



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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University of Heidelberg and **German Cancer Research Center (DKFZ)**;

Institute for Innovation & Valuation in Health Care (Wiesbaden / Germany)



[«A Cycle of Poverty»]

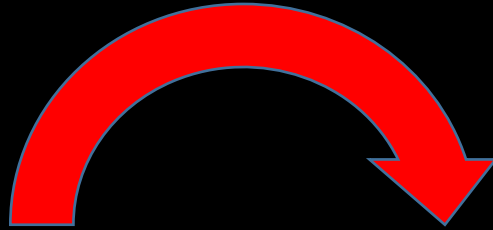
[always?]

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*

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Former Minister of Health, *Croatia*

Sinisa Varga

University of Oslo, Institute of Health
and Society, *Norway*

Eline Aas

Oslo University Hospital, *Norway*

Sigbjørn Smeland

King's College London, *England*

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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***

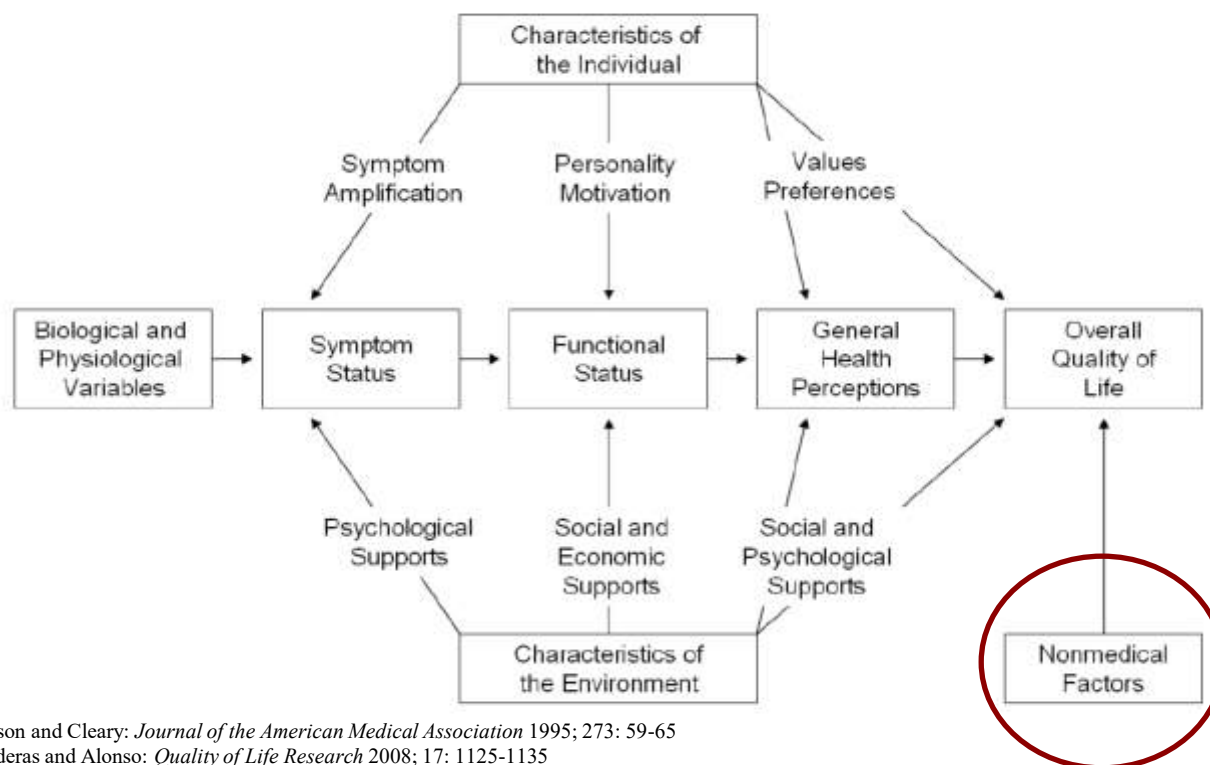
Michael Schlander (*TF Chair*), Karla Hernandez-Villafuerte, Diego Hernandez-Careno,
Rachel Eckford, Phu Duy Pham, Jasper Ubels

Narrow Focus: What About «Nonmedical Factors»?

