



Programme in costing, resource use measurement and outcome valuation for use in multi-sectoral national and international health economic evaluations

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The self-reported PECUNIA resource use measurement (RUM) instrument going global: an update

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Background Challenges



Data accuracy:

 High-quality (trial-based) economic evaluations of health interventions require accurate measurement of relevant resource use



Self-reported resource use data:

 The most practical method of generating valid resource use estimates for the measurement of broader resource use based on patient recall → societal perspective



Cultural and linguistic appropriateness:

 Linguistic and cultural barriers are an important obstacle in ensuring appropriateness for the use in multi-national contexts -> biased data

Availability of a valid and comparable resource use measurement (RUM) instrument is crucial for multi-sectoral and multi-national economic evaluations for evidence-based decision making





Background

PECUNIA project (Jan 2018 – Jun 2021)









- Harmonisation of costs in terms of
 - Unit of analysis
 - Unit of measurement
 - Unit cost valuation methods
 - Availability of comparable unit costs
- Harmonisation of outcomes in terms of
 - Factors of heterogeneity
 - Availabilty
 - Comparability















Methods The PECUNIA Costing Concept

Assuring the link with unit cost valuation









2.
DEFINITION



3.
MEASUREMENT

Identification of services/ interventions Linking of selected services/ interventions to an international coding system (DESDE-LTC, ICHI, ISCO, DHI) - Development of structure, measurement details of PECUNIA RUM instrument





Methods

The RUM Instrument development process

Based on Thorn et al. 2013 and Acquadro et al. 2018

STEP 1: Definition of instrument attributes

STEP 2: Identification and definition of main cost driving elements

STEP 3: Scoping review to identify evidence-based RUM recommendations

STEP 4: Development of a harmonized methodological approach (validation by health economists)

STEPs 5 & 6: Development and harmonization of the pilot PECUNIA RUM

STEP 7a: Professional English language editing and wording review

STEP 7b: Pilot testing of the PECUNIA RUM with potential respondents in AT, DE, NL & UK

STEP 8: Translatability assessment and concept elaboration

MILESTONE: Final RUM optimized for formal translation

STEP 9: Formal psychometric testing





Methods

Translatability assessment (TA) process

- Preparation of instrument for formal translation
- In collaboration with Oxford University Innovation
- Based on guidelines from Acquadro et al. 2018

STEP 7a

Wording review

- ✓ Clarity
- ✓ Grammar and spelling
- ✓ Uniqueness
- ✓ Cultural diversity
- ✓ Layout

STEP 8

Translatability assessment and concept elaboration

- performed by linguists from a linguistic, cultural and societal perspective
- **six languages**: French (France), Polish, Hebrew, Portuguese (Brazil), Russian, Spanish (Spain)
- concept elaboration to guide translators with advice on how to address all problematic issues





Results

PECUNIA RUM is a 37-page pen-and-paper questionnaire in English with 9 sections

Module		Types of resource-use measured	
Α	Place of living and overnight stays	Usual living situation, residential care, and institutional stay selected from a range of residential, health, social, educational and correctional facilities	
В	Non-residential health and social care	Use of health and social services including outpatient, daycare, helplines, and vocational services	
С	Medication Use of medications		
D	Unpaid help (informal care)	help Informal care provided by the respondent's friends, relatives, neighbors of	
E	Education	Highest level of education, current educational status, absenteeism and presenteeism at school, the use of education services (e.g. tutoring)	
F	Employment and Current employment status, absenteeism and presenteeism at paid and unpa productivity work		
G	Safety and justice system	Contacts with police, fire-and-rescue and legal services, material damage caused by the respondent (e.g. theft, vandalism), incarceration	
н	Out-of-pocket and other expenses	Personal expenses including expenses for household help, childcare, purchase of goods (e.g. wheelchair)	
I	Final remarks	Feedback	



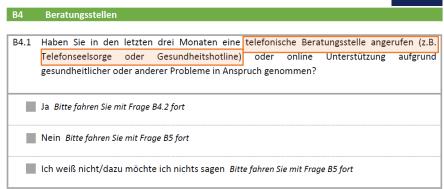
Results – Pilot testing with potential respondents Preparing 1st forward German translation

- Approach: 'in-house' translation by DE partners (MUW & UKE) in Nov 2020 & pilot tested with 2-3 colleagues
- Issues: even in the same language, we found countryspecific differences,
 - e.g. "helpline" → "Sorgentelefon" (DE) vs. "Telefonseelsorge" (AT)
 - Agreed translation: Telefonische Beratung (Telefonseelsorge, Gesundheitshotline)

B4.1 Have you called a helpline or received online support regarding health or other life problems in the past 3 months?

