

# EBC Session, 7 April 2024, 10:00-11:30

## Assessing the Value of Mental Health

## Treatments for Youth in Europe



**EPA 2024**  
Budapest, Hungary • 6-9 April 2024

32<sup>nd</sup> EUROPEAN  
CONGRESS OF  
PSYCHIATRY



# Autism care pathway in Europe

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Centro de Investigación Biomédica En Red  
de Salud Mental



# Disclosure: Celso Arango

Funding source	Consultant	Grant/research support	Speakers bureau
AMGEN	X		
AstraZeneca	X	X	X
Bristol-Myers Squibb	X	X	X
Caja Navarra		X	
Comunidad de Madrid		X	
Fundación Alicia Koplowitz	X	X	
Fundación Marcelino Botín	X		
Fundación Mutua Madrileña		X	
Instituto de Salud Carlos III, Spanish Ministry of Economy and Competitiveness	X	X	
Janssen-Cilag	X		X
Lundbeck			X
NARSAD		X	
Otsuka			X
Pfizer, Inc.	X		X
Roche	X		X
Servier	X		
Schering-Plough	X		
Shire	x		
Spanish Ministry of Education	X	X	
Stanley Foundation			
Takeda	X	X	X
Teva			



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**EBC innovative research: converge data into policy recommendations.**



## Value of Treatment Study VoT2

<https://www.braincouncil.eu/projects-and-initiatives/vot2/>



AIMS-2-TRIALS stands for Autism Innovative Medicine Studies-2-Trials.

WP5 Autism Policies package objectives are:

1. Carry out high quality policy relevant research with autistic people and carers
2. Engage with autistic people and families throughout the project and communicate research outcomes with the community.
3. Communicate research findings to policy makers to help develop and implement policies that support autistic people and their families.

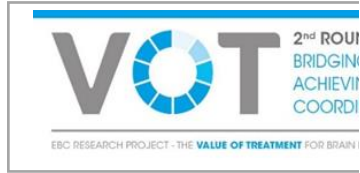
For further information and 10 Points of change survey exploring policy priorities:  
<https://www.aims-2-trials.eu/our-research/autism-policy-across-europe/>

# Value of Treatment (VoT) study



**Step 1: To identify the treatment gaps/unmet needs of autistic children and causing factors → care pathway analysis.**

- A care pathway is a multidisciplinary management tool based on the healthcare plan for a specific group, in which the different tasks by the professionals involved in their care are defined, optimized and sequenced (Schrijvers et al 2012).
- The aim of a care pathway is to enhance quality of care by promoting people's safety, increasing their satisfaction with services, and optimizing the use of resources (Mohr, et al 2018).



### Research Article

**Cite this article:** Mendez MA, Canitano R, Oakley B, San José-Cáceres A, Tinelli M, Knapp M, Cusack J, Parellada M, Violland P, Derk Plas JR, Murphy DGM, Quoidbach V, Arango C (2023). Autism with co-occurring epilepsy care pathway in Europe. *European Psychiatry*, **66**(1), e61, 1–6  
<https://doi.org/10.1192/j.eurpsy.2023.2426>

Step 2: Economic  
<https://link.springer.com/doi/10.1192/j.eurpsy.2023.2426>

Step 3: To propose policy recommendations on how to improve European care pathway.

M€ *European Psychiatry*

### Research Article

**Cite this article:** Mendez MA, Oakley B, Canitano R, San José-Cáceres A, Tinelli M, Knapp M, Cusack J, Parellada M, Violland P, Derk Plas JR, Canal-Bedia R, Bejarano-Martin A, Murphy DGM, Quoidbach V, Arango C (2023). Autism care pathway in Europe. *European Psychiatry*, **66**(1), e81, 1–10  
<https://doi.org/10.1192/j.eurpsy.2023.2435>

## Autism with co-occurring epilepsy care pathway in Europe

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James Cusack<sup>7</sup>, Mara Parellada<sup>1,4,5,8,9</sup>, Pierre Violland<sup>4</sup> , Jan R. Derk Plas<sup>4</sup> ,  
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## Autism care pathway in Europe

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## Step 1:

# Care Pathway analysis:

## Methods:

1. The **care pathway of autistic children and the care pathway of autistic children with associated epilepsy** was analysed from a carer, autistic community and professional perspective.
2. Members of the working group (WG) met in Brussels and remotely (due to the COVID-19 pandemic) between 2019 and 2021.
3. We conducted a **survey aimed at carers of autistic children ages 0 to 18 living in Italy, Spain and the U.K.** Survey was developed based on the one conducted by the Autism Spectrum Disorder in the European Union (ASDEU) network (Bejarano-Martin et al 2019) **with a focus on WG defined critical points: delays in screening and diagnosis, personalised support and comorbidity epilepsy.** Survey was approved by local ethics committees in each country.



# Autism Care Pathway analysis:

## Results:

N total: 712 (48 excluded, did not meet inclusion criteria: <18 years old and resident in the three countries investigated)

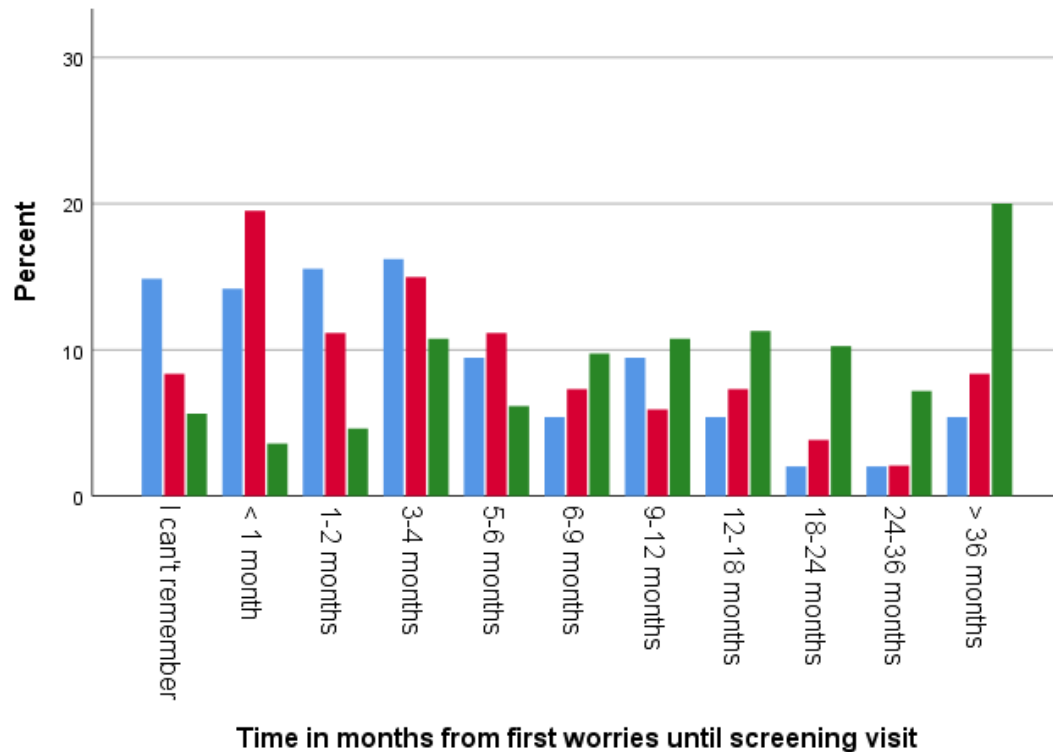
For a N corrected total of 663 (547 completed data, 116 incomplete)

Sample characteristics	
Age of respondents in years, mean (SD)	44 (8.08)
Sex of person completing survey (%male, % female)	16 %, 84 %
Autistic child's age at time of survey, mean (SD)	10 (4.39)
Sex of autistic child (%male, %female)	77 %, 23 %

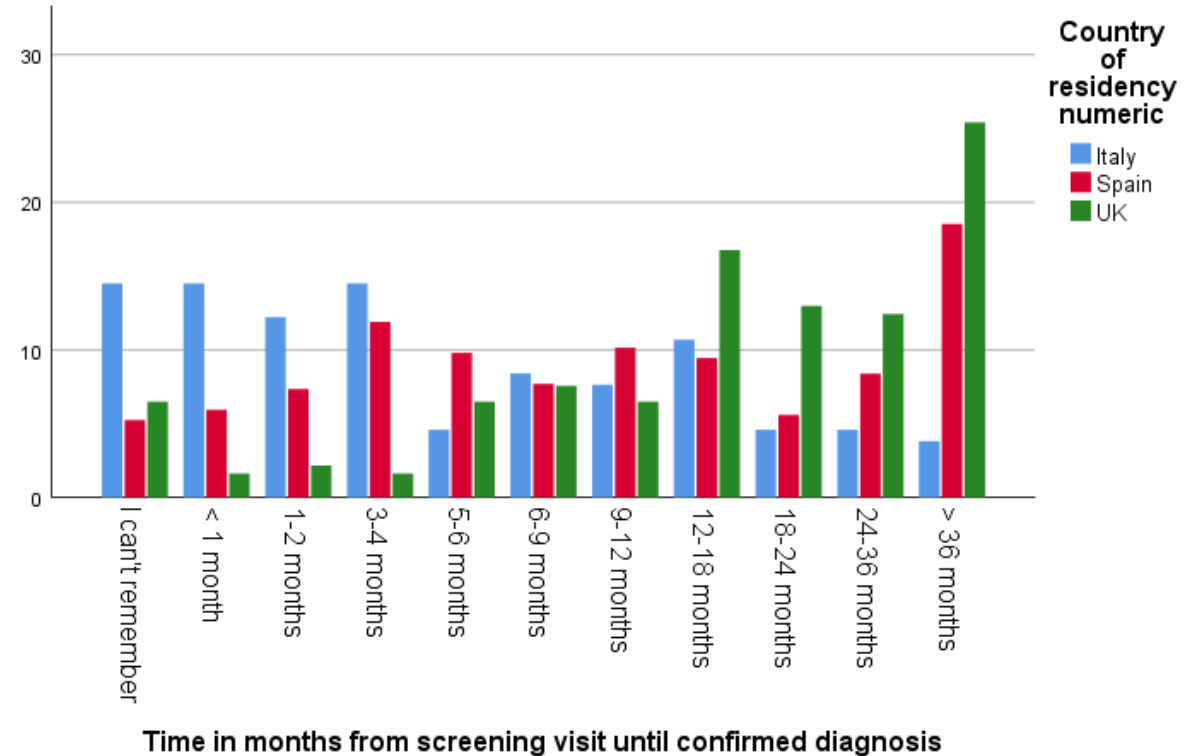
Autistic child's gender per country of residency			
Country	Male	Females	TOTAL
Italy	129	29	158
Spain	222	65	287
UK	158	60	218
Total sample	509	154	663

# Identified treatment gaps:

## Delayed autism screening/diagnosis:



49% of carers in the UK, 22% in Spain and 15% in Italy stated it took them **over a year** after first worries were raised to be offered a screening visit.