The Traditional Perspective on PROs

Wilson and Cleary (1995)¹

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



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

²Valderas 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

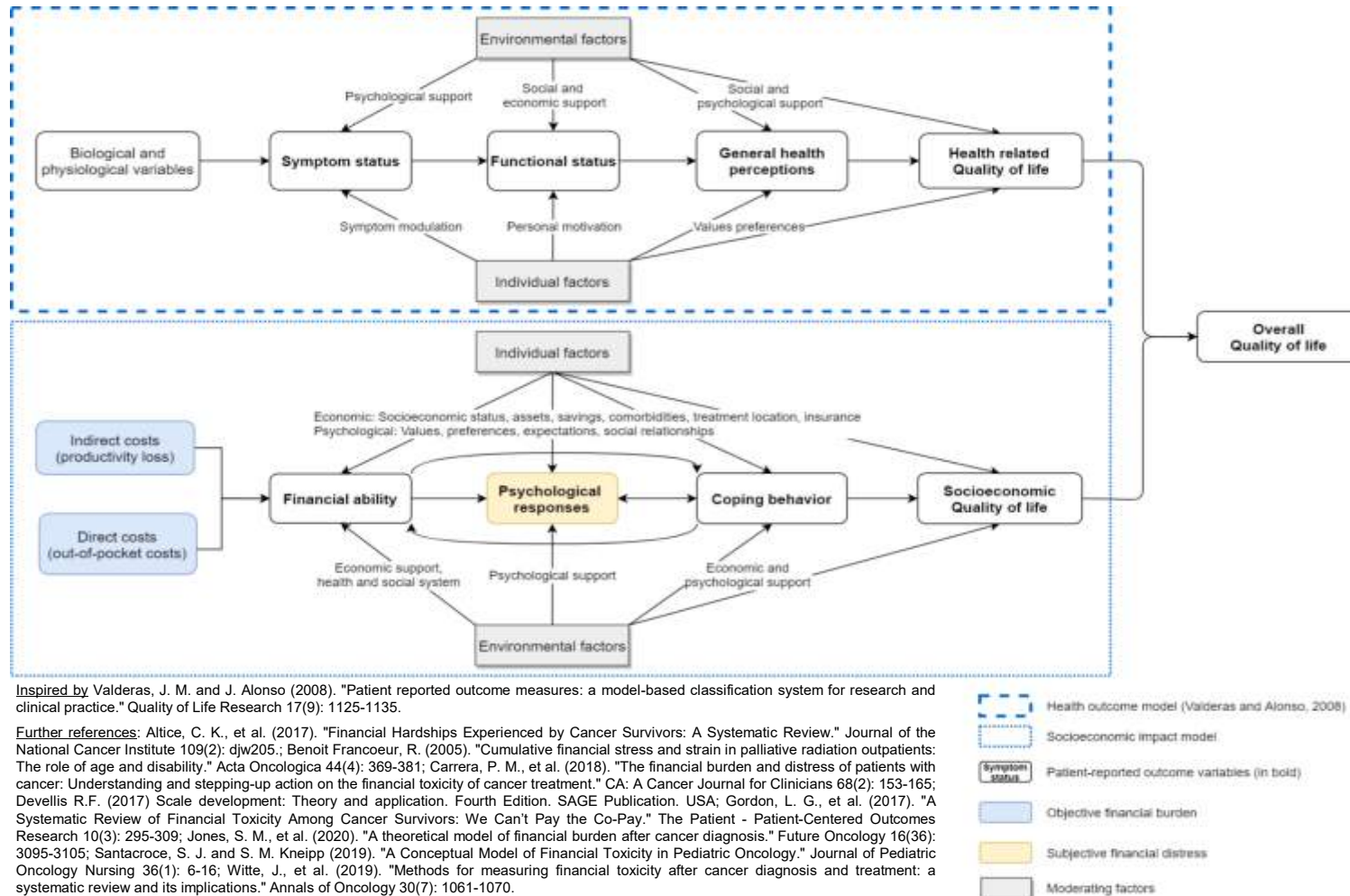
Health-Related Outcomes

[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



Inspired by Valderas, J. M. and J. Alonso (2008). "Patient reported outcome measures: a model-based classification system for research and clinical practice." *Quality of Life Research* 17(9): 1125-1135.

Further references: Altice, C. K., et al. (2017). "Financial Hardships Experienced by Cancer Survivors: A Systematic Review." *Journal of the National Cancer Institute* 109(2): djw205.; Benoit Francoeur, R. (2005). "Cumulative financial stress and strain in palliative radiation outpatients: The role of age and disability." *Acta Oncologica* 44(4): 369-381; Carrera, P. M., et al. (2018). "The financial burden and distress of patients with cancer: Understanding and stepping-up action on the financial toxicity of cancer treatment." *CA: A Cancer Journal for Clinicians* 68(2): 153-165; Devellis R.F. (2017) *Scale development: Theory and application*. Fourth Edition. SAGE Publication. USA; Gordon, L. G., et al. (2017). "A Systematic Review of Financial Toxicity Among Cancer Survivors: We Can't Pay the Co-Pay." *The Patient - Patient-Centered Outcomes Research* 10(3): 295-309; Jones, S. M., et al. (2020). "A theoretical model of financial burden after cancer diagnosis." *Future Oncology* 16(36): 3095-3105; Santacroce, S. J. and S. M. Kneipp (2019). "A Conceptual Model of Financial Toxicity in Pediatric Oncology." *Journal of Pediatric Oncology Nursing* 36(1): 6-16; Witte, J., et al. (2019). "Methods for measuring financial toxicity after cancer diagnosis and treatment: a systematic review and its implications." *Annals of Oncology* 30(7): 1061-1070.

«Financial Toxicity»: A Narrow Definition¹

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

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.

