancer on patients and their relatives: Organisation of European Cancer Institutes task force consensus recommendations on conceptual framework, taxonomy, and research directions. *The Lancet Oncology*, 25 (4), e152–e163



## Validity of SEI Measurement Instruments (Analysis)<sup>1</sup>



**Overall EMPRO and attribute scores of included instruments.** Instruments without scores lacked sufficient information.

Abbreviations: COST = Comprehensive Score for Financial Toxicity; EHQ = Economic Hardship Questionnaire; EMPRO = Evaluating the Measurement of Patient-Reported Outcomes; FIT = Financial Index of Toxicity; HARDS = Hardship and Recovery with Distress Survey; IFDFW = InCharge Financial Distress/Well-being; PFB = Personal Financial Burden; PROFFIT = Patient-Reported Outcome for Fighting Financial Toxicity; SFDQ = Subjective Financial Distress Questionnaire; SWBS = Socioeconomic Well-being Scale; v = version.

### EMPRO Assessment Results

- COST scored highest (66.4/100) and was the only instrument with “acceptable” threshold.
- InCharge ranked second (39/100), far short of the benchmark.
- Several instruments (PROFFIT, EHQ, SFDQ) scored moderately on select attributes.
- No instrument covered all attributes comprehensively.

# Socioeconomic Impact Research: Further Insights

## SEI Measurement Instrument Analysis<sup>1</sup>

Instrument name	Relevant theme(s) covered	Themes <b>not</b> covered
<b>Comprehensive Score for financial Toxicity (COST)</b>	Financial coping ability; Psychological financial response; Indirect costs	Direct costs; Financial coping behavior; Confounding factors
<b>InCharge - Financial Wellbeing Scale</b>	Psychological financial response; Financial coping ability; Financial coping behavior	Direct costs; Indirect costs; Confounding factors
<b>Financial Index of Toxicity (FIT)</b>	Psychological financial response; Financial coping ability; Financial coping behavior; Indirect costs	Direct costs; Confounding factors
<b>Socioeconomic well-being scale (SWBS)</b>	Financial coping ability; Confounding factors; Psychological financial response	Direct costs; Indirect costs; Financial coping behavior
<b>Economic Hardship Questionnaire (EHQ)</b>	Financial coping behavior; Psychological financial response; Financial coping ability	Direct costs; Indirect costs; Confounding factors
<b>The Hardship And Recovery with Distress Survey (HARDS)</b>	Psychological financial response; Financial coping ability, Financial coping behavior	Direct costs; Indirect costs; Confounding factors
<b>Personal Financial Burden (PFB)</b>	Financial coping behavior; Financial coping ability	Direct costs; Indirect costs; Psychological financial response; Confounding factors
<b>Patient-Reported Outcome for Fighting Financial Toxicity (PROFIT)</b>	Financial coping ability; Psychological financial response; Financial coping behavior; Confounding factors; Direct costs	Indirect costs
<b>Subjective Financial Distress Questionnaire (SFDQ)</b>	Psychological financial response; Financial coping ability; Psychological financial response; Indirect costs; Confounding factors	Direct costs

<sup>1</sup>P.D. Pham, J. Ubels, R. Eckford, M. Schlender: Measuring the Socioeconomic Impact of Cancer: A Systematic Review and Standardized Assessment of Patient-Reported Outcomes (PRO) Instruments. PharmacoEconomics Open (2025)

# Socioeconomic Impact Research: Further Insights

## SEI Measurement Instrument Analysis<sup>1</sup>

### – Key Takeaways

- Wide variation exists in the quality and content of instruments measuring the SEI of cancer.
- The COST instrument is the most widely used and scored highest overall, but its applicability outside the U.S. remains limited.
- No instrument fully captures all domains of the OECD SEI framework.
- Many instruments lack sufficient validation data, particularly in non-U.S. settings.
- A standardized, comprehensive PRO instrument is needed to consistently measure SEI and guide policy and interventions.