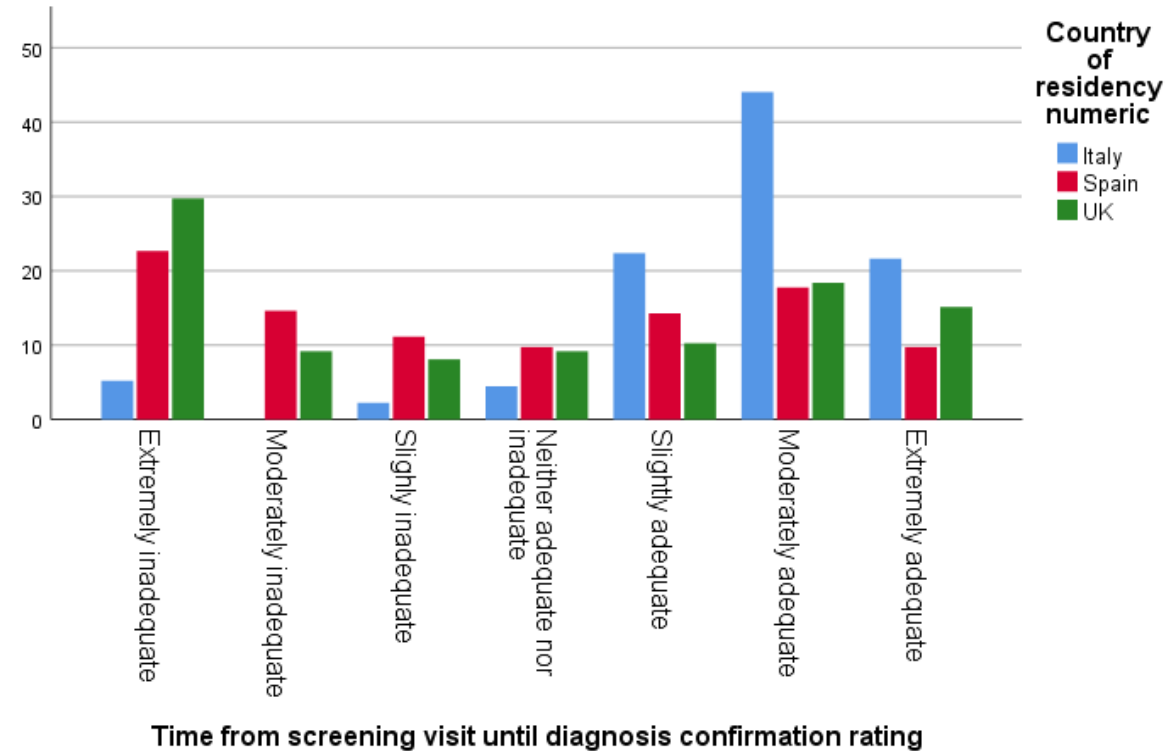
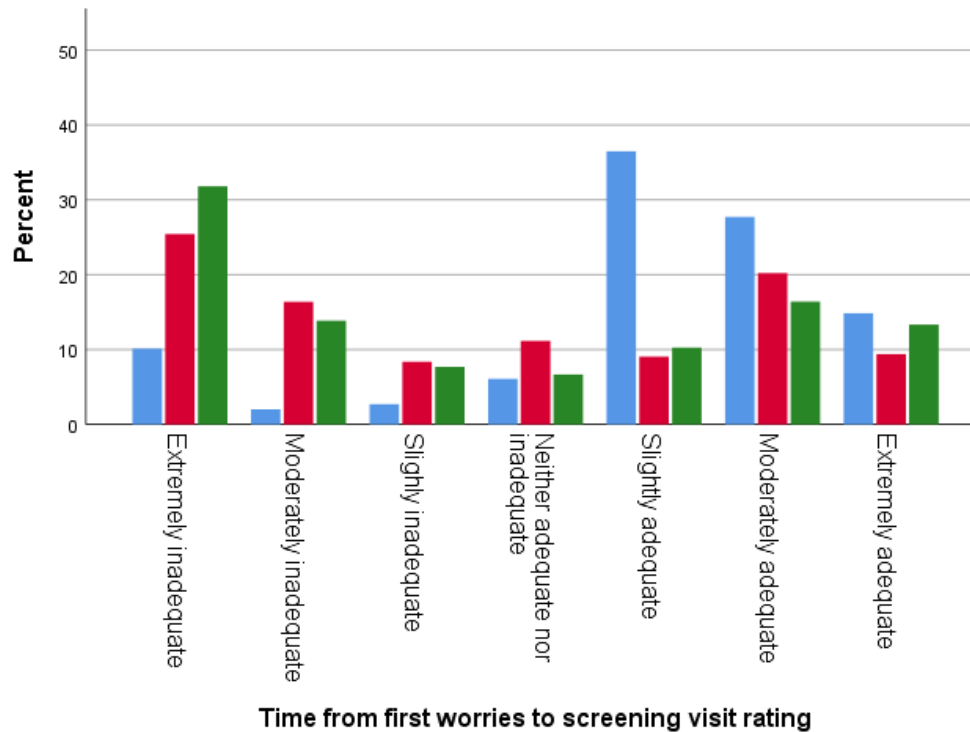


68% of carers in the UK, 42% in Spain and 24% in Italy reported it took them **over a year** after screening visit to have a diagnosis assessment.

UK NICE guidelines (2021) state that if screening visit indicates autism a diagnostic assessment should start within 3 months.

# Identified treatment gaps:

## Overall dissatisfaction with waiting times:



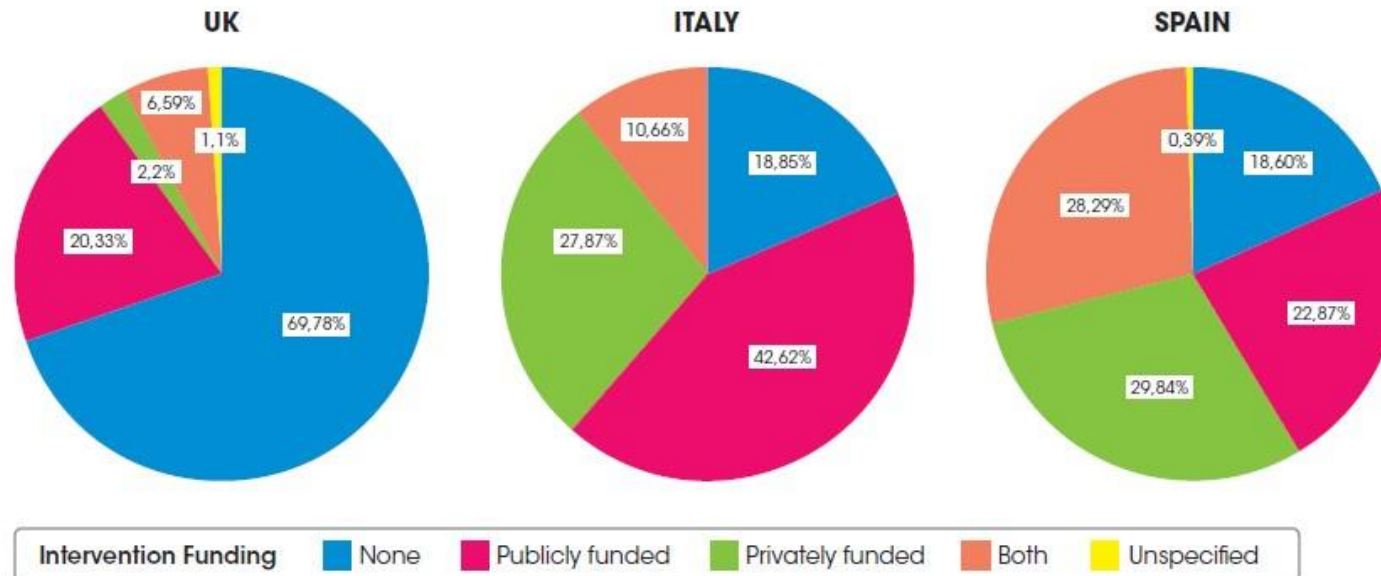
53% of respondents in the UK, 50% in Spain, and 15% in Italy rated the waiting time from first worries until screening visit as inadequate.

48% of respondents in Spain, 47% in the UK, and 8% in Italy rated the waiting time from screening visit until diagnosis as inadequate.

# Identified treatment gaps:

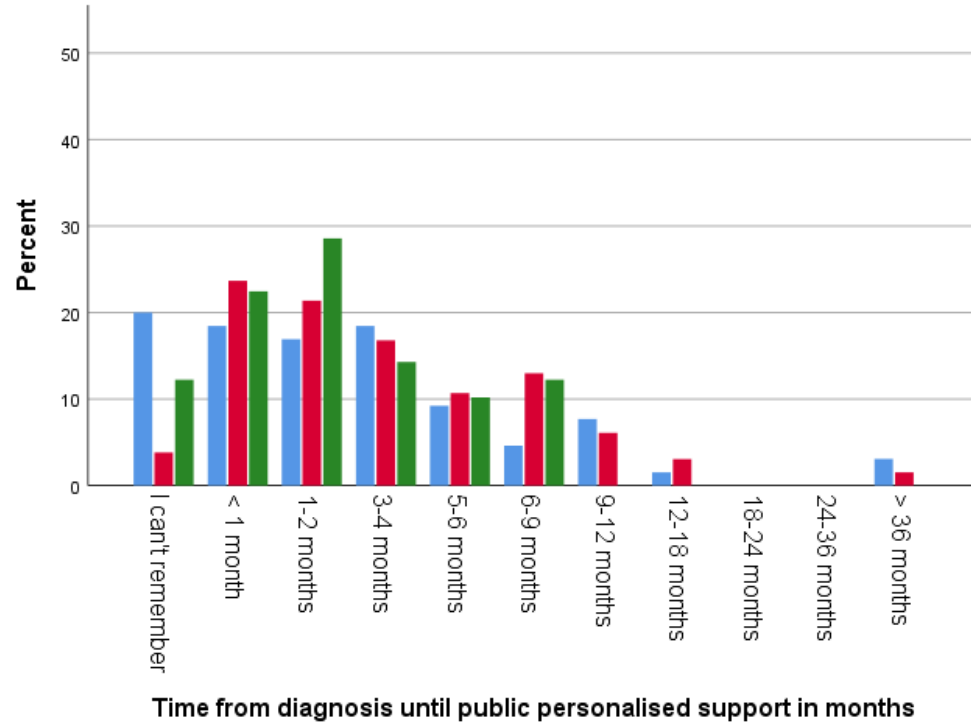
## No access to personalised support once diagnosis has been confirmed:

Only 30% of respondents in the UK stated that the autistic children received any personalised support after diagnosis, compared to 80% in Italy and 82% in Spain. However, a good proportion of these relied on private funding or a combination of both private and public funding.