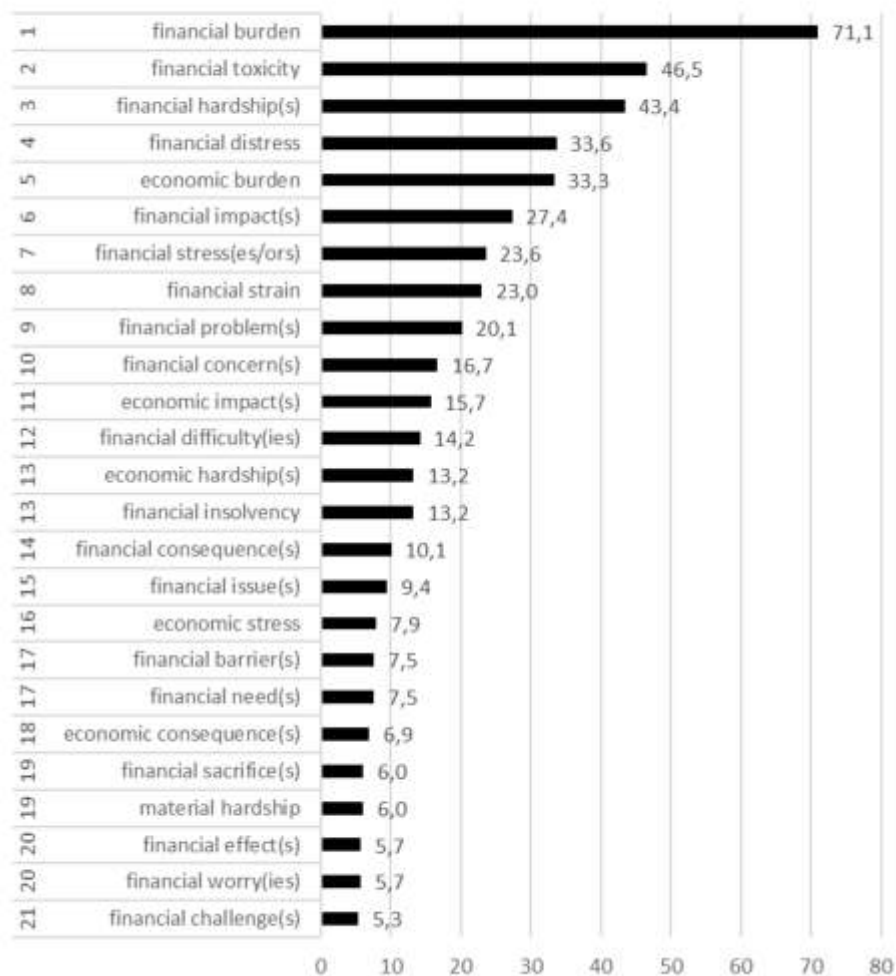
Financial toxicity can also affect a patient's **quality of life** and access to medical care. For example, a patient may not take a prescription medicine or may avoid going to the doctor to save money.

1. 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.)

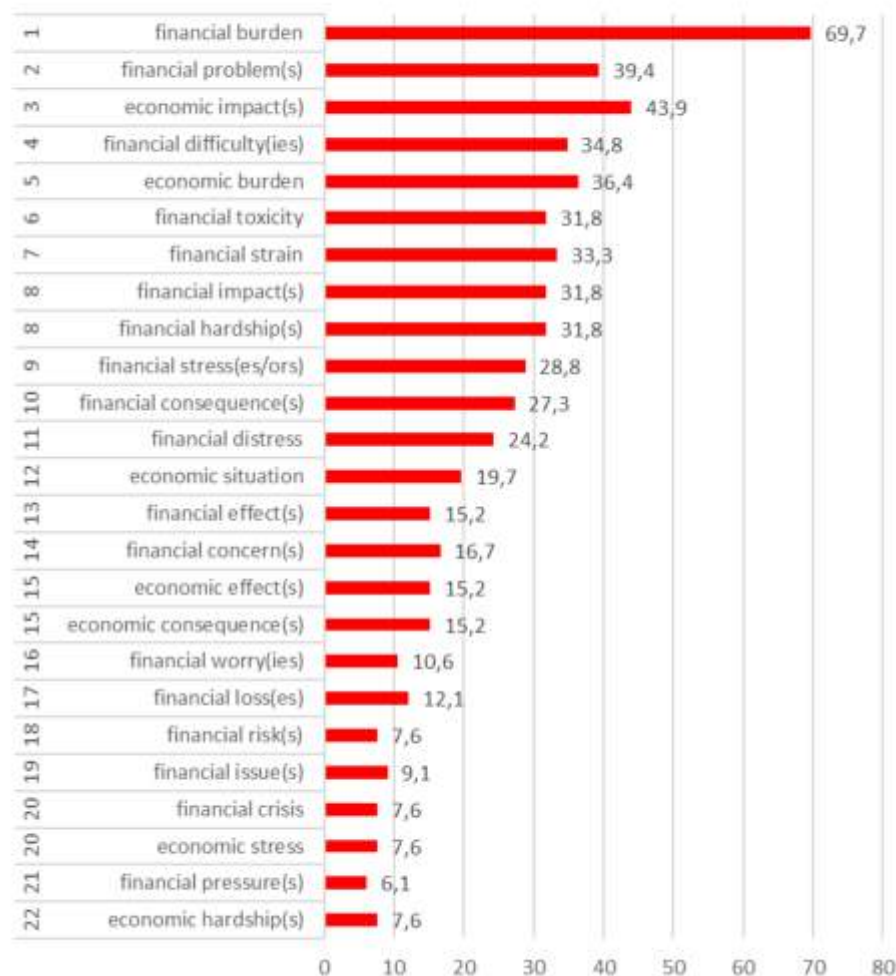
1. focus on “out-of-pocket” (oop) costs, i.e., direct medical & non-medical costs from the perspective of patients
2. what about income loss, i.e., indirect costs from the perspective of patients