Yes Please go to question B4.2

No Please go to question B5



 Solution: generic definitions of concepts with national (or regional) adaptation by adding examples



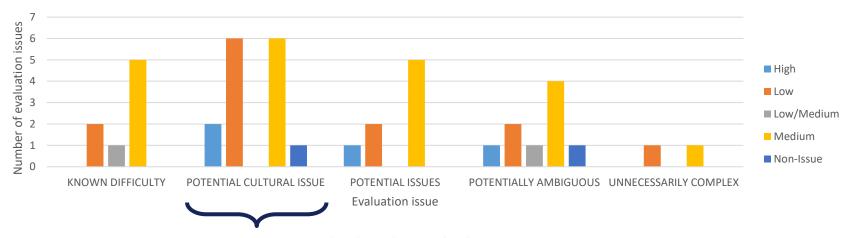
DE

I don't know/I would rather not say Please go to question B5

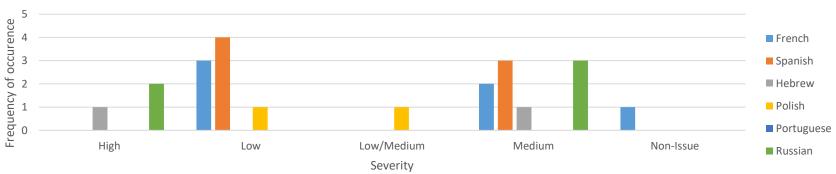


Results – Translatability Assessment Cultural issues were predominant

Translatability assessment evaluation issues by severity, N=42



Potential cultural issue by language, N=22





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Results - Translatability Assessment

Example of a potentially ambiguous issue: "Sheltered housing" I

ATHEA 2021 - Per

BEFORE TA

EN RUM Version 23, Nov 2020

SECTION A: LIVING SITUATION, RESIDENTIAL CARE AND INSTITUTIONAL STAY

In this section, we ask you about your usual place of living and any residential care or overnight institutional stays you have had in the past 3 months (i.e. in the past 90 nights).

A1	Where have you lived and where have you stayed overnight (e.g. in an institution) in the past 3 months?		
	Please tick all answers that apply and indicate the number of nights that you spent in each place. If you are unsure, please tick 'Other' and provide details.		
1	Your own home	nights	
2	Dormitory (e.g. boarding school, college, hostel)	nights	
3	Family or friend's home	nights	
4	Paid for temporary accommodation (e.g. hotel, motel, etc.)	nights	
5	Sheltered housing	nights	
6	Nursing home	nights	
7	Therapeutic community or other residential care home	nights	
8	Hospital	nights	
	Name of hospital department/service:	_	
9	Hospice/palliative care	nights	
10	Prison/jail	nights	
11	On the street	nights	

1st DE forward translation, Nov 2020

TEIL A: LEBENSSITUATION, BETREUTES WOHNEN UND AUFENTHALT IN EINER EINRICHTUNG

In diesem Teil werden Sie über ihren gewöhnlichen Wohnort, die Inanspruchnahme betreuter Wohnmöglichkeiten (z.B. Heimpflege) oder einen Aufenthalt in einer Einrichtung in den letzten drei Monaten (d.h. die letzten 90 Nächte) gefragt.