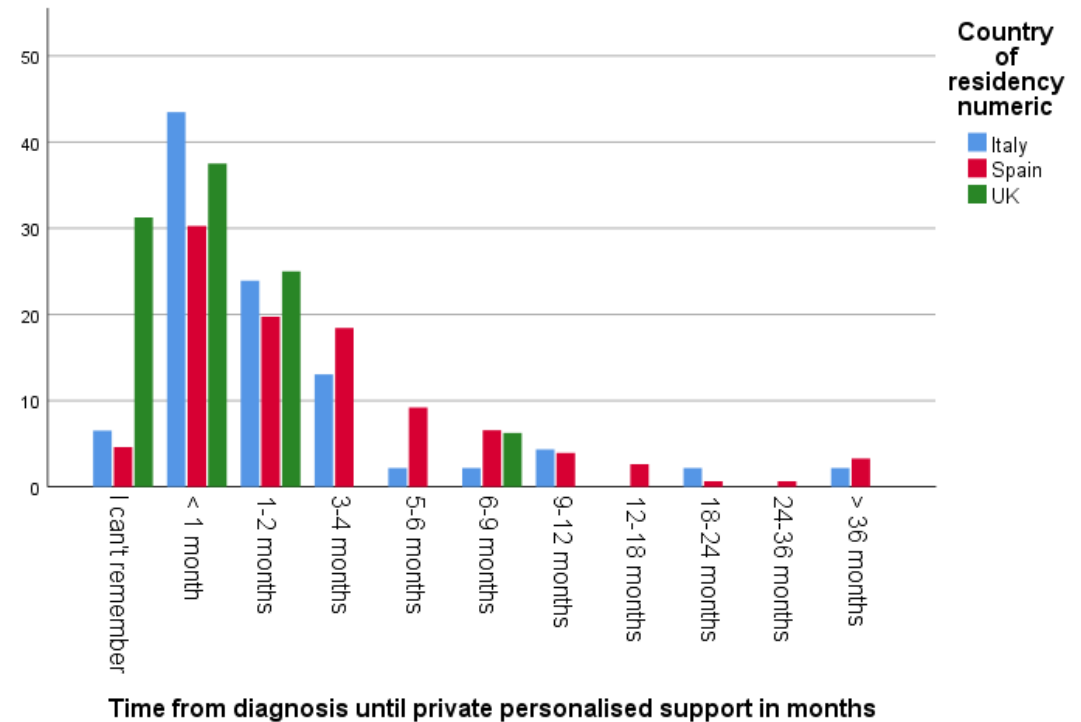


# Identified treatment gaps:

## Delay access to personalised support once diagnosis has been confirmed:



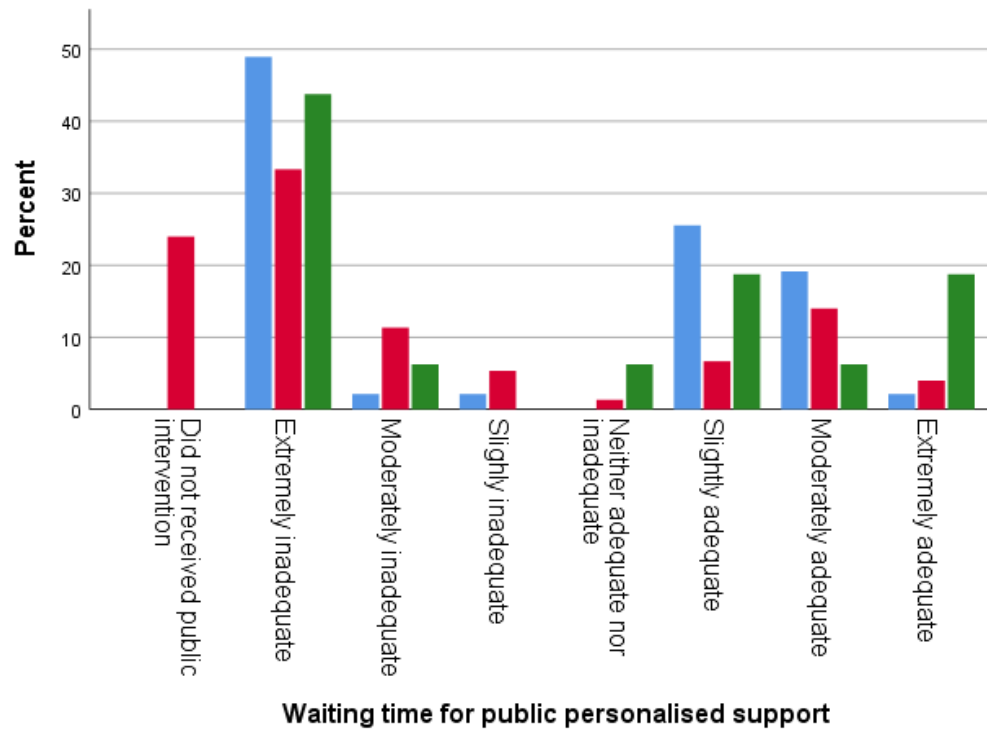
Only 24% of respondents in Spain, 22% in the UK, and 19% in Italy said the time from a confirmed diagnosis until publicly funded personalised support started was less than one month.



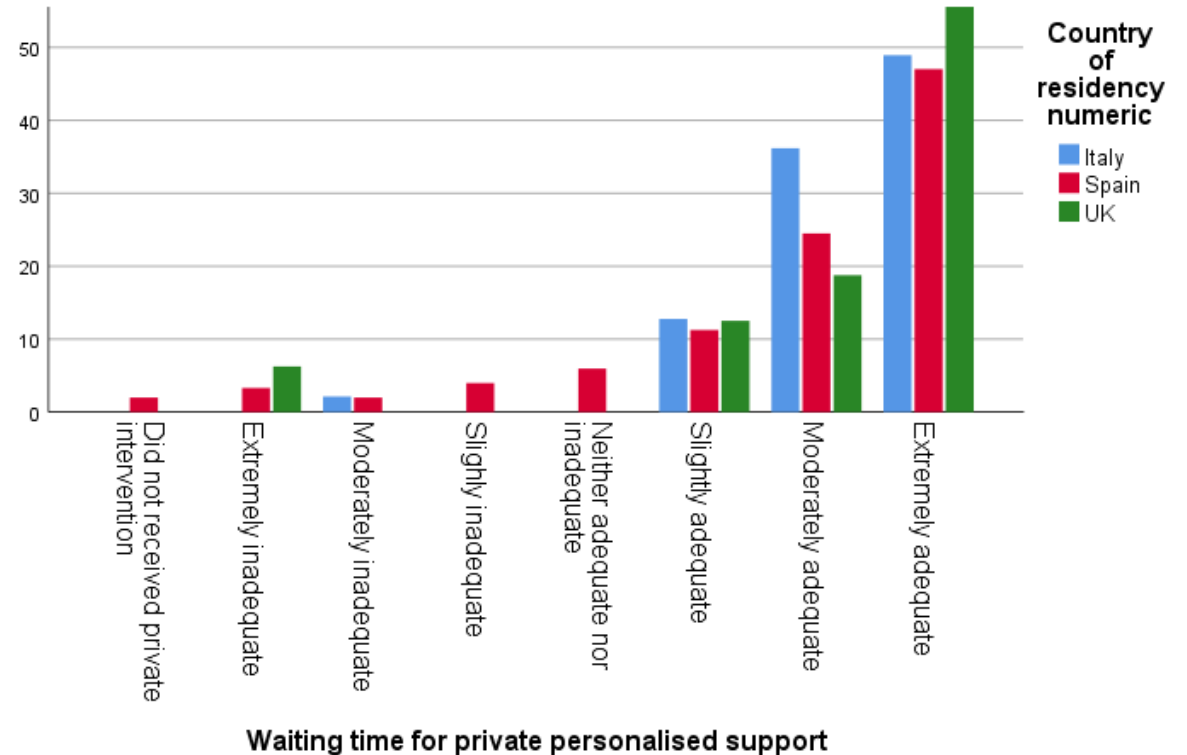
While 44% of respondents in Italy, 38% in the UK, and 30% in Spain stated that it took them less than one month to start a privately funded personalised support.

# Identified treatment gaps:

## Overall dissatisfaction with waiting times for publicly funded personalised support:



58% of respondents in the UK, 47% in Spain, and 34% in Italy rated the waiting time from diagnosis until publicly funded support started as inadequate.



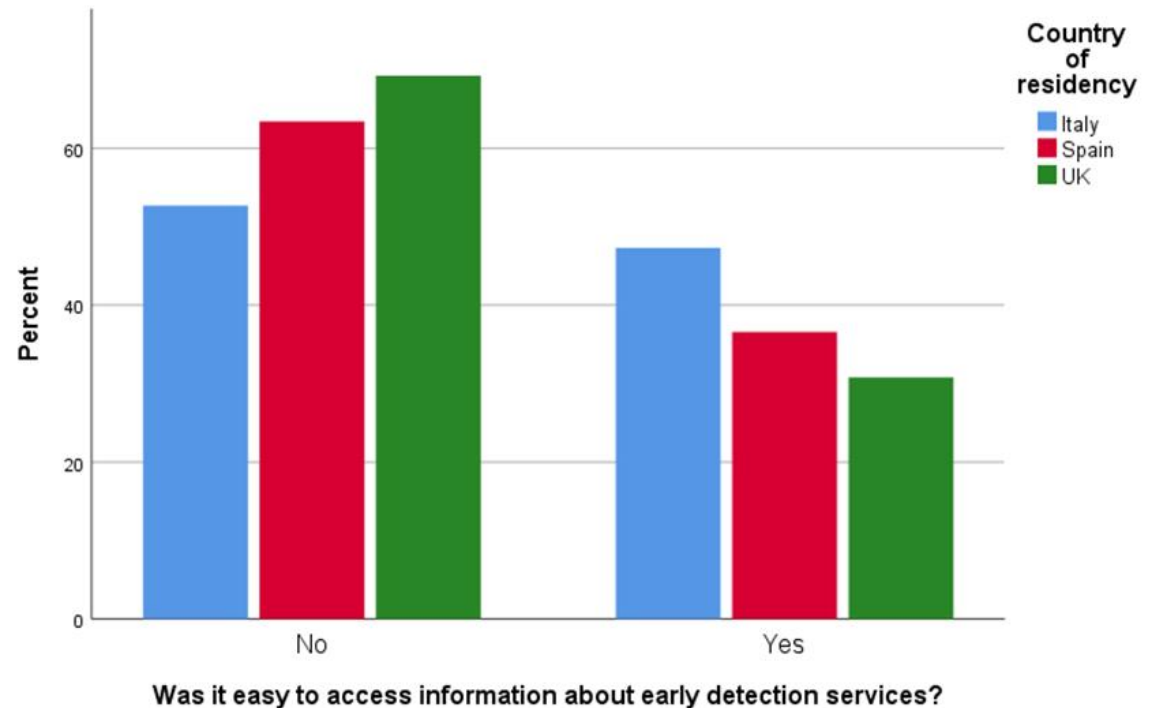
87% of respondents in Italy, 71% in Spain, and 25% in the UK rated the waiting time from diagnosis until privately funded support started as adequate.

# Identified treatment gaps:

## Limited information about autism and how to access early detection services:

62% of carers reported that it was not easy to access information about early detection services.

Was it easy to access information about early detection services?			Italy	Spain	UK
	No	% within Country of residency numeric	52.7%	63.4%	69.2%
	Yes	% within Country of residency numeric	47.3%	36.6%	30.8%
TOTAL		% within Country of residency numeric	100.0%	100.0%	100.0%



## Identified treatment gaps:

### Overall lack of support to parents/carers of autistic children:

- 41% of carers (46% in Italy, 44% in the UK, and 36% in Spain) reported receiving no guidance or support after raising their first worries to their assigned professional.
- 31% of carers (42% in the UK, 28% in Spain and 22% in Italy) said they received very little or no support after the diagnosis was confirmed.
- 58% of carers (69% in Italy, 56% in the UK and 55% in Spain) said they had not received any training, coaching, or counselling to help them cope with their children's difficulties.

Parents of autistic children report high levels of stress  
(Schieve et al, 2007; Kiami and Goodgold, 2017; Estes et al, 2009;  
Dabrowska, 2010; Giovagnoli et al, 2015; Miranda et al, 2019)



## Quotations from survey respondents (parents or carers):

*“No one from health services mentioned a possibility of autism until my child was 11 years old”*

*“Health professionals are not trained in autism”*

*“There are not enough diagnostic clinics/services”*

*“Never received any early intervention programme”*

*“Early intervention is crucial”*

*“I was given minimal information after diagnosis”*

## In conclusion:

- The identified gaps in the care pathway may be caused by **insufficient availability of publicly funded autism specialist clinics** and autism trained specialists (Crane et al, 2018; National Autistic Society, 2019; Lord et al; 2021).
- Our results highlight the fact that publicly funded diagnostic and therapeutic services are **unable to accommodate the number of autistic children** in need of these services nor the needs of a growing autistic population. This results in long waiting lists or the necessity to rely on privately funded services.

## In conclusion:

- Despite autism's known societal and personal impact, Europe-wide consensus and support for early detection, diagnosis, and intervention are lacking.
- These findings call for policy harmonisation in Europe to shorten long wait times for diagnosis and personalised support and therefore, improve autistic people and their families' journey experience and quality of life.

# SPECIAL THANKS TO:

## OUR SPONSORS:



## MEMBERS OF THE WG:

**Andreina Méndez**  
**Vinciane Quoidbach**  
**Roberto Canitano**  
**Bethany Oakley**  
**Declan Murphy**  
**Antonia San Jose-Caceres**  
**Mara Parellada**  
**James Cusack**  
**Martin Knapp**  
**Michela Tinelli**  
**Ricardo Canal**  
**Aurelie Baranger**  
**Sue Bailey**  
**Lydia Lanman**  
**Veronique Crutel**  
**Maud Beillat**  
**Anne-Claire Julienne**  
**Leo Finn**  
**Antonio Persico**  
**Roland Pochet**  
**Aine Roddy**  
**Jose Luis Trejo**  
**Spyros Zorbas**

## TO ALL THE CARERS

Who completed the survey



## University of Cambridge team:

Molly McCabe  
and Rosie Holt.