«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

Task Force Objectives

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:

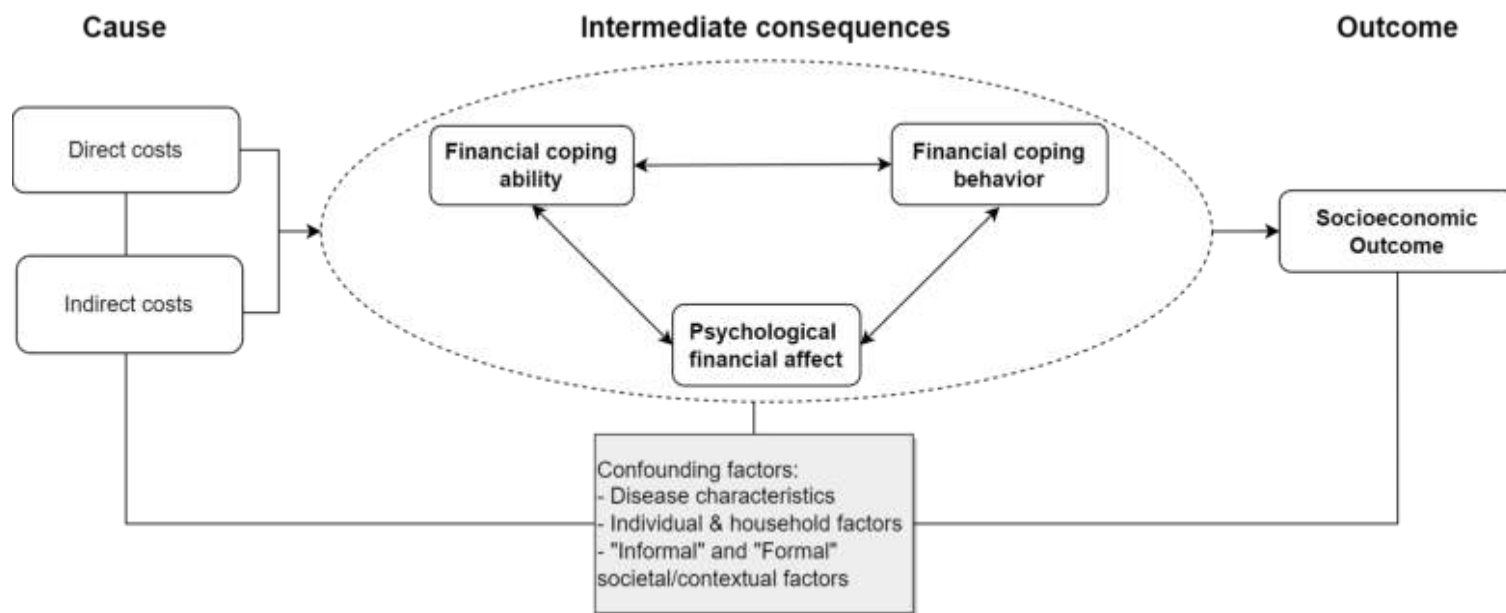
The socioeconomic impact of cancer on patients and their relatives: Organisation of European Cancer Institutes task force consensus recommendations on conceptual framework, taxonomy, and research directions

