

DKK Highlight Session

«Sozioökonomische Folgen einer Krebserkrankung»

Facts & Figures aus der Arbeit der **OECD Task Force**

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DKFZ Heidelberg [«*Division of Health Economics*», bis 30. Sept. 2025]

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37. Deutscher Krebskongress (DKK)

Berlin, 21. Februar 2026

UNIVERSITÄT
HEIDELBERG



Hintergrund (beruflich)

Michael Schlander M.D., Ph.D., M.B.A.

- Chairman & Scientific Director – **InnoVal^{HC}** / Wiesbaden (seit 2005)
 - Univ.-Prof. [em.] für **Gesundheitsökonomie** – **Universität Heidelberg**
Medizinische Fakultät Mannheim (seit 2017)
Alfred Weber Institut (AWI) für Wirtschaftswissenschaften (seit 2020)
 - Prof. [em.] für **(Gesundheits- & Innovations-) Management**
– Hochschule für Wirtschaft [und Gesellschaft] **Ludwigshafen** (2002-2016)
 - Gründer & Leiter d. ehem. «*Division of Health Economics*» am **DKFZ** (2017-2025)
 - Board Member, Health Economics Working Group der **OECD** (seit 2021);
Gründer & Leiter der OECD Task Force «*Socioeconomic Impact Research*» (seit 2021)
- Internationale biopharmazeutische **Industrie** (1987-2002)
 - C.E.O. – **Turn-Around-Management** & strategische Neuausrichtung (in D; 1999-2002)
 - Director of **Strategic Business Unit** – forschungsbasierte Arzneimittelindustrie
(Byk Gulden, Gastroenterologie; J&J, Onkologie; in D, B & USA; 1993-1999)
 - Leiter, **European Clinical Development** (Sandoz AG; in D & CH; 1987-1993)
- Wiss. Mitarbeiter (**Experimentelle Hirnforschung & Klinische Neurologie**)
an den Universitätsklinika Frankfurt a.M. und Mainz (1982-1987)
- Studium in Frankfurt a.M., Würzburg, Seattle (WA), Stockholm; Habilitation in Heidelberg

The largest network
of Cancer Centres
and Institutes across
Europe and beyond its
borders

AUSTRIA / BELGIUM / BULGARIA / CHILE
CYPRUS / COLOMBIA / CROATIA / CZECH REPUBLIC
DENMARK / ESTONIA / FINLAND / FRANCE
GERMANY / GREECE / HUNGARY / IRELAND / ITALY / JORDAN
LATVIA / LITHUANIA / NORWAY / POLAND / PORTUGAL / ROMANIA
RUSSIA FEDERATION / SERBIA / SLOVAKIA / SLOVENIA / SPAIN
SWEDEN / SWITZERLAND / TANZANIA / THE NETHERLANDS
TURKEY / UKRAINE / UNITED KINGDOM / VIETNAM



– Cancer Economics Working Group

- Lead: **Wim van Harten** (Chair), Amsterdam (NKI)



– **Task Force** on Socioeconomic Impact Research

- Lead: **Michael Schlander** (Chair), Heidelberg (DKFZ) and Wiesbaden (InnoVal^{HC})

Task Force on «Socioeconomic Impact Research»

Objectives of Task Force

Phases 1 & 2

- ▭ Development of and a **European Consensus** on a comprehensive **conceptual framework**
- ▭ **European Recommendations** for a consistent **taxonomy & terminology**

Phases 3 & 4

- ▭ **Empirical Research** into the **dimension** of the problem and **vulnerable populations**
- ▭ **Instrument Development & Validation** for **measuring** the socioeconomic impact of cancer from the perspective of patients and their relatives