	A1	Wo haben Sie in den letzten drei Monaten gelebt und wo haben Sie die (z.B. in einem Krankenhaus)?	Nächte verbracht	
		Bitte kreuzen Sie alle zutreffenden Antworten an und geben Sie die Anzahl der Nächte in		
		der dafür vorgesehenen Zeile an. Wenn Sie unsicher sind, wählen Sie "Andere" und schreiben Sie Ihre Antwort in die dafür vorgesehene Zeile.		
	1	In meinem Zuhause	Nächte	
	2	Schlafsaal (z.B. Internat)	Nächte	
	3	Bei Familie oder Freunden	Nächte	
	4	Bezahlte, zeitweilige Unterkunft (z.B. Hotel, Motel)	Nächte	
	5	Obdachlosenunterbringung, Notschlafstelle	Nächte	
Ī	6	Pflegeheim	Nächte	
	7	Therapeutische Wohngemeinschaft oder anderes betreutes Wohnen	Nächte	
	8	Krankenhaus Fachrichtung der Station:	Nächte	
	9	Hospiz/palliative Versorgung	Nächte	
	10	Gefängnis	Nächte	
	11	Auf der Straße	Nächte	
	12	Andere, und zwar:	Nächte	







Results – Translatability Assessment

Example of a potentially ambiguous issue: "Sheltered housing" II

AFTER TA

Meaning in the UK is different

FINAL EN RUM Version 28, Jul 2021

SECTION A: PLACE OF LIVING AND OVERNIGHT STAYS

in this section, we ask you about your <mark>usual place of living</mark> and any overnight stays you have had in the past 3 months (i.e. in the past 90 nights).

	Tricie nave journed or stayed overinging (e.g. in	nospital) in the past 3 months		
	Please tick all answers that apply and indicate the number of nights that you spent in each place.			
	If you are unsure, please tick 'Other' and provide de	etails.		
1	Individual or shared flat or house	nights		
2	Family or friend's flat or house	nights		
3	Dormitory (e.g. boarding school, university residen	ce)nights		
4	Paid temporary accommodation (e.g. hotel)	nights		
5	Emergency shelter (e.g. temporary shelter for hom	eless)nights		
6	Sheltered housing (e.g. housing with assistance)	nights		
7	Nursing home (e.g. residential care home with nurs	sing)nights		
8	Other long-term residential care home	nights		
9	Therapeutic community home (e.g. temporary groutherapeutic purposes)	up residence fornights		
10	Hospital			
	Type of hospital department/service (e.g. oncology psychiatry):	, surgery,nights		
	Type of hospital department/service (e.g. oncology psychiatry):	, surgery,		
	Type of hospital department/service (e.g. oncology psychiatry):	, surgery,nights		
11	Palliative care (e.g. hospice)	nights		
12	Place of detention (e.g. prison)	nights		
13	On the street	nights		
14	Other, please A	THEA 2021 - Perić nights		

FINAL RUM DE forward translation, Sep 2021

TEIL A: WOHNORT UND ÜBERNACHTUNGEN

Wo haben Sie in den letzten drei Monaten geleht und wo haben Sie die Nächte verbracht (z.B.

In diesem Teil werden Sie über Ihren Wohnort und etwaige Übernachtungen in den letzten drei Monaten gefragt (die letzten 90 Nächte).

	in einem Krankenhaus)?	,	
	Bitte kreuzen Sie alle zutreffenden Antworten an und geben Si dafür vorgesehenen Zeile an. Wenn Sie unsicher sind, wählen S Antwort in die dafür vorgesehene Zeile.		
1	Eigene Wohnung, Haus oder Wohngemeinschaft	Nächte	
2	Bei Familie oder Freunden	Nächte	
3	Schlafsaal (z.B. Internat, Studentenwohnheim)	Nächte	
4	Bezahlte, zeitweilige Unterkunft (z.B. Hotel)	Nächte	
5	Notschlafstelle (z.B. Obdachlosenunterbringung)	Nächte	
6	Betreutes Wohnen	Nächte	
7	Pflegeheim	Nächte	
8	Andere betreute Wohnform	Nächte	
9	Therapeutische Wohngemeinschaft	Nächte	
LO	Krankenhaus		
	Fachrichtung der Station (z.B. Onkologie, Chirurgie, Psychiatrie):	Nächte	
	Fachrichtung der Station (z.B. Onkologie, Chirurgie, Psychiatrie):	Nächte	
	Fachrichtung der Station (z.B. Onkologie, Chirurgie, Psychiatrie):	Nächte	
11	Palliative Versorgung (z.B. Hospiz)	Nächte	
12	Haftort (z.B. Gefängnis)	Nächte	
13	Auf der Straße	Nächte	
14	Andere, und zwar:	Nächte	