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

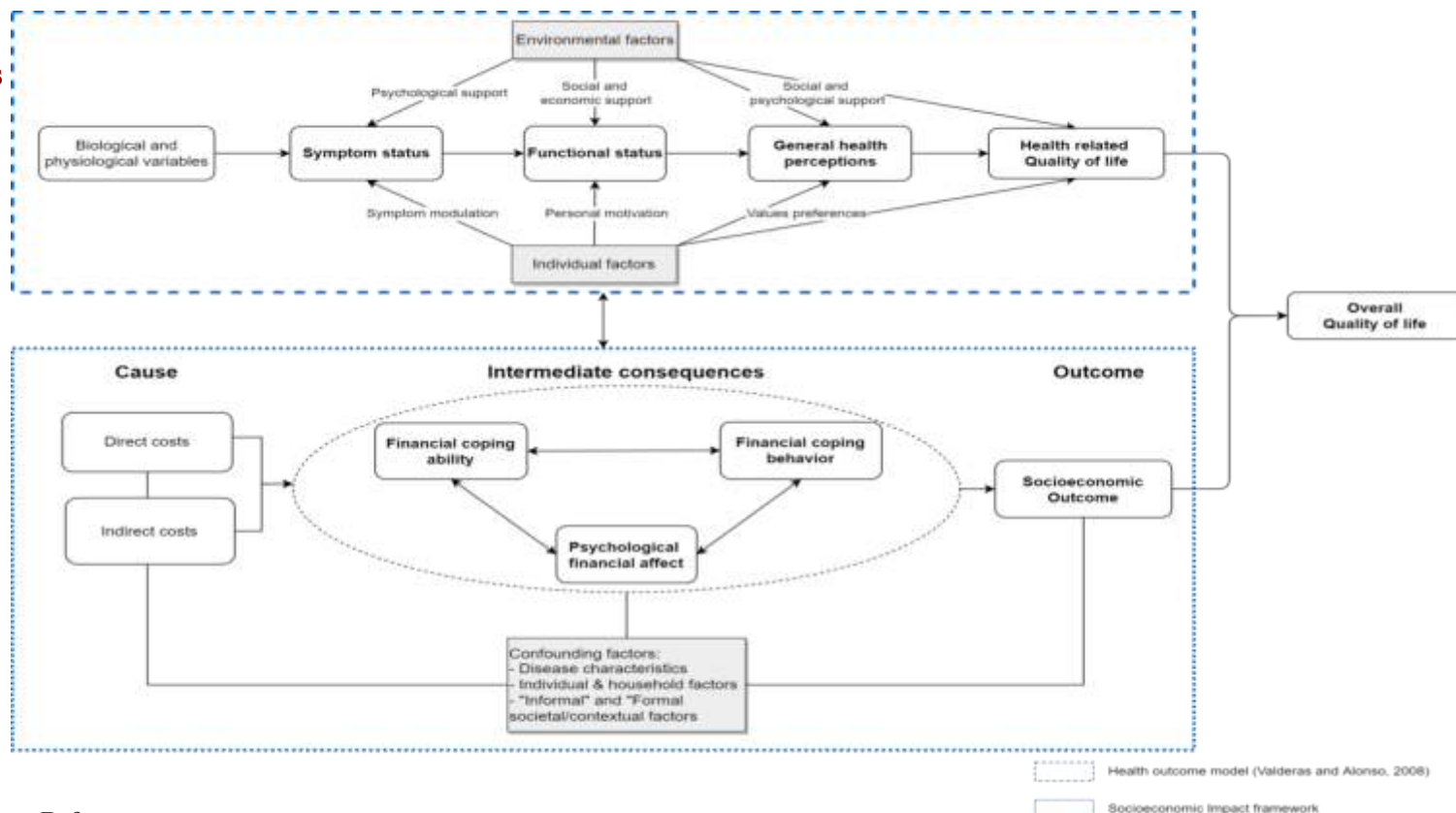
Causes and Outcomes



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 Study¹

– 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

¹J. 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 Study¹

– 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
• Inability to pay for food, housing of medication

Financial strain score
• Satisfaction of financial situation • Worrying about financial situation • Financial situation when young • Borrowing money for treatment related expenses

Lost productivity score
• Quitting of job patient • Quitting of job caregiver

¹J. 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 Study¹

– 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**

¹J. 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 Study¹

– 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%)

¹J. 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 Study¹



¹J. 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, OEI Working Group Health Economics

Socioeconomic Impact of Cancer: Research (I)

The European SEC Study¹

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



¹J. 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

Socioeconomic Impact of Cancer: Research (I)

Primary Results at a Glance: The European SEC Study¹

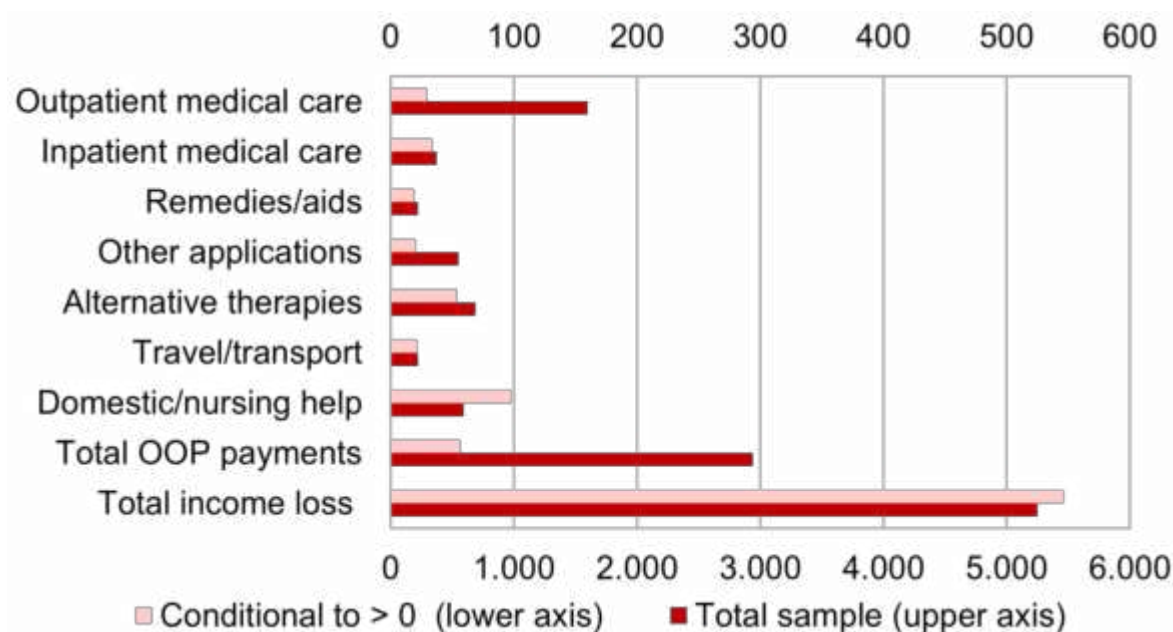
- A multinational study to explore the socio-economic impact and financial toxicity among patients with cancer across Europe.
- 56% of patients suffered from income loss and 86% reported additional treatment-related expenses.
- 16% of patients delayed or avoided medical visits, buying medication, surgery 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.