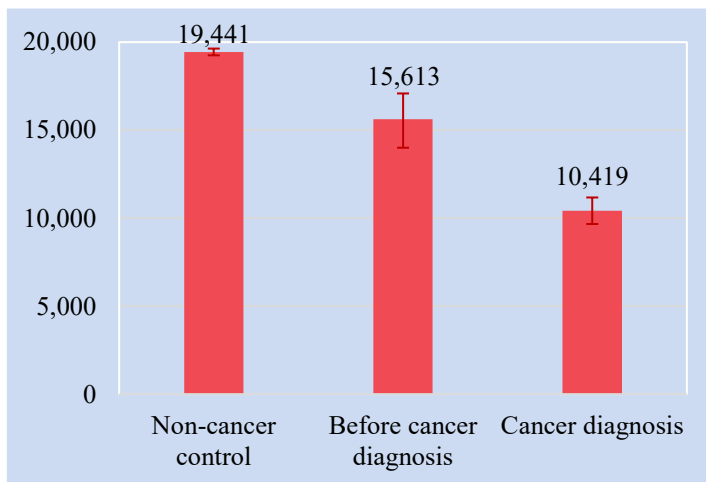
Phase 5

- ▭ Development of **Policy Recommendations** and **outreach** to relevant stakeholder groups, including health care policy makers

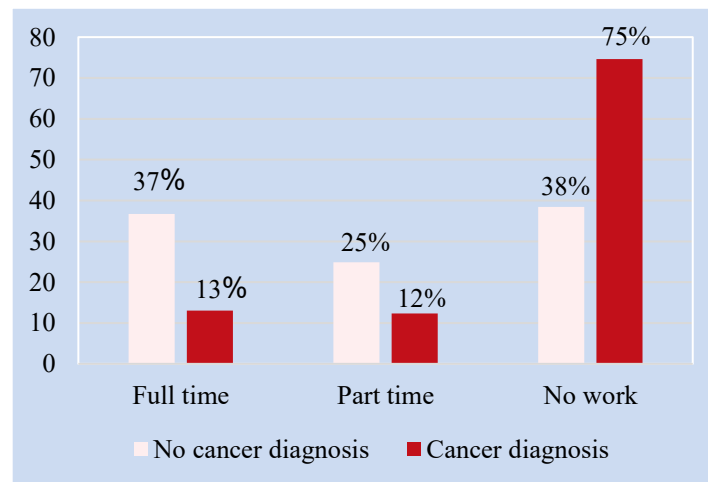
A Representative Sample from the «SOEP» Panel

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

Job Income Average [€ 2016]



Work Status (Period from 2009 – 2015)

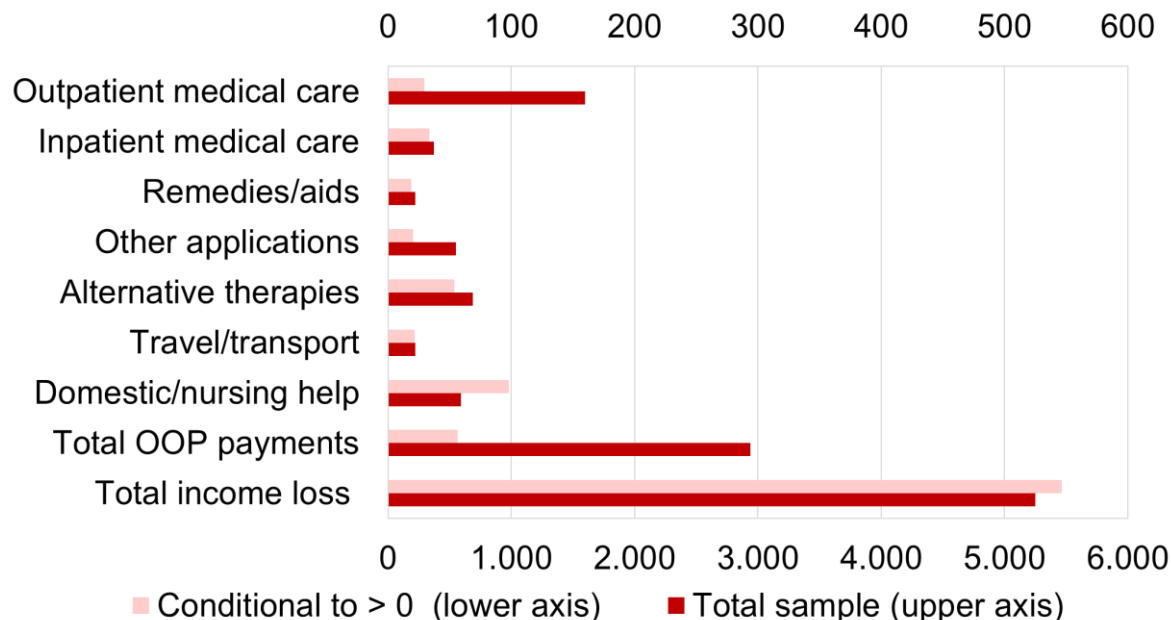


Reference:

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

Income Loss and Out-of-Pocket Expenditures

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

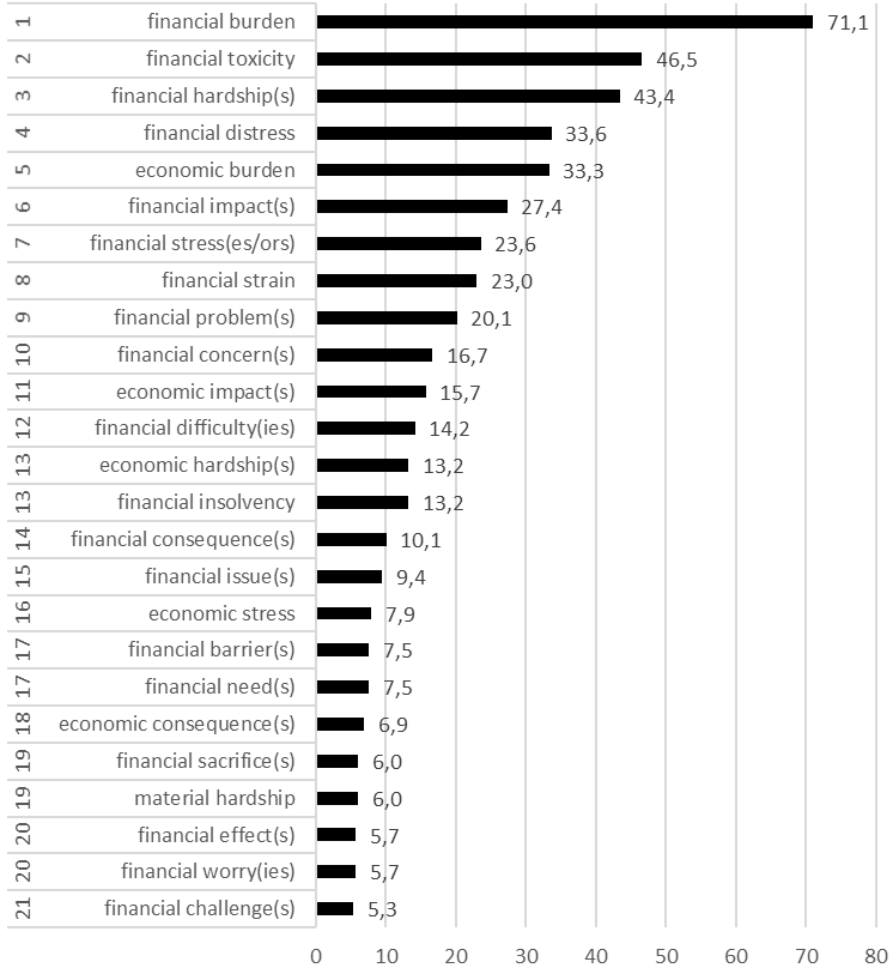


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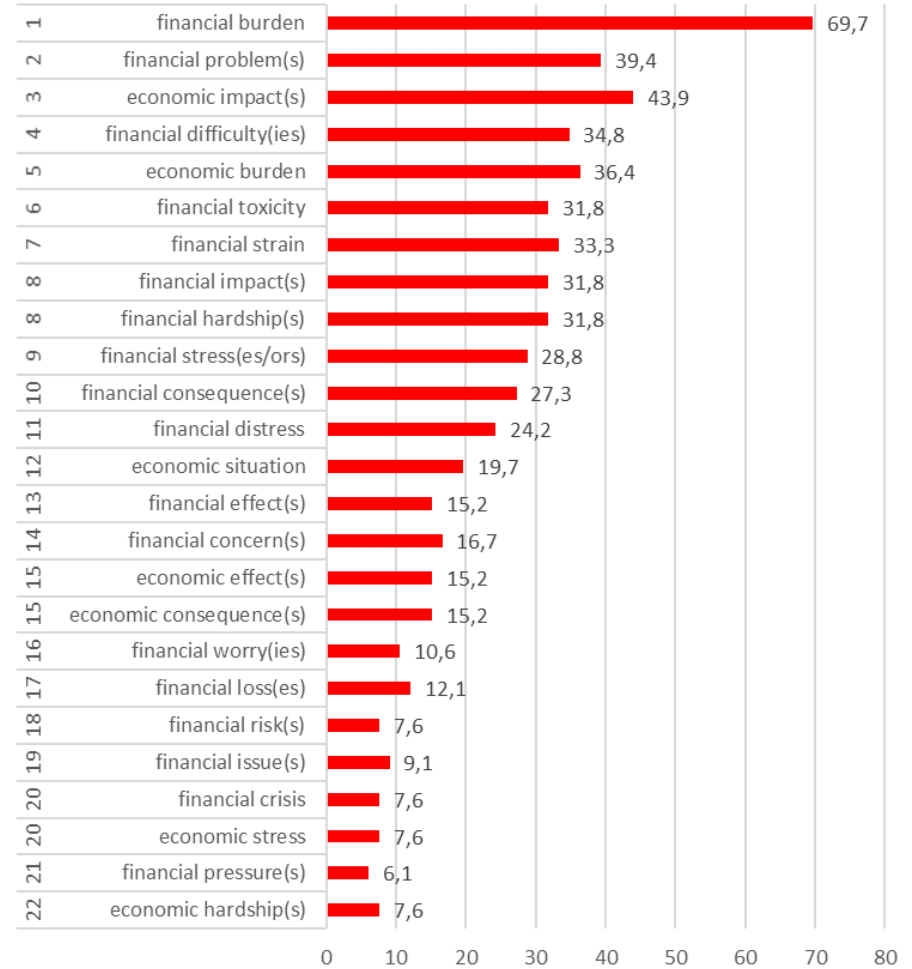
Schneider J, Hernandez D, CAESAR Study Group, Schlander M, Arndt V. Out-of-pocket payments and loss of income among long-term breast cancer survivors in Germany: A multi-regional population-based study. *J Cancer Survivorship* 2023; 17 (6): 1639-1659.