# Secondary SEC-based Analyses (I)

## Towards a Validated European Instrument<sup>1</sup>

### Our Approach

- Secondary analysis of the SEC study to test the validity of the FIT-instrument in Europe
- Training dataset (random subsample) and full data set

Two models tested:

FIT - model

SEI - model

*Based on the original, Canadian instrument*

Subscales	Items
<b>Financial Stain</b>	1. Satisfaction with finances
	2. Worry about finances
	3. Comparison of finances with others
	7. Borrow money because of cancer treatment
<b>Financial Stress</b>	4. Ability to pay daily living expenses: food
	5. Ability to pay daily living expenses: housing
	6. Ability to pay daily living expenses: medical
<b>Loss of productivity</b>	8. Quit job because of cancer
	9. Caregiver quit job because of cancer

*Mapping FIT items based on the OECD taxonomy*

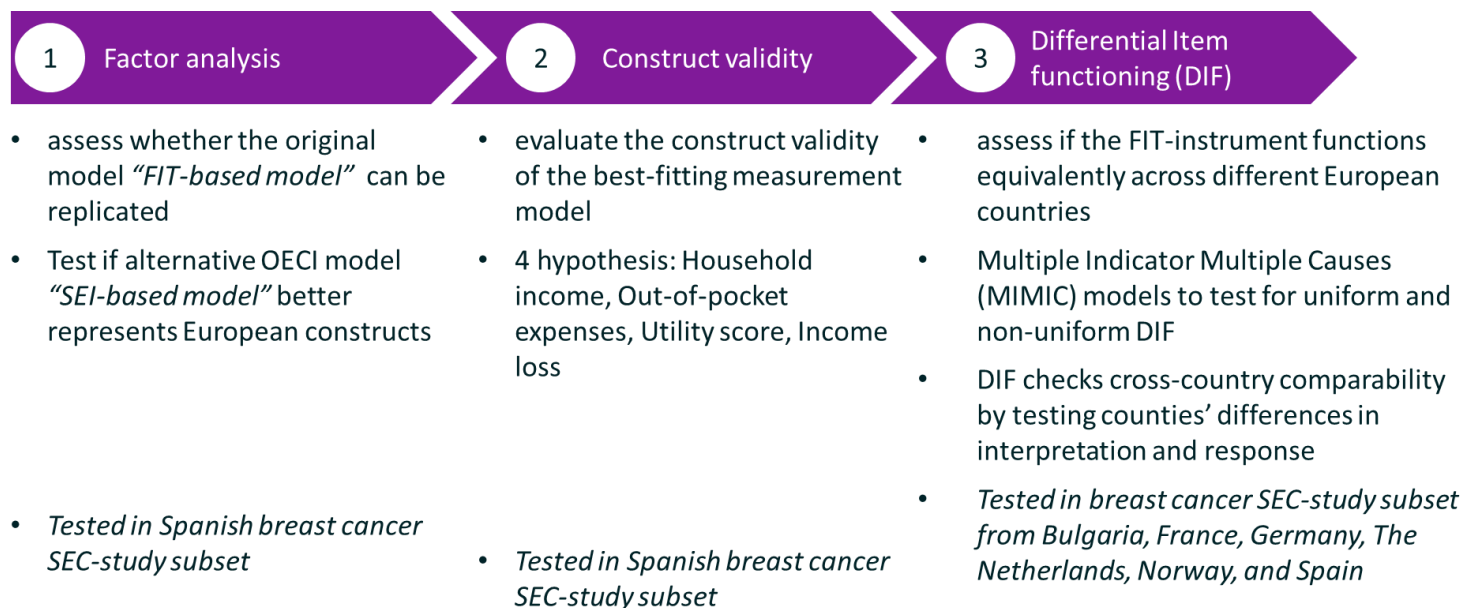
Subscales	FIT items
<b>Financial Experience</b>	1. Satisfaction with finances
	2. Worry about finances
	3. Comparison of finances with others
<b>Financial coping behavior</b>	4. Ability to pay daily living expenses: food
	5. Ability to pay daily living expenses: housing
	6. Ability to pay daily living expenses: medical
	7. Borrow money because of cancer treatment
<b>Indirect cost</b>	8. Quit job because of cancer
	9. Caregiver quit job because of cancer