Academic Psychiatry

Professor Allan Young

Centre for Affective Disorders

Institute of Psychiatry, Psychology & Neuroscience

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Care Pathways for People with  
Major Depressive Disorders

## Disclosures

Employed by King's College London;  
Honorary Consultant Maudsley and Bethlem Hospitals (NHS);  
Head of Mood Disorders Service, National Affective Disorders Service, Maudsley Hospital;

Paid lectures and advisory boards for all major pharmaceutical companies with drugs used in affective and related disorders;

No direct share holdings in pharmaceutical companies or related companies;

Grant funding (past and present): NIMH (USA); CIHR (Canada); NARSAD (USA); Stanley Medical Research Institute (USA); MRC (UK); Wellcome Trust (UK); Royal College of Physicians (Edin); BMA (UK); NIHR (UK); EU Horizon 2020.

Formerly Chair of Special Committee for Psychopharmacology RCPsych; past-President of International Society for Affective Disorders and past-President of British Association for Psychopharmacology.

# Global DALYs by mental disorder in 2019

- Proportion of mental disorder DALYs:
  - Depressive disorders 37.3%
  - Anxiety disorders 22.9%
  - Schizophrenia 12.2%
- Burden due to mental disorders present across all age groups, although relative contribution by disorder varied by age
- For both sexes, DALYs:
  - Increased steadily during childhood/adolescence
  - Peaked between 25-34
  - Decreased steadily after 35

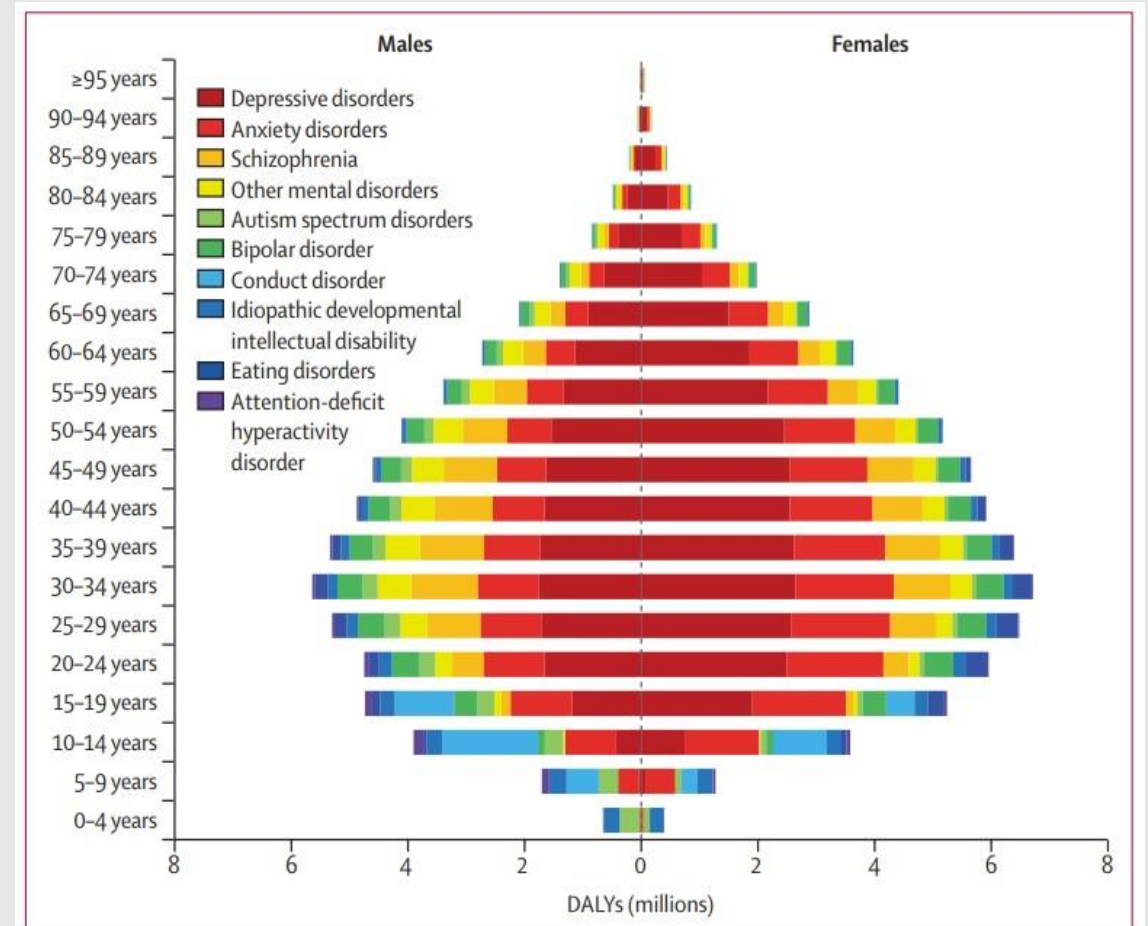


Figure 1: Global DALYs by mental disorder, sex, and age, 2019

DALYs=disability-adjusted life-years.

GBD 2019 Mental Disorders Collaborators, Lancet Psychiatry, 2022

## Two-thirds of Britons with depression get no treatment

If these figures related to cancer patients the nation would be in uproar, says new president of Royal College of Psychiatrists

Sarah Boseley, health editor

The Guardian, Wednesday 13 August 2014 13.12 BST

 Jump to comments (881)



The gap between treatment for mental health problems and physical illnesses is so huge that it may prove impossible to bridge, says Professor Simon Wessely.

Photograph: Denis Closon/Rex

Less than a third of people with common mental health problems get any treatment at all – a situation the nation would not tolerate if they had cancer, according to the incoming president of the Royal College of

## Undertreatment of people with major depressive disorder in 21 countries\*

Graham Thornicroft, Somnath Chatterji, Sara Evans-Lacko, Michael Gruber, Nancy Sampson, Sergio Aguilar-Gaxiola, Ali Al-Hamzawi, Jordi Alonso, Laura Andrade, Guilherme Borges, Ronny Bruffaerts, Brendan Bunting, Jose Miguel Caldas de Almeida, Silvia Florescu, Giovanni de Girolamo, Oye Gureje, Josep Maria Haro, Yanling He, Hristo Hinkov, Elie Karam, Norito Kawakami, Sing Lee, Fernando Navarro-Mateu, Marina Piazza, Jose Posada-Villa, Yolanda Torres de Galvis and Ronald C. Kessler

### Background

Major depressive disorder (MDD) is a leading cause of disability worldwide.

### Aims

To examine the: (a) 12-month prevalence of DSM-IV MDD; (b) proportion aware that they have a problem needing treatment and who want care; (c) proportion of the latter receiving treatment; and (d) proportion of such treatment meeting minimal standards.

### Method

Representative community household surveys from 21 countries as part of the World Health Organization World Mental Health Surveys.

### Results

Of 51 547 respondents, 4.6% met 12-month criteria for DSM-IV MDD and of these 56.7% reported needing treatment. Among those who recognised their need for treatment, most (71.1%) made at least one visit to a service provider. Among those who received treatment, only 41.0%

received treatment that met minimal standards. This resulted in only 16.5% of all individuals with 12-month MDD receiving minimally adequate treatment.

### Conclusions

Only a minority of participants with MDD received minimally adequate treatment: 1 in 5 people in high-income and 1 in 27 in low-/lower-middle-income countries. Scaling up care for MDD requires fundamental transformations in community education and outreach, supply of treatment and quality of services.

### Declaration of interest

In the past 3 years, R.C.K. received support for his epidemiological studies from Sanofi Aventis, was a consultant for Johnson & Johnson Wellness and Prevention and served on an advisory board for the Johnson & Johnson Services Inc. Lake Nona Life Project. R.C.K. is a co-owner of DataStat Inc., a market research firm that carries out healthcare research.

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# The challenge of MDD

 Despite being a **leading cause of disability**<sup>1</sup>, only a minority of patients receive **minimally adequate treatment**<sup>2</sup>

**1 in 5**

in high-income countries<sup>2</sup>

**1 in 27**

in low-/lower-middle-income countries<sup>2</sup>

## Barriers to treatment include:<sup>2</sup>



- Scarce mental health services
- Lack of awareness of MDD as treatable
- Stigma and social exclusion

## Research Article

**Cite this article:** Strawbridge R, McCrone P, Ulrichsen A, Zahn R, Eberhard J, Wasserman D, Brambilla P, Schiena G, Hegerl U, Balazs J, Caldas de Almeida J, Antunes A, Baltzis S, Carli V, Quoidbach V, Boyer P, Young AH (2022). Care pathways for people with major depressive disorder: A European Brain Council Value of Treatment study. *European Psychiatry*, **65**(1), e36, 1–12  
<https://doi.org/10.1192/j.eurpsy.2022.28>

Received: 31 January 2022

Revised: 19 May 2022

Accepted: 19 May 2022












### Keywords:

Care pathways; diagnosis; major depressive

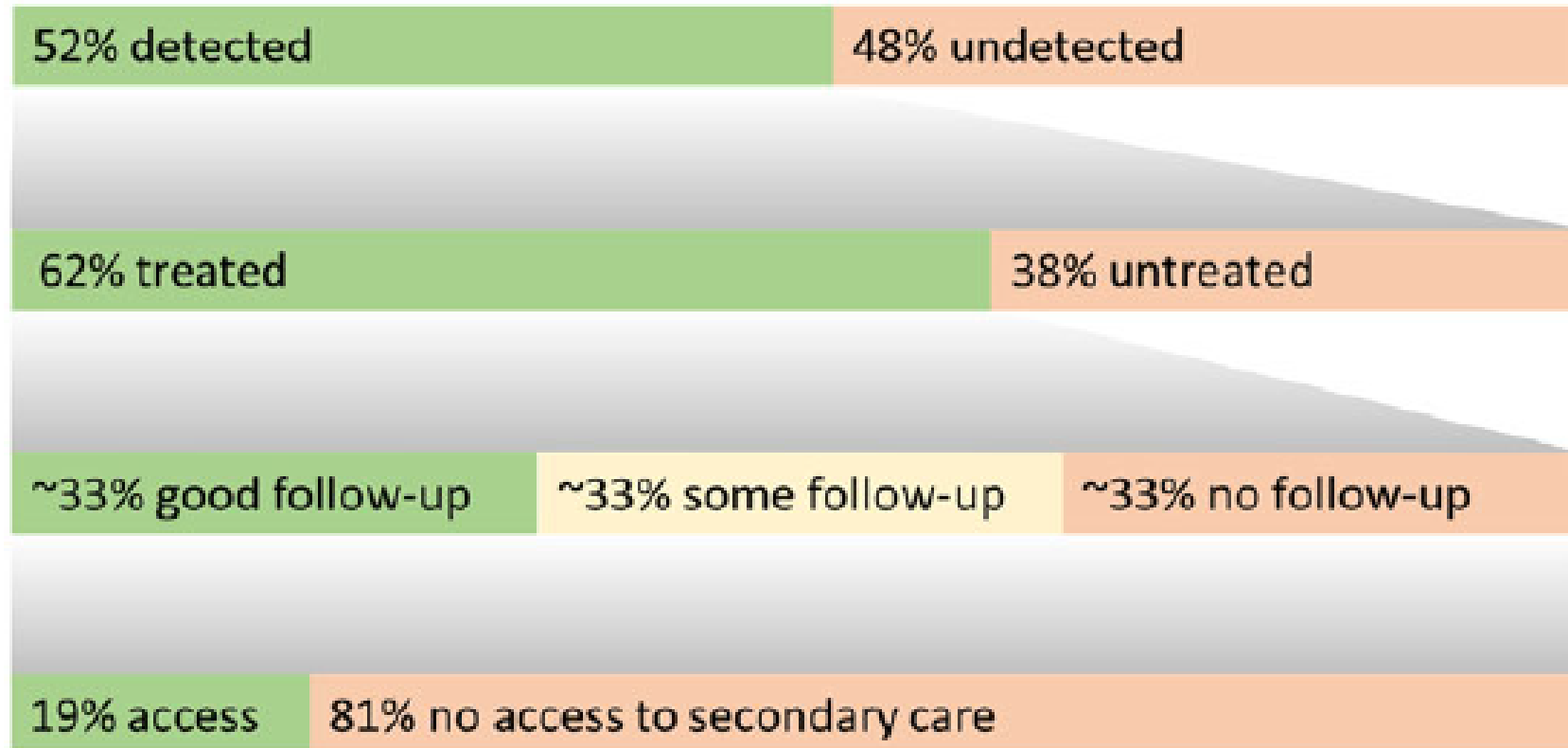
Article link:



# Care pathways for people with major depressive disorder: A European Brain Council Value of Treatment study

Rebecca Strawbridge<sup>1\*</sup> , Paul McCrone<sup>2</sup> , Andrea Ulrichsen<sup>1</sup> , Roland Zahn<sup>1</sup> ,  
Jonas Eberhard<sup>3</sup> , Danuta Wasserman<sup>4</sup> , Paolo Brambilla<sup>5,6</sup> ,  
Giandomenico Schiena<sup>5</sup>, Ulrich Hegerl<sup>7</sup>, Judit Balazs<sup>8,9</sup> , Jose Caldas de Almeida<sup>10</sup>,  
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**Figure 3.** Summary graphic integrating treatment gap estimates.