«Financial Toxicity» / Inconsistent Use of Terminology

A. United States



B. Europe



Terminology: Ranking of terms mentioned at least once.

«Socioeconomic Impact» – An Integrated Framework

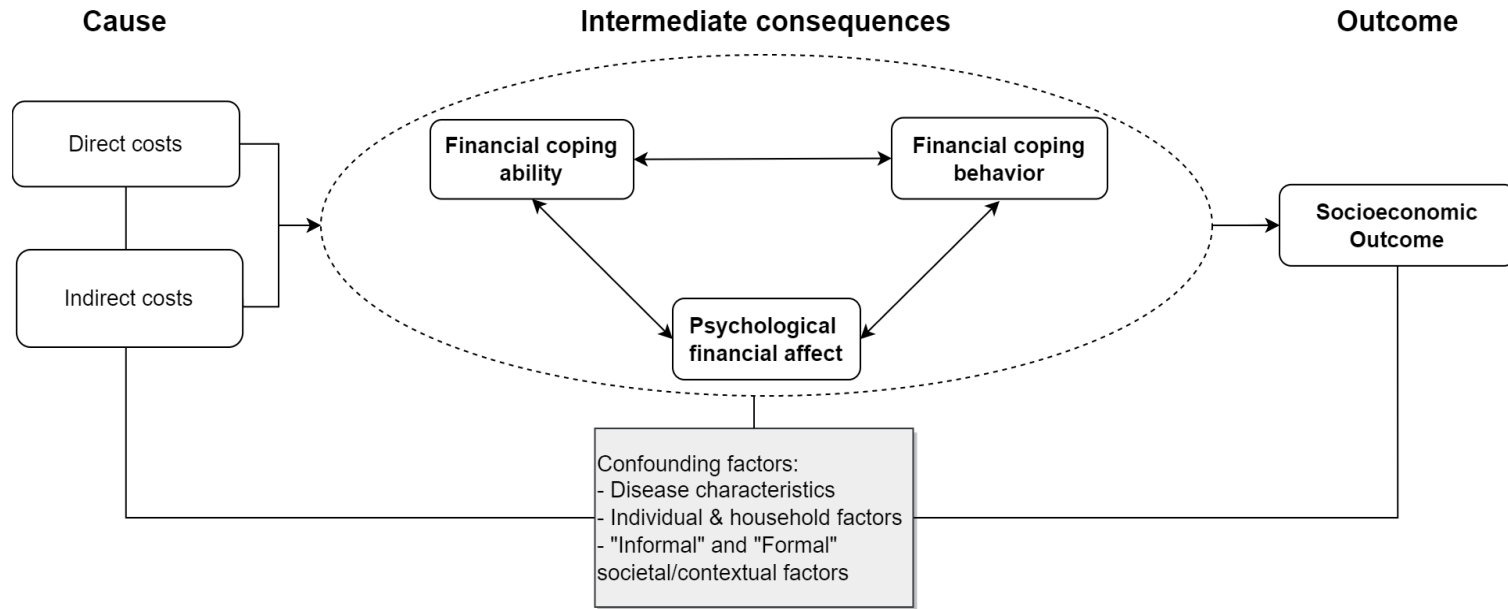
The socioeconomic impact of cancer on patients and their relatives: Organisation of European Cancer Institutes task force consensus recommendations on conceptual framework, taxonomy, and research directions