<sup>1</sup>J. Ubels, J. Vancoppenolle, J. Tetteh, W. van Harten, V. Retel, M. Schlender, N. Franzen (2025) Towards a validated European Instrument to measure the Socioeconomic impact of Cancer. Unpublished Manuscript ([confidential data / currently undergoing peer review](#))

# Secondary SEC-based Analyses (I)

## Towards a Validated European Instrument<sup>1</sup>

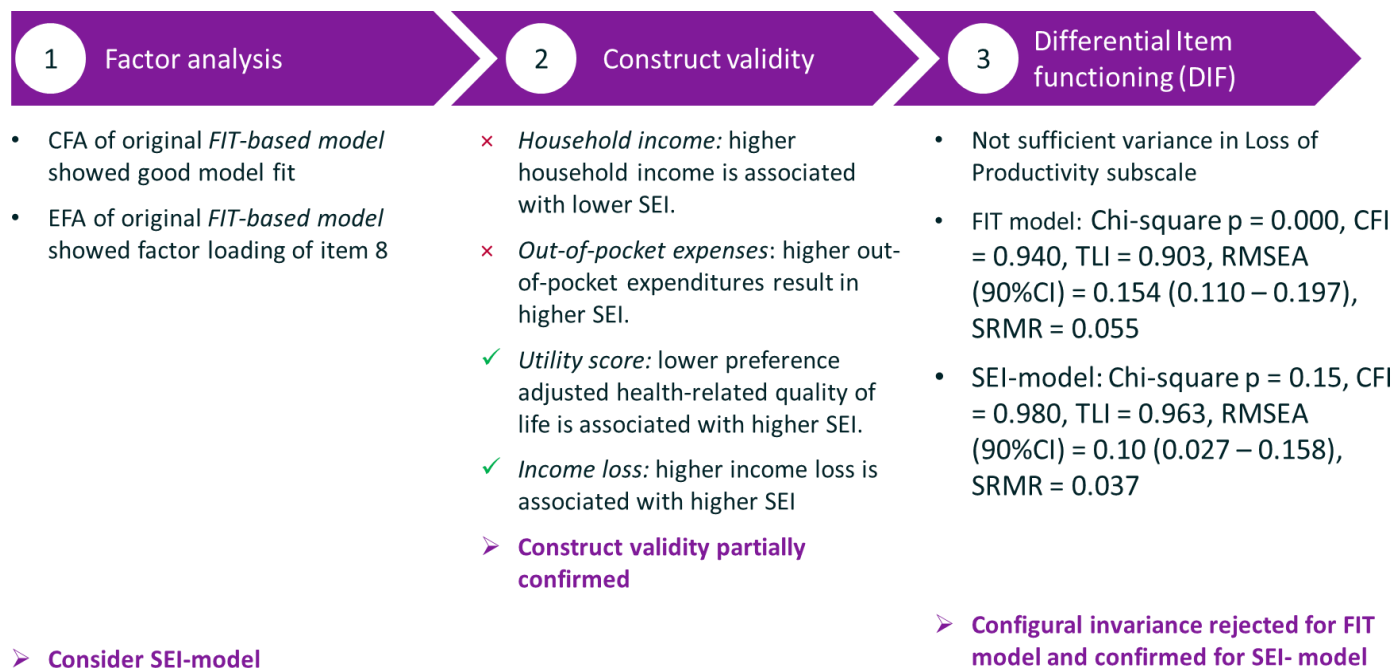
### Method: Three Steps



<sup>1</sup>J. Ubels, J. Vancoppenolle, J. Tetteh, W. van Harten, V. Retel, M. Schlender, N. Franzen (2025) Towards a validated European Instrument to measure the Socioeconomic impact of Cancer. Unpublished Manuscript ([confidential data / currently undergoing peer review](#))