24/09/2021



Results – Translatability Assessment

Example of a potentially ambiguous issue: "Sheltered housing" III

Concept Elaboration specified meanings

- Sheltered housing → refers to a type of accommodation designed especially for elderly or disabled people consisting of a group of individual premises, often with some shared facilities and a caretaker. Also called: sheltered accommodation, sheltered homes.
- Emergency shelter → a sanctuary for temporary housing, set up to provide for the needs of homeless people/women, often including shelter, food, sanitation and other forms of support, or for the needs of those using mental health services.







Results – Translatability Assessment Concept Elaboration Document



Concept Elaboration Report - Version #1 – 5/2021

Ref	Questionnaire Wording	Concept Elaboration	Developer's Comments	Additional Localization recommendations
60	Emergency ambulance (<u>e.g.</u> paramedics)	One of the possible answers to this question. It refers to any ride in an emergency ambulance or any visit from paramedics.		Note to Translators: please localize examples as needed (for example, there might not be paramedics)
61	Out-of-hours medical service (<u>e.g.</u> night care)	One of the possible answers to this question. It refers to any contact with an emergency physician that was available at any given moment.		
62	Accident and Emergency (A&E) department	One of the possible answers to this question. It refers to any visit to a healthcare department that treats emergencies or accident-related injuries.		Note to Translators: please localize as needed

56 page document







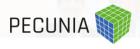
Discussion

- Concept Elaboration Document is crucial
 - Improving translation quality and comparability already during the development stage of the RUM instrument and not just at the translation stage is important
- Cooperation of linguists and RUM developers is key
 - Close collaboration at the onset of the translation phase has a positive impact on minimizing the hurdles in the creation of future translations and counteract translation problems before they arise
- Multi-national applicability & diffusion is fostered
 - The PECUNIA RUM is a linguistically and culturally appropriate RUM for the translation in six languages (French, Polish, Hebrew, Portuguese, Russian and Spanish)
 - Comparable economic evaluations around the globe are enabled



Access the PECUNIA RUM Instrument

https://www.pecunia-project.eu/tools/rum-instrument



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PECUNIA RUM Instrument

The PECUNIA Resource Use Measurement (PECUNIA RUM) Instrument is a Microsoft Word©-based internationally standardised, harmonised and validated, generic, self-reported RUM instrument that measures resource use in all relevant sectors for costing from a societal perspective in the adult population: health and social care, education, (criminal) justice, productivity losses, and informal care. It is consistent with the harmonised PECUNIA Costing Concept (PECUNIA Care Atom, PECUNIA Service Lists, PECUNIA Coding System) and therefore with other PECUNIA Costing Tools (PECUNIA RUC Templates, PECUNIA RUC Compendium) to achieve cross-country and cross-sectoral comparability by referring to activity-based rather than linguistic equivalence of services. The PECUNIA RUM was developed as a 37-page pen-and-paper questionnaire in English by the scientific partners of the PECUNIA Consortium between mid-2019 and June 2021. It has a modular structure of 9 sections covering questions related to

- · Place of living and overnight stays (Section A)
- Non-residential health and social care (Section B)
- Medication (Section C)
- Unpaid help (informal care) (Section D)
- Education (Section E)
- Employment and productivity (Section F)
- Safety and justice system (Section G)
- Out-of-pocket and other expenses (Section H)
- Final remarks (Section I).

While Sections A, B, C, D, E, G, H were all developed newly, the section on 'Employment and productivity' (Section F, the so called IPCQ PECUNIA) is based on the existing IPCQ instrument. The different modules have been harmonised with each other alongside the following steps: a

Access/permission

Anyone whishing to use the PECUNIA RUM for non-commercial research, healthcare and academic teaching activities can do so free-of-charge. For further information on access for non-commercial purposes and details of permission to use for commercial purposes, please contact the PECUNIA Consortium via e-mail at pecunia@meduniwien.ac.at.

Sample copy of the PECUNIA RUM





Thank you for your attention!



Further information on PECUNIA

Our website:

https://www.pecunia-project.eu





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