For treatment gaps 1, 3, 4, and 5, this graphic summarizes the estimated proportion of individuals with each outcome. The top row represents all individuals with a major depressive episode, the second represents those with a diagnosis, and the third/fourth of those treated for depression.

# MDD treatment gaps

Current care pathways (split by treatment gap) averaged across data sources and countries.

- 1: Rate of depression detection: ~ 50% episodes**
- 2: Delays to detection or treatment of depression: ~ 1-5 years**
- 3: Rates of treatment: ~ 25-50% of patients. Low rates particularly of psychological therapy**
- 4: Follow-up after treatment initiation: ~ 30-65% of patients seen < 3 months**
- 5: Access to secondary (psychiatric) services: ~ 5-25% of patients**
- 6: Access to specialist mood disorders services: Limited/no data**

*“Primary care should have also employed psychologist, social workers and links with psychosocial rehabilitation units and institutions supporting employment seekers” [Psychiatrist, Sweden]*

*“We're 10,000 GPs short in England... We need as much help as we can get to deliver a caring, effective service.” [GP, UK]*

*“I feel that physicians MUST be able to allocate the time that is really needed for a thorough evaluation of the patient and careful integrated therapy plan (pharmacological + psychological) prescription” [Person with lived experience, Italy]*

*“Increases in access to secondary care for those who are suffering from depression is very important - rejection to access these services can really be damaging to the patient” [Person with lived experience, UK]*

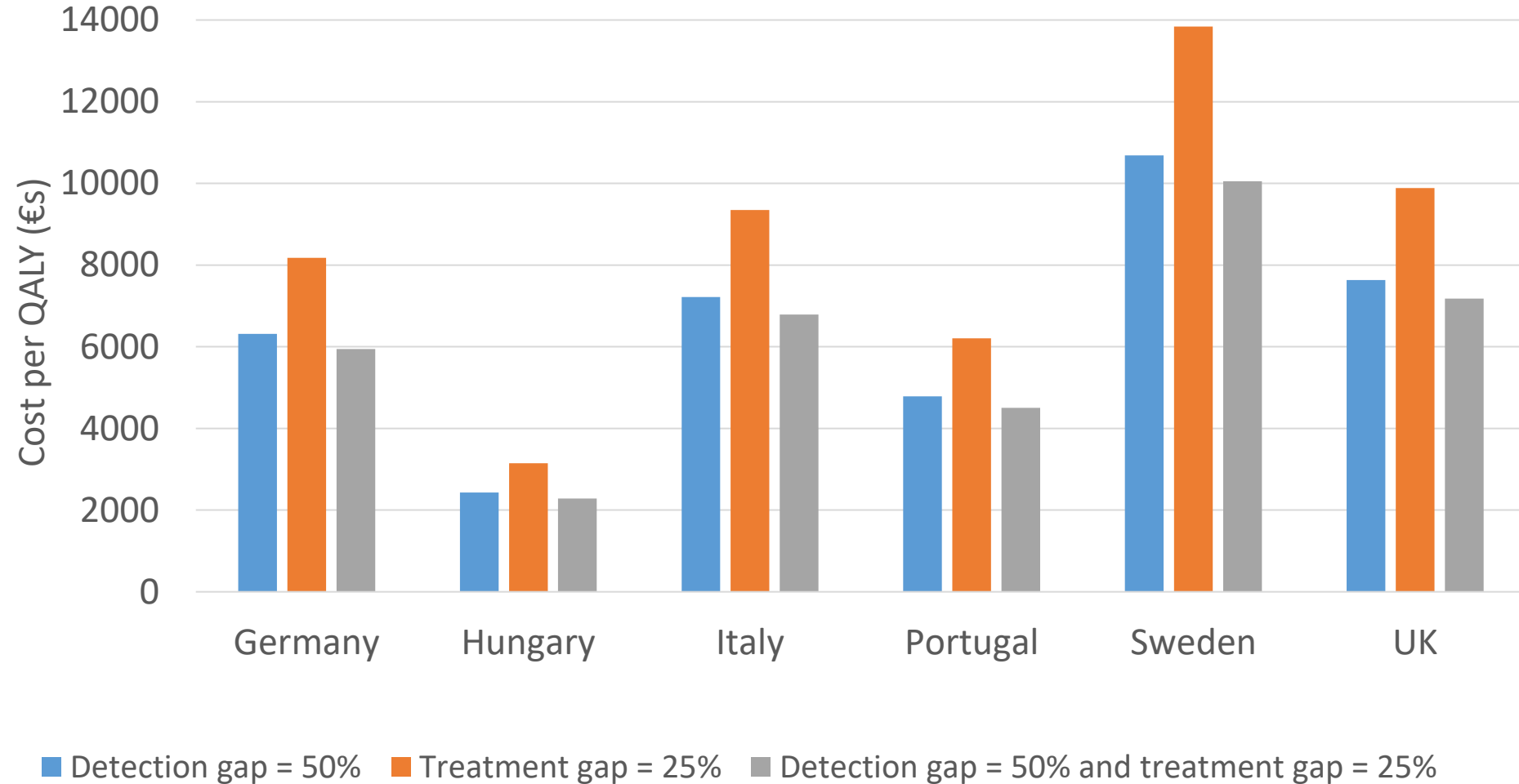
# Economic impact of reducing treatment gaps in depression

- Use of decision model to assess economic impact of treatment gaps
- Expected costs and outcomes from reducing gaps were estimated
- Costs and outcomes obtained from published literature and official sources

## Expected costs for baseline model by country (2020 €s)

	Germany	Hungary	Italy	Portugal	Sweden	UK
Expected costs	1236	476	1413	938	2093	1495
Sensitivity analysis 1	1097	422	1254	832	1857	1327
Sensitivity analysis 2	1376	529	1572	1043	2328	1663

# Incremental cost per QALY of reducing detection and treatment gaps



# Recommendations

Consensus reached on 28 recommendations to optimise care pathways:

- 1. Enhance detection (pathway entry):** improved information provision, increased service availability, integrate self-management e-mental health tools with healthcare practice.
- 2. Improve treatment provision:** The right treatment to each patient (e.g. decision-support tools, information provision, encourage patient preference), prescribing support tools (integrate electronic health records & facilitate shared-care provision between types of staff), increased provision of various psychological therapies, help for patients time off from work/education.
- 3. Continuity of follow-up after treatment:** Optimise self-management tools & feedback to clinicians, automatic appointment scheduling & reminders, increased service provision, standardised assessment of symptoms and side effects, screen for risk factors to indicate extent of follow-up needed.
- 4. Access to specialist care:** Enhance training for clinicians to obtain specialism, clear & more lenient criteria for accepting psychiatric referrals, increased resources to services, integrating specialists into primary care, systems for transition in/out of specialist services – *applies to both secondary and tertiary care.*



# Thank you

Contact details:

**Professor Allan Young**



# Economic modelling of the Value of Early Intervention and Continuity of Care for Anorexia Nervosa in England, Germany and Spain: improving the care pathway.

David McDaid

Associate Professor

London School of Economics and Political Science

32<sup>nd</sup> European Congress of Psychiatry

Budapest, April 7, 2024

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Funding: The study was organised by the European Brain Council (EBC) and financially supported by the European Psychiatric Association (EPA)

# Background

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- Anorexia nervosa has typical onset in adolescence/early adulthood. Profound physical as well as mental health consequences. Over one-third of people develop a severe and enduring illness (SE-AN)
- Lifetime prevalence: 2-4% among women and 0.3% among men (Van Eeden et al 2021).
- 153,058 Disability Adjusted Life Years (DALYs) in WHO European Region in 2019, 78% for women. (IHME 2021). 117,946 (77%) of DALYs are for people aged over 20.
- Reviews, mainly of European studies, indicate average duration of untreated anorexia nervosa between 15 months and 2 with long periods of time between disorder onset, diagnosis, assessment and commencement of treatment.
- Interventions, including outpatient psychotherapy, can lead to improved outcomes
- Substantial inpatient resource use for severe anorexia nervosa

Received: 20 March 2020 | Revised: 23 November 2020 | Accepted: 22 December 2020  
DOI: 10.1002/erv.2820

WILEY

REVIEW

### Length of stay for anorexia nervosa: Systematic review and meta-analysis

Carol Kan<sup>1</sup> | Ysabella-Rozetta Hawkins<sup>2</sup> | Hannah Cribben<sup>1</sup> | Janet Treasure<sup>1</sup>

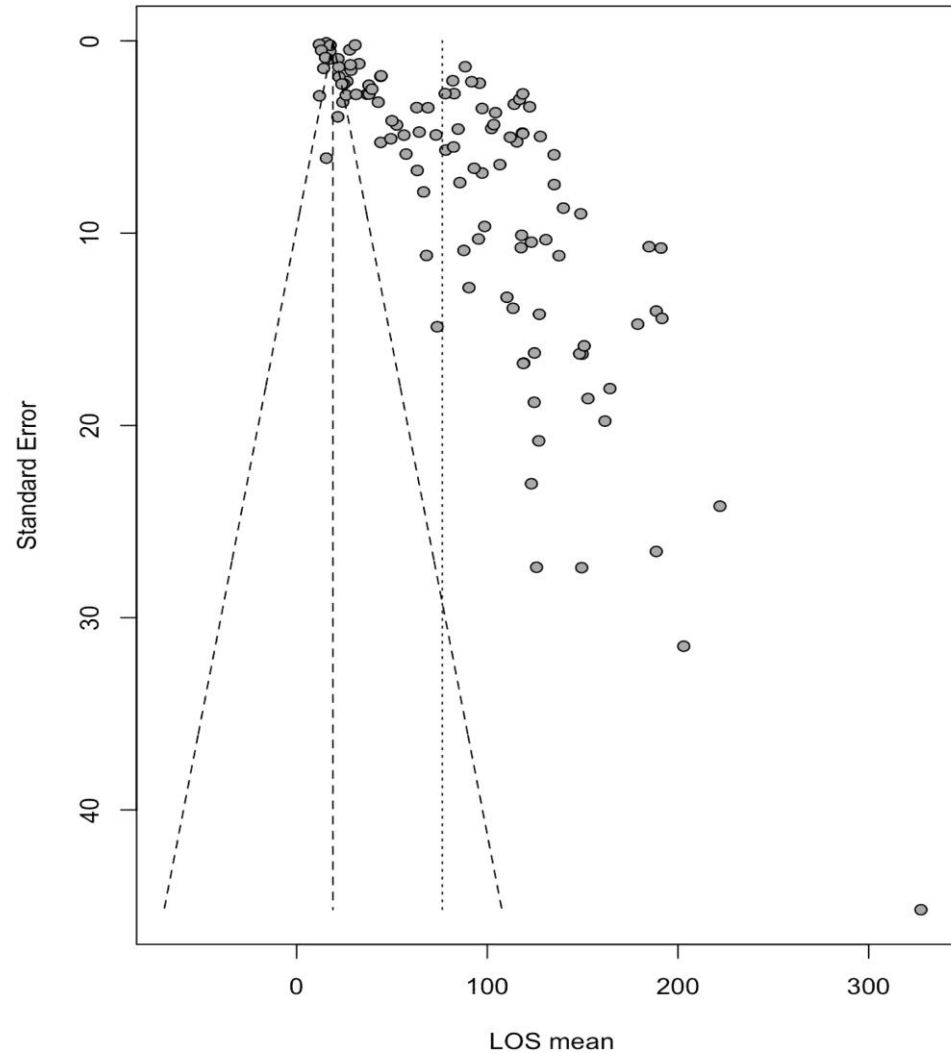
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**Funding information**  
NHR Mental Health Biomedical Research Centre; Marie Curie Cancer Care; Novo Nordisk UK Research Foundation