## Towards a Validated European Instrument<sup>1</sup>

### Key Results



<sup>1</sup>J. Ubels, J. Vancoppenolle, J. Tetteh, W. van Harten, V. Retel, M. Schlender, N. Franzen (2025) Towards a validated European Instrument to measure the Socioeconomic impact of Cancer. Unpublished Manuscript ([confidential data / currently undergoing peer review](#))

## Secondary SEC-based Analyses (I)

### Towards a Validated European Instrument<sup>1</sup>

#### Implications

- ▮ The original Canadian FIT model showed partial validity: it was reliable, but construct validity was only partly confirmed.
  - ▮ Cross-country analyses revealed limited replicability, with DIF indicating variation in how items were interpreted across settings.
  - ▮ A model based on the SEI framework showed better fit & conceptual clarity.
- ▮ Caution is needed when comparing scores across countries due to DIF.
  - ▮ The SEI model seems likely to provide a stronger foundation for instrument validation and development.
  - ▮ This study supports the creation of a pan-European instrument to assess the socio-economic impact of cancer.
  - ▮ Further refinement is required to improve construct validity and to ensure broad applicability across cancer types and health systems.

<sup>1</sup>J. Ubels, J. Vancoppenolle, J. Tetteh, W. van Harten, V. Retel, M. Schlander, N. Franzen (2025) Towards a validated European Instrument to measure the Socioeconomic impact of Cancer. Unpublished Manuscript ([confidential data](#) / [currently undergoing peer review](#))

## Secondary SEC-based Analyses (II)

### Adolescents and Young Adults (AYAs) in Europe<sup>1</sup>

#### NKI-Driven Project

- ▢ Two surveys explored the socioeconomic impact of cancer among AYAs and their support systems in 11 EU-countries
  1. Sub-analysis the of cross-sectional SEC study (n=3,157); n=577 AYAs
  2. One-time survey targeting health care providers from 11 EU-countries
- ▢ AYAs reported financial difficulties (79%) and concerns (75%) about their financial situation post-diagnosis
- ▢ AYAs (70%) reported efforts to increase their financial resources to cope with treatment-related expenses
- ▢ Two in three health care providers indicated no or limited awareness of AYAs' financial difficulties within their countries
- ▢ Services for socioeconomic impact are not always available, and if available, most are not AYA-specific

<sup>1</sup>J. Vancoppenolle, S.H.M. Janssen, N. Franzen, W.-T.A. van der Graaf, V. Retel, O. Husson, W. van Harten (2025) Socioeconomic impact among and socioeconomic support services for adolescents and young adulty (AYSs) with cancer: a European perspective. *International Journal of Cancer*, in press



## Publications (I)

J. Vancoppenolle, S.H.M. Janssen, N. Franzen, W.-T.A. van der Graaf, V. Retel, O. Husson, W. van Harten :  
Socioeconomic impact among and socioeconomic support services for adolescents and young adults (AYSA) with cancer: a European perspective.

*International Journal of Cancer*, in press

P.D. Pham, J. Ubels, R. Eckford, M. Schlander:

Measuring the Socioeconomic Impact of Cancer: A Systematic Review and Standardized Assessment of Patient-Reported Outcomes (PRO) Instruments.

*Pharmacoeconomics*, 2025: Published online April 4, 2025.

M. Schlander, W. van Harten, V.P. Retel, P.D. Pham, J. M. Vancoppenolle, J. Ubels, O.S. López, C. Quirland, F. Maza, E. Aas, B. Crusius, A. Escobedo, N. Franzen, J. Fuentes-Cid, D. Hernandez, K. Hernandez-Villafuerte, I. Kirac, A. Paty, T. Philip, S. Smeland, R. Sullivan, E. Vanni, S. Varga, T. Vermeulin, R.D. Eckford:

The socioeconomic impact of cancer on patients and their relatives: Organisation of European Cancer Institutes task force consensus recommendations on conceptual framework, taxonomy, and research directions.

*The Lancet Oncology*, 2024: 25(4) e152–e163.

P.D. Pham, M. Schlander, R. Eckford, K. Hernandez-Villafuerte, J. Ubels:

Developing a conceptual framework for socioeconomic impact research in European cancer patients: A 'best-fit' framework synthesis.