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 2024; 25 (4): e152-e163. doi: 10.1016/S1470-2045(23)00636-8.

Proposed General Framework

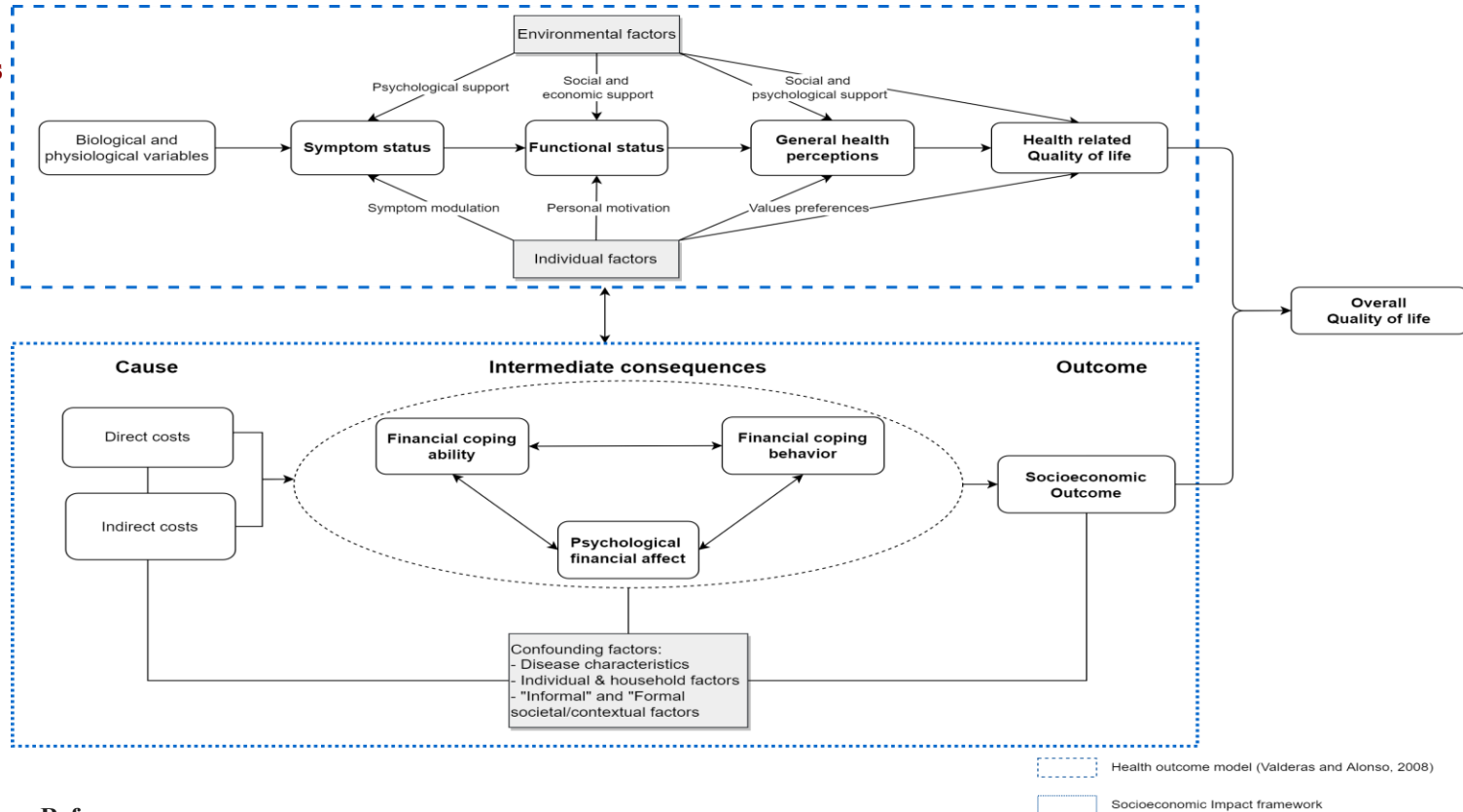
Causes and Outcomes



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: Participants