**Abstract**  
**Objective:** Evidence regarding global trends in length of stay for patients with anorexia nervosa is limited. The aim of this study is to conduct a meta-analysis examining the length of stay for anorexia nervosa patients globally, and to investigate moderators of the variance.  
**Method:** Medline, EMBASE and PsycINFO were searched for studies published up to January 2019. Two independent reviewers assessed the eligibility of each report based on predefined inclusion criteria. A meta-analysis was performed to calculate a pooled mean length of stay using the random-effects model. Subgroup analyses and meta-regression were conducted to explore potential sources of heterogeneity between studies.  
**Results:** Of 305 abstracts reviewed, 71 studies met the inclusion criteria, generating 111 datasets. The pooled mean length of stay (95% confidence interval) was 76.3 days (73.3, 79.4) using the random-effects model, with marked variation across countries and time. Heterogeneity between studies was explained by age and admission body mass index.  
**Conclusions:** This meta-analysis found that although clinical features do contribute to length of admissions for anorexia nervosa, there are also global and temporal variations. Future research should provide an in-depth analysis of why and how this variation exists and what the impact is on the well-being of people with anorexia nervosa.

**KEYWORDS**  
anorexia nervosa, eating disorders, length of stay, meta-analysis



**Worldwide average length of stay: 76 days**

**Europe: average length of stay: 106 days**

# Aims and approach

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- Assess the potential economic benefits of earlier and /or increased access to enhanced care for adults newly diagnosed with anorexia nervosa
- Case examined in England, Germany and Spain
- 5 different care pathway scenarios compared
- Markov model constructed; hypothetical adult with AN followed along these care pathway scenarios over 312 weeks (6 years).
- Disability Adjusted Life Years Averted and impacts on health service costs estimated. Net Monetary Benefits for each scenario then calculated

# Five Scenarios Compared

## Scenario 1

Current care pathways with existing data on wait times, hospitalisation, rehospitalisation, and length of inpatient stay

## Scenario 2

Halving wait times from diagnosis of AN in primary care settings to referral to outpatient care. No change in referral patterns

## Scenario 3

No change to wait times from referral, but everyone referred to specialist eating disorder outpatient care

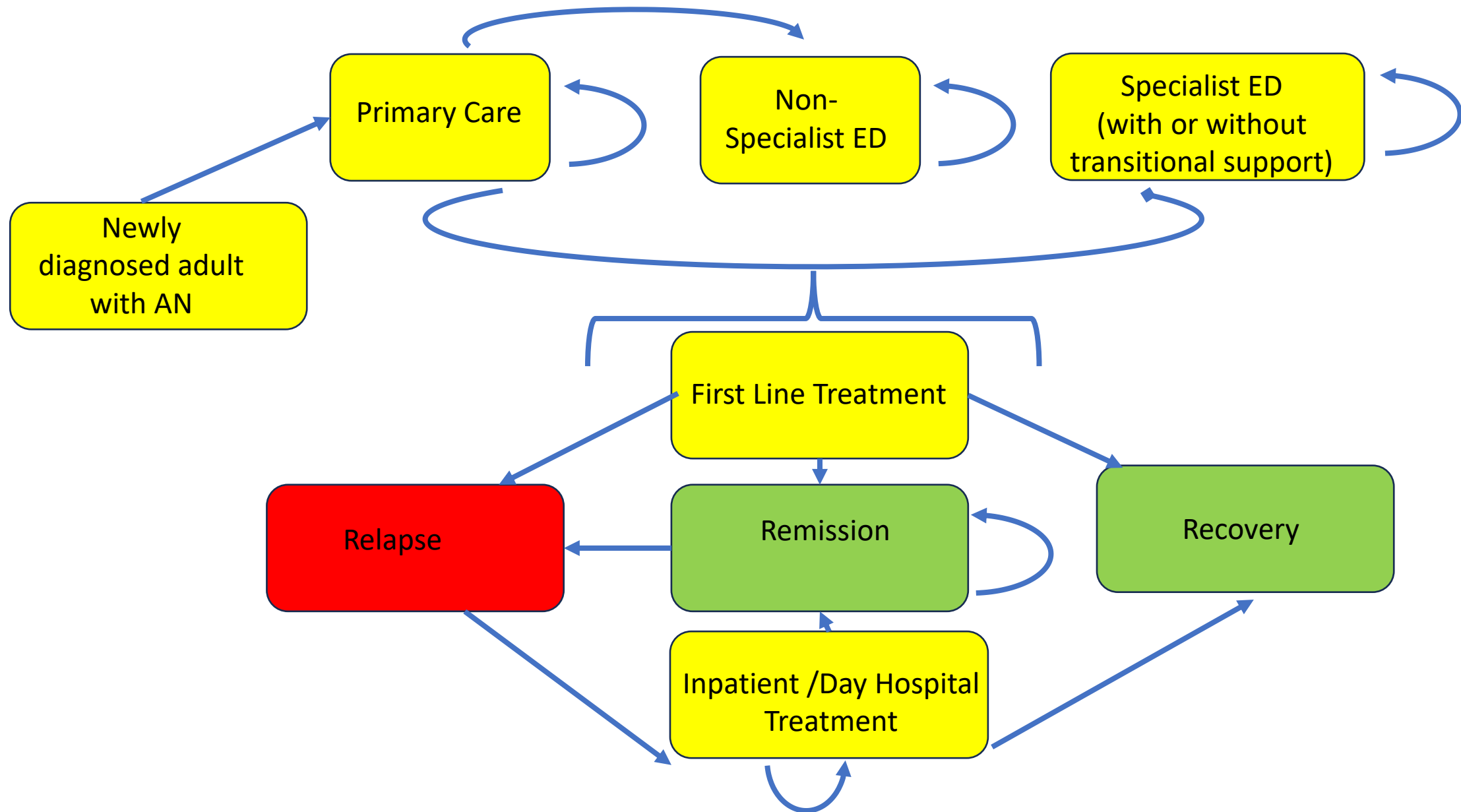
## Scenario 4

No change to wait times or referral patterns. Transitional support, (carer support) for all receiving specialist ED outpatient care

## Scenario 5

Combination of reduced wait times, all referred to specialist ED outpatient care with transitional support