*The Patient*, 2023: 16 (5) 515-536.

J. Schneider, D. Hernandez, CAESAR study group, M. Schlander, V. Arndt:

Out-of-pocket payments and loss of income among long-term breast cancer survivors in Germany: A multi-regional population-based study.

*Journal of Cancer Survivorship*, 2023: 17 (6) 1639-1659.

D. Hernandez, M. Schlander:

Income loss after a cancer diagnosis in Germany: An analysis based on the socio-economic panel survey.

*Cancer Medicine*, 2021: 10 (11) 3726-3740.

## Publications (II)

*Currently undergoing peer review or in preparation:*

J. Ubels, J. Vancoppenolle, J. Tetteh, W. van Harten, V. Retel, M. Schlander, N. Franzen:  
Towards a validated European Instrument to measure the socioeconomic impact of Cancer

R. Eckford et al.  
The Socioeconomic Impact of cancer on patients and their families:  
taxonomy in Europe & proposal for definition.

R. Eckford et al.  
The Socioeconomic Impact of cancer on patients and their families:  
a systematic review and bibliometric analysis

M. Schlander et al.  
Patient-Reported Outcomes in Oncology: The Socioeconomic Impact of Cancer and Cancer Care  
from the Perspective of Patients and their Relatives  
(«Rationale Paper»)

## Selected Conference Presentations (I)

P.D. Pham, J. Ubels, R. Eckford, M. Schlander:

The Socioeconomic Impact of Cancer and Cancer Care on Patients and their relatives: Assessing the Content Validity of Dedicated Patient Reported Outcomes Measurement (PROM) Instruments.

Poster presented at ISPOR 2025.

Montreal, Canada. 13-16 May 2025.

R. Eckford, K. Hernandez-Villafuerte, A. Escobedo, N. Franzen, J. Fuentes-Cid, I. Kirac, F. Maza, D. Pham, C. Quirland, V.P. Retel, O. Seoane, J. Ubels, E. Vanni, J. Vancoppenolle, T. Vermeulin, W. van Harten, M. Schlander:

The Socioeconomic Impact of Cancer on Patients and their Relatives: Consensus Definition.

Oral presentation at World Cancer Congress (WCC) 2024.

Geneva, Switzerland. 17-19 September 2024.

P.D. Pham, J. Ubels, M. Schlander:

Measuring the socioeconomic impact of cancer:

A systematic review and standardized assessment of patient-reported outcome (PRO) instruments.

Poster presentation at ISPOR Europe 2023.

Copenhagen, Denmark. 12-15 November 2023.

P. D. Pham, J. Ubels, K. Hernandez-Villafuerte, R. Eckford, M. Schlander:

Developing a conceptual framework for socioeconomic impact research in European cancer patients: A best-fit framework synthesis.

Poster presentation at ISPOR Europe 2022.

Vienna, Austria. November 6–9, 2022.

C. Quirland, F. Maza, J. Fuentes, R. Eckford, J. Ubels, O. Seoane, D. Hernandez, K. Hernandez-Villafuerte, P.D. Pham, V. Retel, M. Schlander:

Costing for Socioeconomic Impact Analysis: Implications of Adopting a Patient's Perspective.

Poster presentation at ISPOR Europe 2022.

Vienna, Austria. November 6–9, 2022.

M. Schlander, J. Ubels, C. Quirland, V. Retel: Towards a broader patients' perspective:

The theory and practice of socioeconomic impact research.

Concurrent Breakout Session 4 at ISPOR Europe 2022.

Vienna, Austria. November 6–9, 2022.

## Selected Conference Presentations (II)

J. Schneider, D. Hernandez, CAESAR study group, M. Schlander, V. Arndt:

To what extent are long-term breast cancer survivors subjected to financial burden in Germany? Results from a patient survey-based study.

Poster presentation at ISPOR Europe 2022. Vienna, Austria. November 6–9, 2022.