– 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

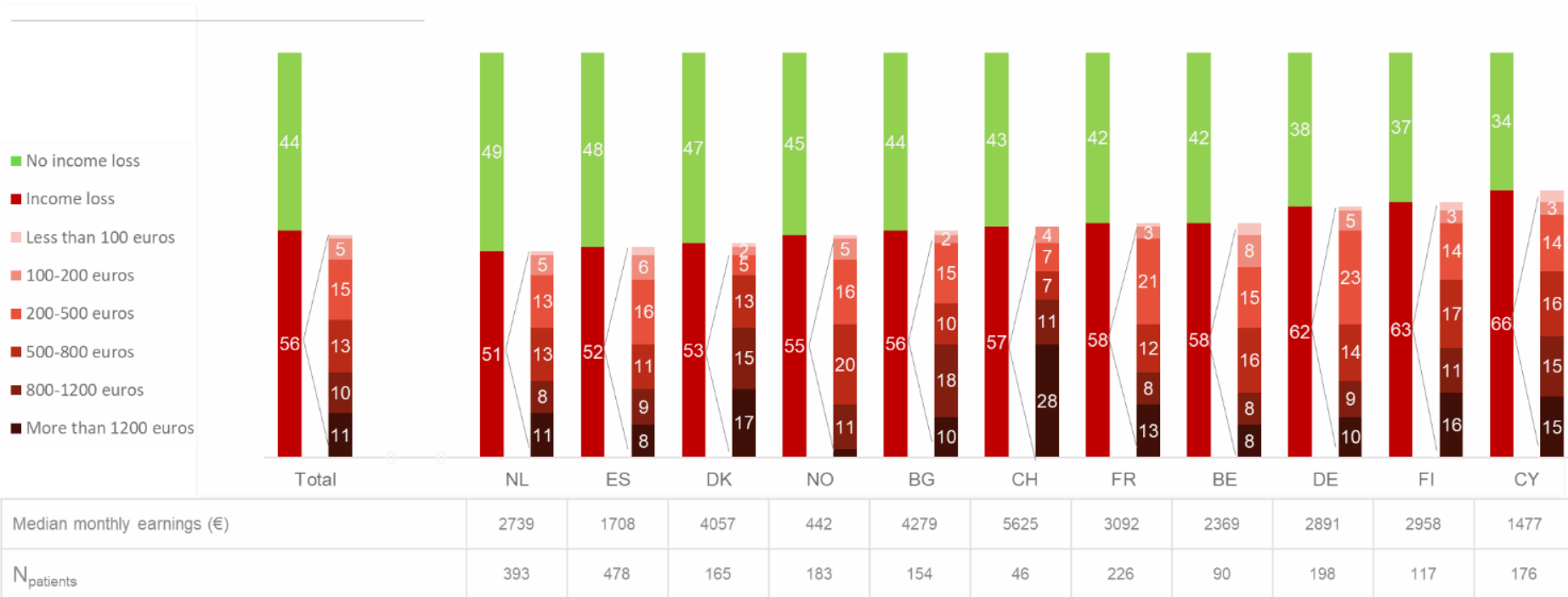
- N=2507 (ES, 520; NL, 413; F, 241; D, 208; BG, 201;...)
- hereof, female 1832 (73.1%); breast cancer, 1181 (47.1%)