¹J. 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

Socioeconomic Impact of Cancer: German Data (I)

Income Loss and Out-of-Pocket Expenditures¹ [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.¹



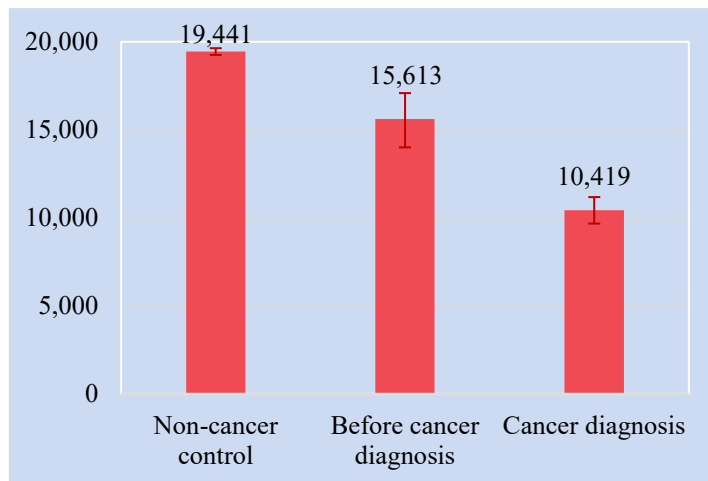
¹J. Schneider; D. Hernandez; CAESAR Study Group; M. Schlander; V. Arndt. Out-of-pocket payments and loss of income among long-term breast cancer survivors in Germany: A multi-regional population-based study. *Journal of Cancer Survivorship* 2023; 17 (6): 1639-1659.

Socioeconomic Impact of Cancer: German Data (II)

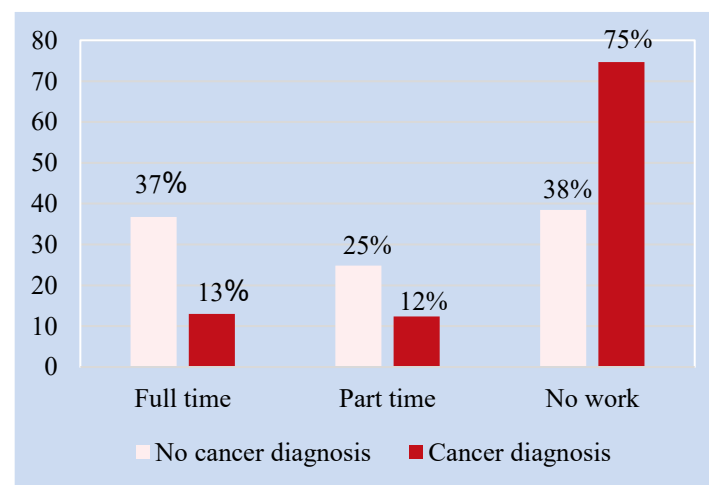
Income Loss Associated with a Cancer Diagnosis¹

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

Job Income Average [€ 2016]



Work Status (Period from 2009 – 2015)



¹D. 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)¹

— 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.