# Model structure



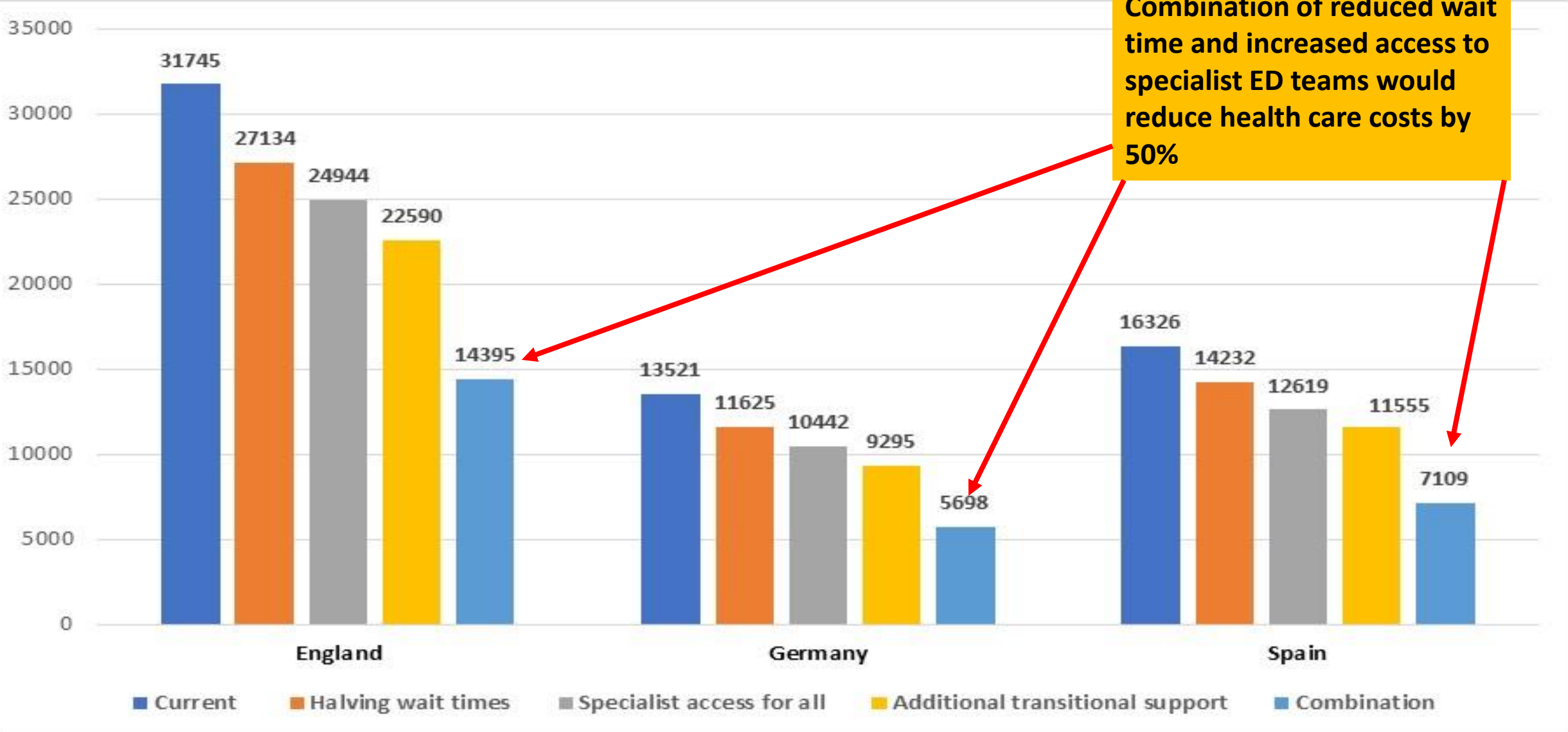


# Overview of results



# Expected six-year cumulative costs of different AN care pathways

2020 PPP Euros

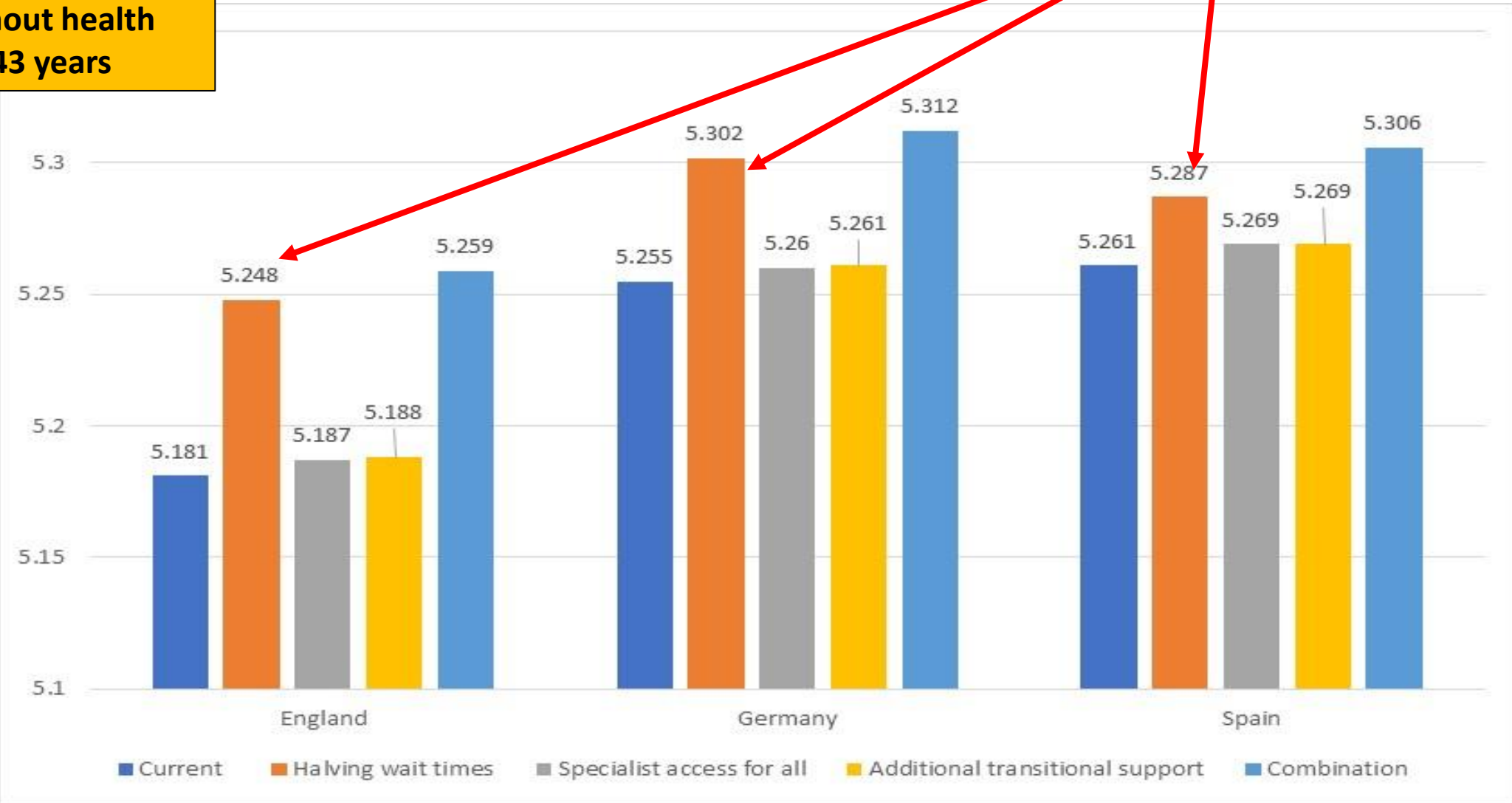


Combination of reduced wait time and increased access to specialist ED teams would reduce health care costs by 50%

# Expected mean Disability Adjusted Life Years averted from different care pathways

Improvement in disability free life in model driven by reduction in wait times

Maximum possible DALYs averted without health problems 5.43 years



# England: model results

	Current	Halving wait times	Specialist access for all	Additional transitional support	Combination
Primary Care Management	1315	672	1315	1315	672
Non-Specialist Outpatient Care	1217	1229	0	1217	0
Specialist Outpatient Care	3972	4013	5675	3972	5732
Inpatient Care	25240	21220	17953	16085	7991
<b>Total Cost (€'s 2020)</b>	<b>31744</b>	<b>27134</b>	<b>24943</b>	<b>22589</b>	<b>14395</b>
<b>DALYs averted</b>	<b>5.181</b>	<b>5.248</b>	<b>5.187</b>	<b>5.188</b>	<b>5.259</b>
<b>Incremental DALYs averted</b>		<b>0.067</b>	<b>0.006</b>	<b>0.007</b>	<b>0.078</b>

# Net Monetary Benefits (2020 PPP adjusted Euros)

	England	NMB gained	% gain	Germany	NMB gained	% gain	Spain	NMB gained	% gain
Combined	248,575	21,316	9.38%	259,909	10,722	4.30%	258,167	11,491	4.66%
Transitional support	236,824	9,565	4.21%	253,748	4,561	1.83%	251,920	5,244	2.13%
Referral to specialist ED	234,387	7,128	3.14%	252,533	3,346	1.34%	250,838	4,162	1.69%
Halving wait times	235,243	7,984	3.51%	253,489	4,302	1.73%	250,142	3,466	1.41%
Usual care	227,259	0	0.00%	249,187	0	0.00%	246,676	0	0.00%

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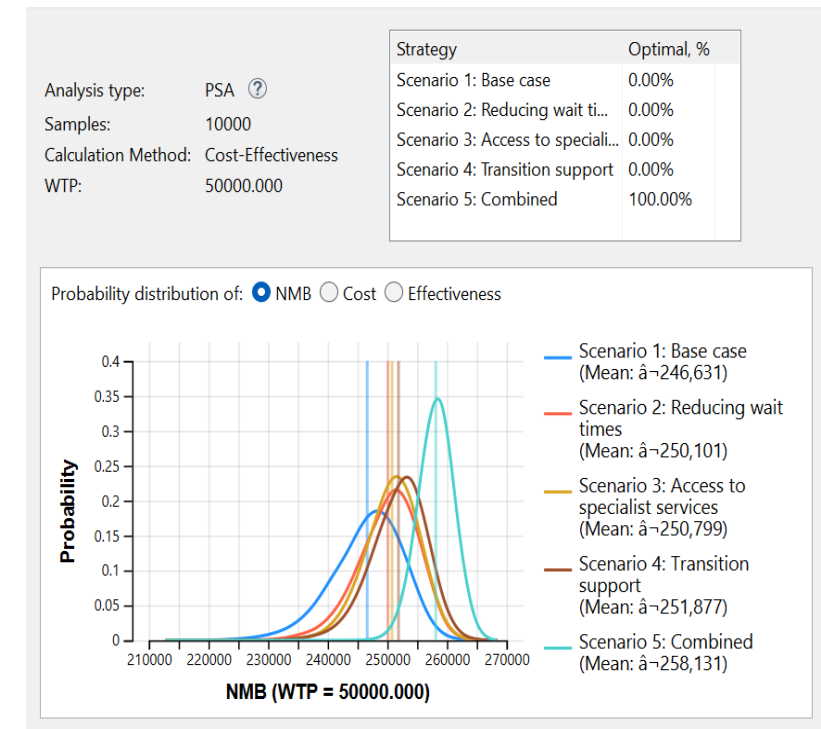
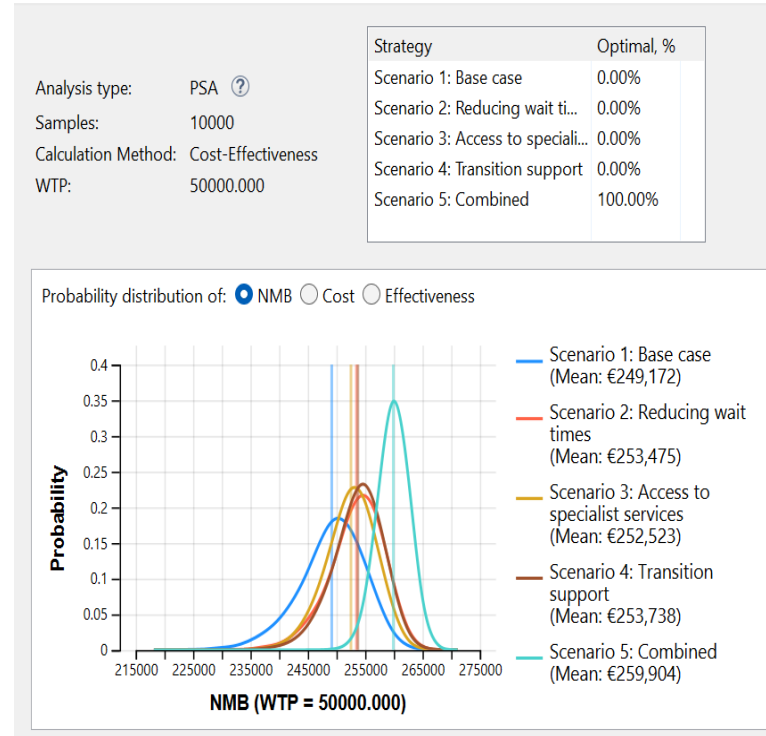
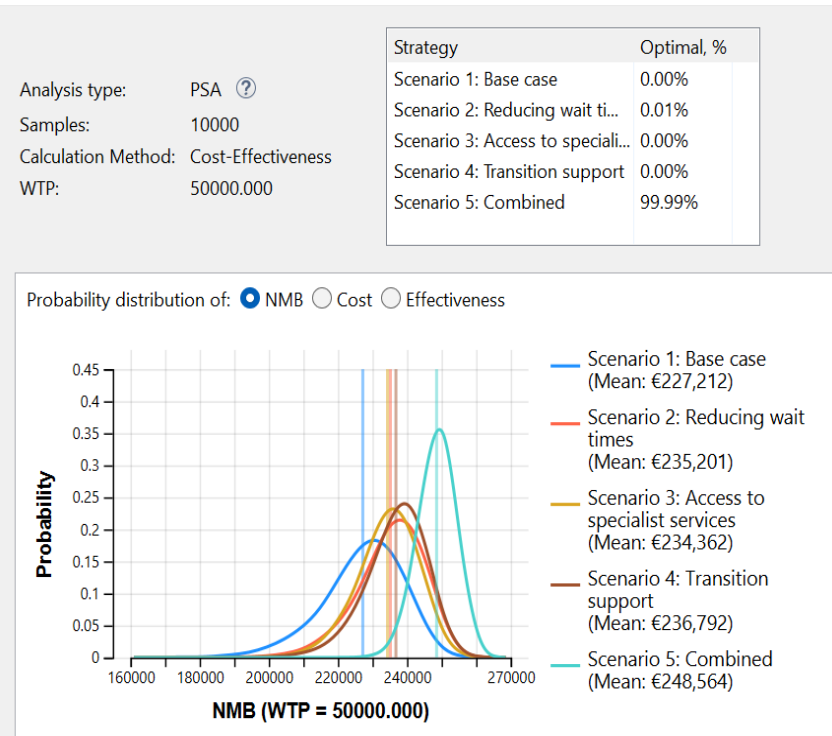
# Sensitivity analysis

- Ranking of scenarios robust in series of one-way and probabilistic sensitivity analyses

## England

## Germany

## Spain



# Result summary

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- Greatest improvements in quality of life from reduced wait times; greatest cost averted from specialist outpatient care with transitional support.
- Combined strategy has best health outcomes and lowest costs over a 6 year time window
- Reduced risk of hospitalisation and re-hospitalisation
- Investing in strategies that reduce time to any outpatient mental health and/or specialist eating disorder services associated with greater likelihood of recovery and reduced costs compared to care as usual.