K. Hernandez-Villafuerte, R. Eckford, A. Spier, M. Schlander:

How to Describe the Socioeconomic Impact of Cancer on Patients and their Families:

An Evaluation of Terminology by Global Regions and Healthcare Systems.

Presentation at iHEA 14th World Congress on Health Economics.

Virtual. July 12-15, 2021.

### *Invited presentations*

M. Schlander, W. van Harten, V.P. Retèl, P.D. Pham, J. M. Vancoppenolle, J. Ubels, O.S. López, C. Quirland, F. Maza, E. Aas, B.

Crusius, A. Escobedo, N. Franzen, J. Fuentes-Cid, D. Hernandez, K. Hernandez-Villafuerte, I. Kirac, A. Paty, T. Philip, S. Smeland, R.

Sullivan, E. Vanni, S. Varga, T. Vermeulin, R.D. Eckford:

The socioeconomic impact of cancer on patients:

OECD Task Force consensus recommendations on framework, taxonomy, and research directions.

Poster presented at DKFZ (PoF Evaluation). Heidelberg, Germany: 13 March 2025.

R.D. Eckford:

Measuring financial toxicity: Approaches to assessing socioeconomic impact of cancer on patients and their relatives.

Oral presentation (pre-recorded lecture). CCI4EU - Cost of health care and drugs, 4th Online Course. 3 February 2025.

M. Schlander:

Krebs und Armut. Oral presentation. Krebsaktionstag 2024. The German Cancer Congress (Deutscher Krebsskongress) 2024.

Berlin, Germany. 21-24 February 2024

M. Schlander:

Krebs und Armut: Pandemie als Brennglas für soziale und ökonomische Ungleichheit.

Invited oral presentation at the 35th German Cancer Congress (DKK).

Berlin, Germany. November 13-16, 2022.

## Some Considerations for OECI

- Keeping the Momentum
- **Advocacy** for Patient Interests
  - Positioning of OECI (!)
- **Balancing** Self-Responsibility, Empowerment, and Solidarity
  - Targeted Support for High-Risk / Vulnerable Patient Groups
- **Tackling** Co-Payments for Seriously Sick (Cancer) Patients
  - Economic Rationale versus [Sometimes] Dire Consequences for Vulnerable Groups?
- **Better Integration of the Patient Perspective in HTA**
  - Patient-Reported Outcomes including (!) Socioeconomic Consequences

## Suggestions for OECD: Active Engagement

- Unique Positioning Opportunity for OECD (!)
- **Sustainable Research Priority**
  - Research **Focus & Standards** (cf. TF Consensus Statement)
  - **Validation** of Concept and Measurement Instrument(s), Tailor-Made for European Needs
  - Identification of Risk Factors and **Predictors** of Vulnerability
  - **Governance** of Working Group & Task Force
- **Outreach**
  - Clear Messages
  - Fostering Network & Seeking Partnerships (at all levels)
  - Engagement of OECD Membership (institutional and individual)

## Socioeconomic Impact: Outreach

### Suggested Immediate Next Steps for OECD

- Build on Prior Work and Realize the Opportunity
- **European-Level Networking**
  - Awareness of Relevance
  - Creating Interest & Support
  - Mobilizing Relevant Stakeholders
    - European Commission (DG Santé)
    - Patient Advocacy Groups
    - European Cancer League
  - Development & Validation of a Harmonized European Instrument
  - Consensus on Reporting Standards for SEI Studies
  - Qualitative Research into Severity and Vulnerability

### «Heidelberg Health Economics Summer School» 2025



Cost Effectiveness Evaluation in Theory & Practice  
[Health-Related] Quality of Life & Patient-Reported Outcomes  
The Socioeconomic Dimension of Severe Disease  
Social Norms & Preferences in Health Technology Assessments  
Impact for the Evaluation of Cancer Medicines

Brunico, Alto Adige, Italia  
[Bruneck, South Tyrol, Italy]  
**September 11 - 13, 2025**

For more information

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- (b) or see: [www.innoval-hc.com](http://www.innoval-hc.com) / Summer School