Reference:

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

The European SEC Study: Income Loss

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

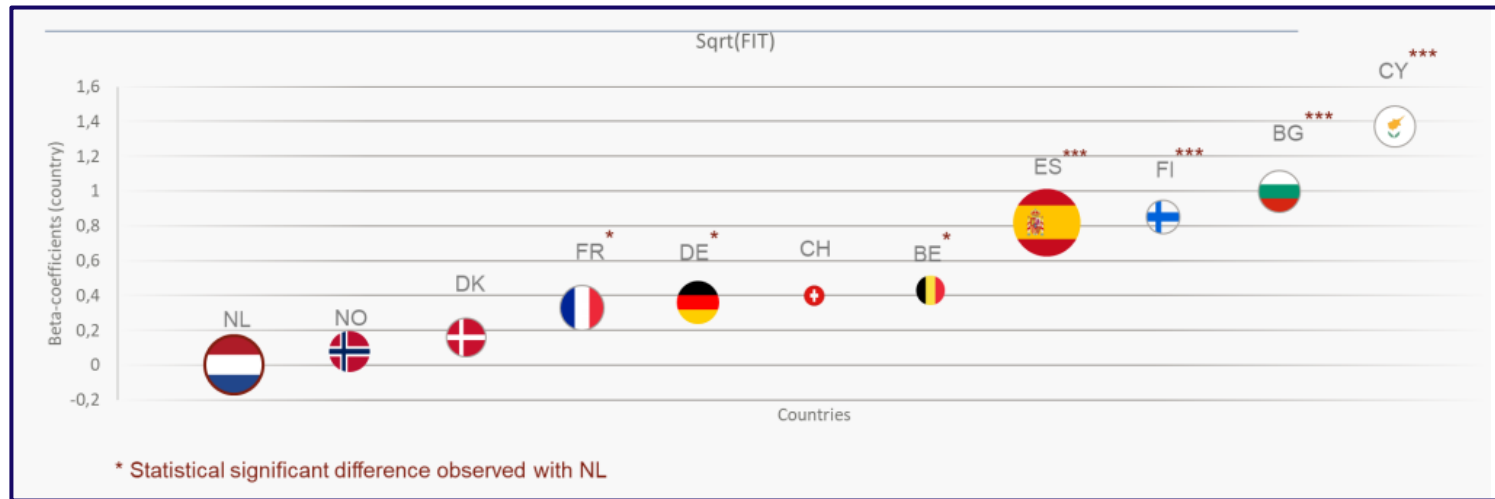


Reference:

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

The European SEC Study: International Comparison

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



Reference:

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

Primary Results at a Glance: The European SEC Study

- 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.

Reference:

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

Adolescents and Young Adults (AYAs) in Europe

- ▭ 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=577 AYAs (15-39 years at initial cancer diagnosis)
 2. **One-time survey targeting health care providers from 11 EU-countries (n=41; 54% of them routinely discussed financial difficulties)**
- ▭ 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 (68%) health care providers indicated no or limited awareness of AYAs' specific financial difficulties within their countries.**
- ▭ Services for socioeconomic impact are not always available, and if available, most are not AYA-specific.

Reference:

Vancoppenolle J, Janssen SHM, Franzen N, van der Graaf WTA, Retel V, Husson O, van Harten W. Socioeconomic impact among and socioeconomic support services for adolescents and young adulty (AYsS) with cancer: a European perspective. *Int J Cancer* 2025;157: 1433-1445.

Towards a Validated European Instrument

Testing the Validity of the FIT Instrument in the European Context

- The original Canadian FIT model showed partial validity only: it was reliable, but construct validity was only partly confirmed.
- Cross-country analyses revealed limited replicability, with DIF¹ indicating variation in how items were interpreted across settings.
- A model based on the OECD framework showed better fit and conceptual clarity.