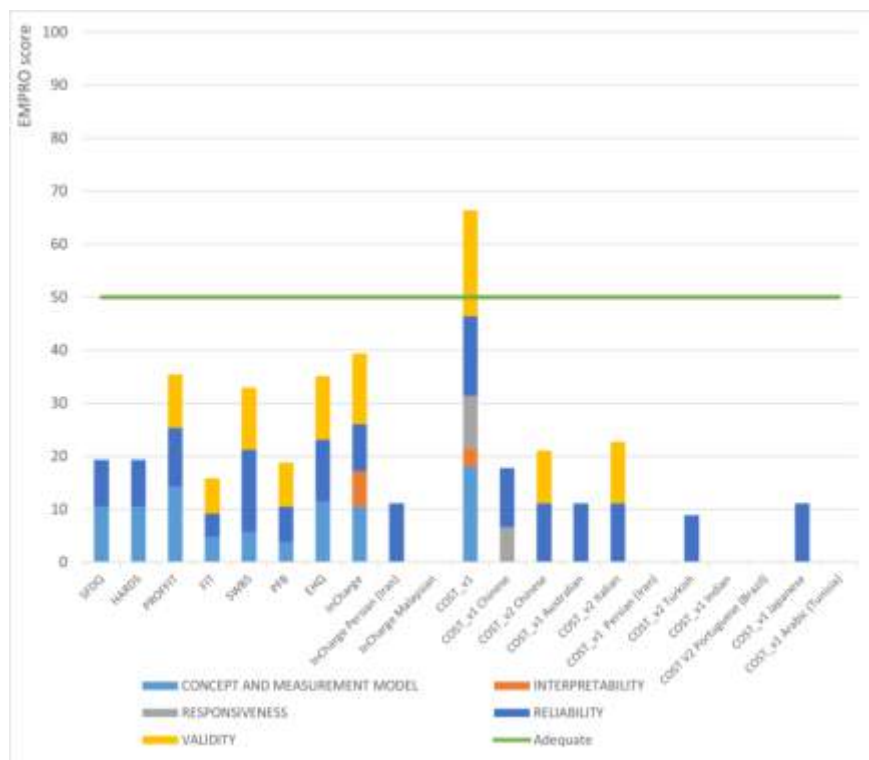
— Objectives

- 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 framework² for SEI analysis.

¹P.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)

²M. 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)¹



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.

¹P.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 Analysis¹

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

¹P.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 Analysis¹

– 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 Instrument¹

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

Mapping FIT items based on the OECD taxonomy

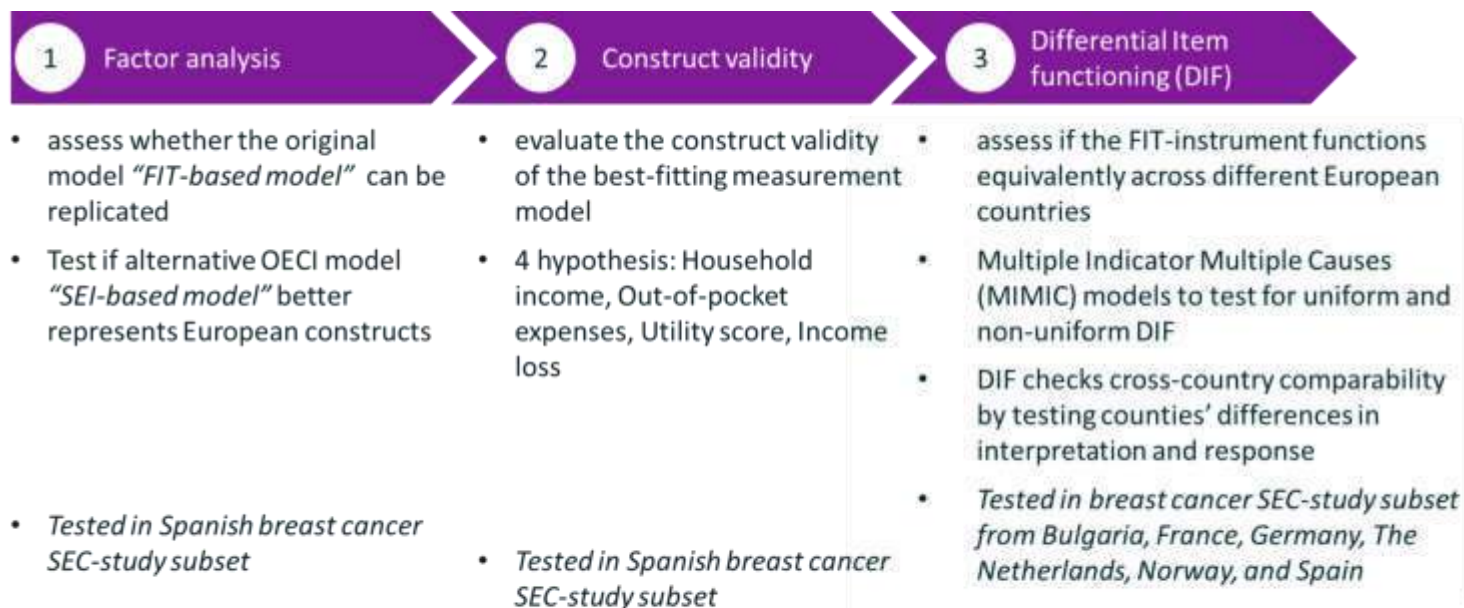
Subscales	FIT items
Financial Experience	1. Satisfaction with finances
	2. Worry about finances
	3. Comparison of finances with others
Financial coping behavior	4. Ability to pay daily living expenses: food
	5. Ability to pay daily living expenses: housing
	6. Ability to pay daily living expenses: medical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