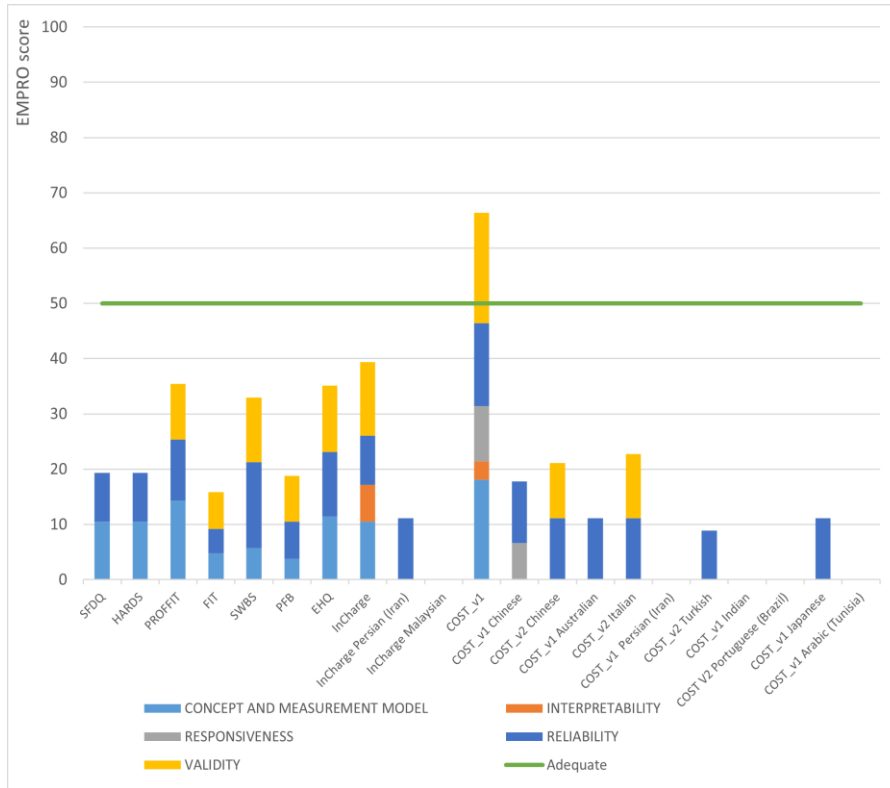
- **Caution** is needed when **comparing scores across countries** (due to DIF).
- The **OECD SEI model** seems likely to provide a stronger foundation for instrument validation and development.
- The analysis supports the creation of a **pan-European instrument**.
- Further work is required to **improve construct validity** and to ensure broad applicability across cancer types and health systems.

Reference:

Ubels, Vancoppenolle J, Tetteh JA, van Harten W, Retel V, Schlander M, Franzen N. Towards a validated European Instrument to measure the Socioeconomic impact of Cancer. *Int. J. Cancer* 2026 (in press)

¹DIF: differential item functioning

Systematic Review and Analysis of Instrument Validity



EMPRO Assessment Results

(psychometric properties, applicability: Valderas et al., 2008)

- **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.

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.

Reference:

Pham PD, Ubels J, Eckford R, Schlander M. Measuring the Socioeconomic Impact of Cancer: A Systematic Review and Standardized Assessment of Patient-Reported Outcomes (PRO) Instruments. *PharmacoEconomics Open* 2025; 9: 519-539.

OECD Task Force – **Further Insights**

Need a European SEI Measurement Instrument

– **Key Takeaways**

- Wide variation exists in the quality and content of existing instruments measuring the SEI of cancer.
- The COST instrument is the most widely used instrument, scoring 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.**
- **Alignment with the comprehensive OECD framework and pan-European standardization should enhance interpretability, replicability, comparability, and enable insights from international benchmarking.**

Reference:

Pham PD, Ubels J, Eckford R, Schlander M. Measuring the Socioeconomic Impact of Cancer: A Systematic Review and Standardized Assessment of Patient-Reported Outcomes (PRO) Instruments. *Pharmacoeconomics Open* 2025; 9: 519-539.

OECI Task Force – **Next Steps**

– **Research & Funding**

- Development of a European Measurement Instrument
(content validity [OECI framework]; international comparability)
- Empirical Research
(e.g., better prediction of particularly vulnerable subgroups,
enabling targeted interventions)

– **Outreach**

- Patient Representatives and Health Care Policy Makers
(inclusive approach also w.r.t. other research groups)
- White Paper:
Developing Consented OECI Policy Recommendations

– **Next Task Force Meeting**

- Online, Tuesday, February 24, 2026, 2:00pm – 4:00 pm

OECI Task Force – **Contact**

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