¹J. 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 Instrument¹

Method: Three Steps

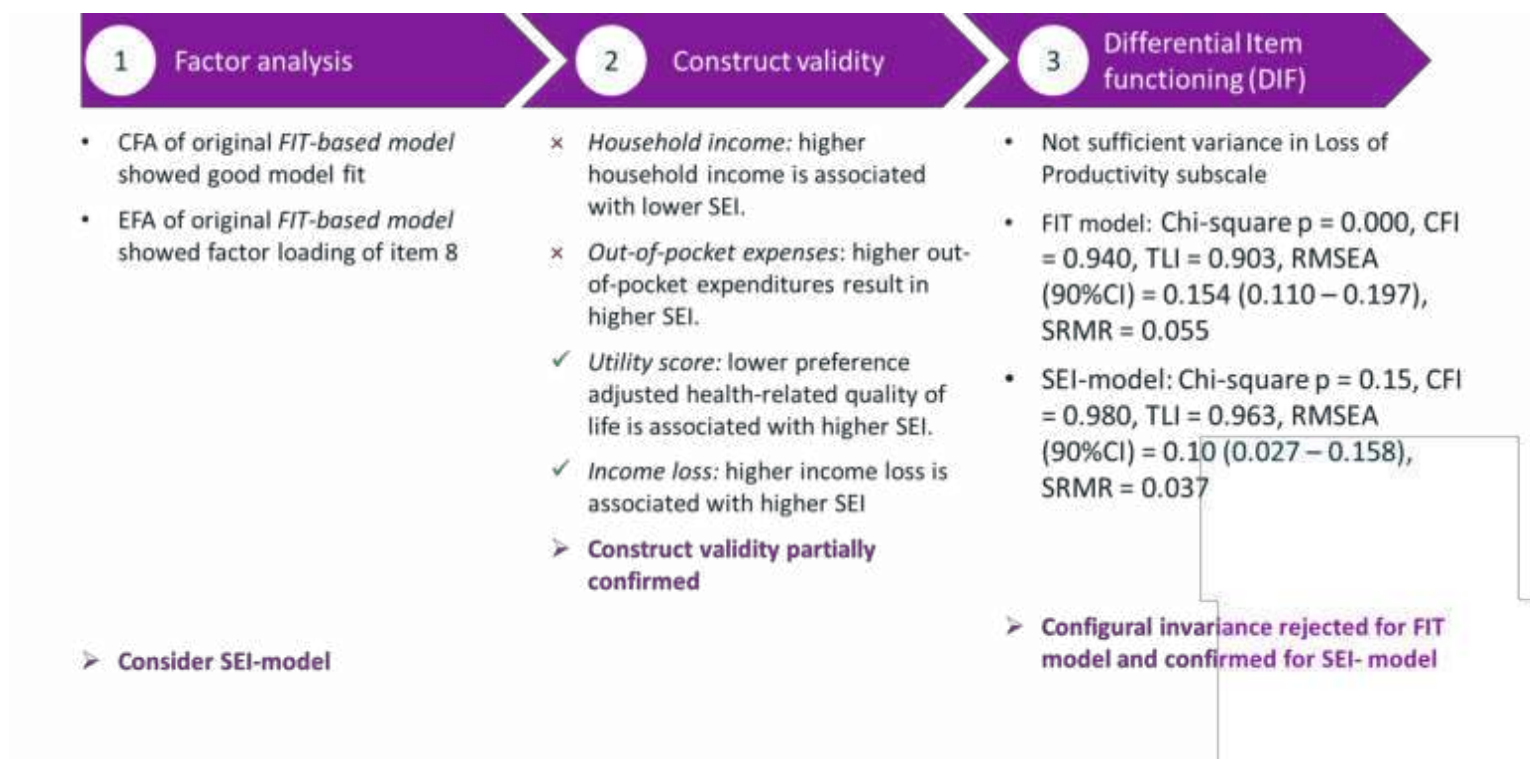


¹J. Ubels, J. Vancoppenolle, J. Tetteh, W. van Harten, V. Retel, M. Schlender, N. Franzen (2025) Towards a validated European Instrument to measure the Socioeconomic impact of Cancer. Unpublished Manuscript (confidential data / currently undergoing peer review)

Secondary SEC-based Analyses (I)

Towards a Validated European Instrument¹

Key Results



¹J. 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 Instrument¹

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.

¹J. 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 (II)

Adolescents and Young Adults (AYAs) in Europe¹

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

¹J. 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

Socioeconomic Impact: Accomplishments to Date

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 (AYAs) 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)

Continued:

J. Vancoppenolle, N. Franzen, L. Azarang, T. Juslin, M. Krini, T. Lubbers, J. Mattson, D. Mayeur, R. Menezes, J. Schmitt, F. Scotte, O. Seoane López, T. Skaali, J. Ubels, M. Schlander, V. Retel, W.H. van Harten; OECD Working Group Health Economics: Financial toxicity and socioeconomic impact of cancer in Europe.
ESMO Open, 2025 (Jun 9);10 (6): 105293.

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»)

Socioeconomic Impact: Accomplishments to Date

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.

Socioeconomic Impact: Accomplishments to Date

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.

Socioeconomic Impact: Policy Implications

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

Socioeconomic Impact: Research Opportunities

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

Education: The Perspective of Patients in HTA

«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

- (a) please contact => ms@michaelschlander.com
- (b) or see: www.innoval-hc.com / Summer School