# Limitations

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- Not all care pathways considered, e.g. models of enhanced primary care management, immediate hospitalisation not considered
- Additional referral routes to care (e.g. via contact with other outpatient services)
- Need to explore whether different care pathways may be more effective for some different individual groups; Need to explore care pathways for adolescents
- Economic analysis conservative: not included impacts on time out of usual role, e.g. education or employment, impacts on families
- Only one DALY weight for AN – but impacts will vary by severity level
- Look at even longer term impacts if data available



# Policy implications

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- Policy and practice guidelines should put an **emphasis on enhanced care pathway measures to reduce wait times and enhance access to specialist care.**
- Mechanisms to reduce wait times post diagnosis for referral to outpatient care, e.g. use of **wait time targets, financial support/ reimbursement incentives, improved co-ordination; awareness raising measures** in primary care and more generally
- Different **budgetary impacts and costs** associated with these strategies
- **Scaling up of skills** in ED within psychiatrists and psychology;
- Scaling up **capacity to deliver psychological therapies** within **primary care and non-specialist outpatient services**; more use of **digital interventions**
- Importance of **investment in transitional support**, including more focus on support for families



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# Assessing the value of mental health treatments in Europe

**Judit Simon**

Professor of Health Economics, Medical University of Vienna

Visiting Professor, University of Oxford & Corvinus University Budapest

# Disclosures

- Academic advisor to the EBC's VoT2 project
- PREDICT study received funding from the H2020 programme of the EC
- OXTEXT programme received funding from the UK NIHR
- 'Physical comorbidity costs of MHDs' project has received funding from the ECNP
- PECUNIA has received funding from the H2020 programme of the EC
- STREAMLINE has received funding from the Viennese WWTF
- Judit Simon is co-developer and guardian of the OxCAP-MH instrument

# Value of mental health care

(Simon et al. Eur Psych 2023)



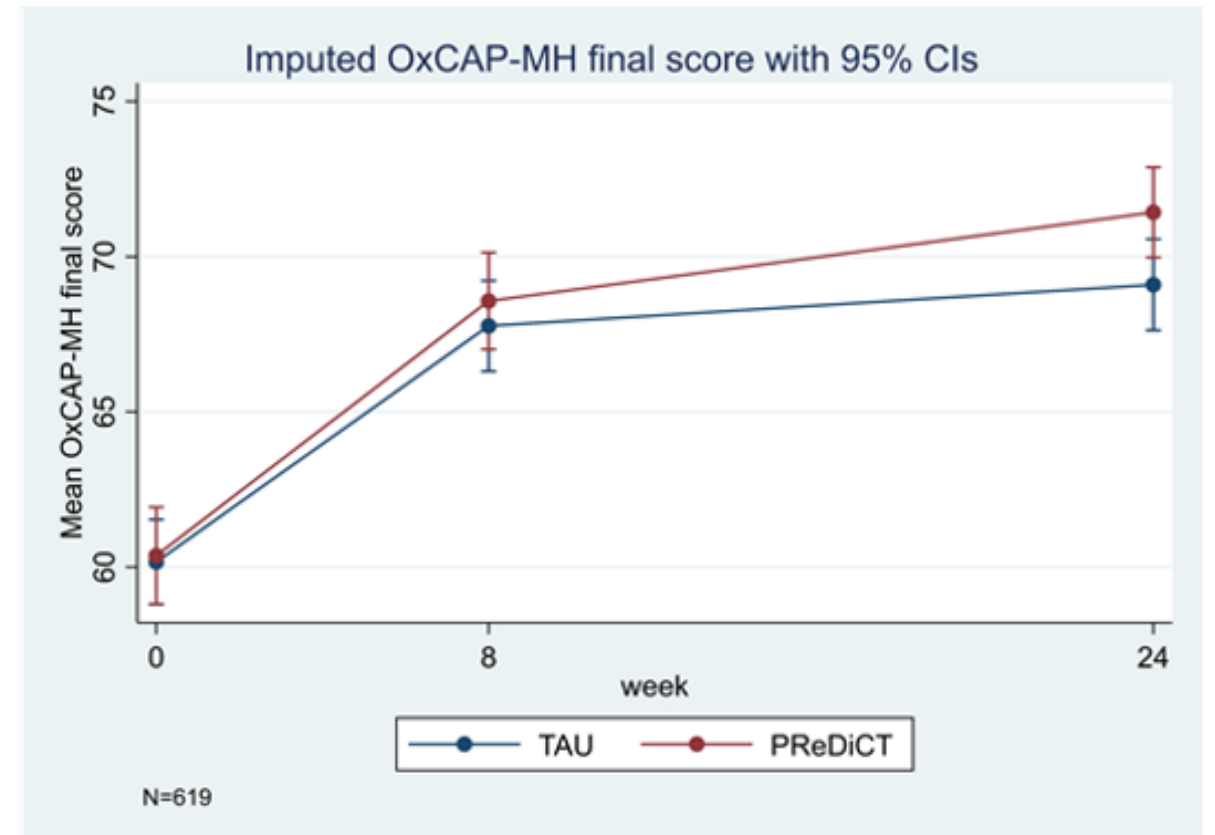
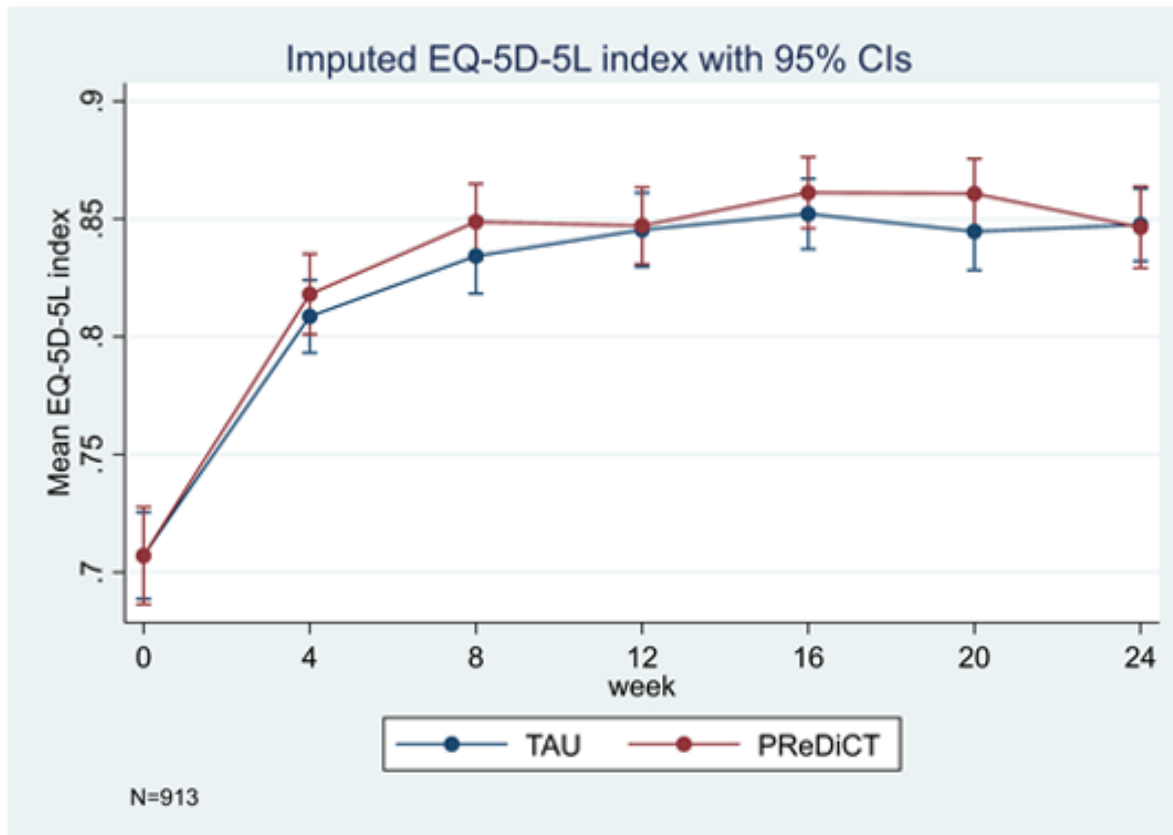
- MHDs are prevalent, enduring, disabling
- 1 in 8 persons worldwide lives with MHDs
- $\frac{3}{4}$  of all MHDs develop before the age of 25
- Socioeconomic burden is >4% of GDP across the EU-28 (>EUR 600 billion)
- Health and social care costs < broader societal costs

# Issues with current value assessments

1. Impact on QoL including informal carers/families -> **importance of broad outcome assessment**
2. Spill-over effects to other sectors (e.g. education, employment, justice) -> **importance of broad cost assessment**
3. Close link between mental and physical health problems -> **importance of comorbidity impact assessment**
4. Multi-national evaluations with unknown magnitude of heterogeneity -> **importance of standardised and comparable estimates** (cost, outcome and cost-effectiveness)
5. Limited implementation due to system and funding fragmentation -> **importance of link to health services mapping**

# Outcome assessment

(Browning et al. 2021, Neuropsychopharm. | PREDICT study EE, forthcoming)



# OxCAP-MH: Capability well-being assessment for MH

**OxCAP MH**

**OxCAP-MH**

This questionnaire asks about your overall quality of life.

1	Does your health in any way limit your daily activities, compared to most people of your age? <i>[Please tick one]</i>	<input type="checkbox"/> Always <input type="checkbox"/> Most of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> Hardly ever <input type="checkbox"/> Never	1 2 3 4 5
2	Are you able to meet socially with friends or relatives? <i>[Please tick one]</i>	<input type="checkbox"/> Always <input type="checkbox"/> Most of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> Hardly ever <input type="checkbox"/> Never	5 4 3 2 1
3	In the past 4 weeks, how often have you lost sleep over worry? <i>[Please tick one]</i>	<input type="checkbox"/> Always <input type="checkbox"/> Most of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> Hardly ever <input type="checkbox"/> Never	1 2 3 4 5
4	In the past 4 weeks, how often have you been able to enjoy your recreational activities? <i>[Please tick one]</i>	<input type="checkbox"/> Always <input type="checkbox"/> Most of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> Hardly ever <input type="checkbox"/> Never	5 4 3 2 1
5	How suitable or unsuitable is your accommodation for your current needs? <i>[Please tick one]</i>	<input type="checkbox"/> Very suitable <input type="checkbox"/> Fairly suitable <input type="checkbox"/> Neither suitable nor unsuitable <input type="checkbox"/> Fairly unsuitable <input type="checkbox"/> Very unsuitable	5 4 3 2 1
6	Please indicate how safe you feel walking alone in the area near your home: <i>[Please tick one]</i>	<input type="checkbox"/> Very safe <input type="checkbox"/> Fairly safe <input type="checkbox"/> Neither safe nor unsafe <input type="checkbox"/> Fairly unsafe <input type="checkbox"/> Very unsafe	5 4 3 2 1

**OxCAP MH**

7	Please indicate how likely you believe it to be that you will be assaulted in the future (including sexual and domestic assault): <i>[Please tick one]</i>	<input type="checkbox"/> Very likely <input type="checkbox"/> Fairly likely <input type="checkbox"/> Neither likely nor unlikely <input type="checkbox"/> Fairly unlikely <input type="checkbox"/> Very unlikely	1 2 3 4 5
8	How likely do you think it is that you will experience discrimination? <i>[Please tick one]</i>	<input type="checkbox"/> Very likely (Go to Q8a) <input type="checkbox"/> Fairly likely (Go to Q8a) <input type="checkbox"/> Neither likely nor unlikely (Go to Q9) <input type="checkbox"/> Fairly unlikely (Go to Q9) <input type="checkbox"/> Very unlikely (Go to Q9)	1 2 3 4 5
8a	On what grounds do you think it is likely that you will be discriminated against? <i>[Please tick up to three]</i>	<input type="checkbox"/> Race/ethnicity <input type="checkbox"/> Gender <input type="checkbox"/> Religion <input type="checkbox"/> Sexual orientation <input type="checkbox"/> Age <input type="checkbox"/> Health or disability (incl. mental health) <input type="checkbox"/> Other: .....	
9	Please indicate how strongly you agree or disagree with the following statements: <i>[Please tick one]</i>		Strongly Agree 5 Agree 4 Neither agree nor disagree 3 Disagree 2 Strongly disagree 1
9a	I am free to influence decisions affecting my local area.		
9b	I am free to express my views, including political and religious views.		
9c	I am able to appreciate and value plants, animals and the world of nature.		
9d	I am able to respect, value and appreciate people around me.		
9e	I find it easy to enjoy the love, care and support of my family and/or friends.		
9f	I am free to decide for myself how to live my life.		
9g	I am able to use my imagination and to express myself creatively (e.g. through art, literature, music, etc.).		
9h	I have access to interesting forms of activity (or employment).		

Simon et al. (2013) Soc Sci Med

Vergunst et al. (2017) HQoLO

Simon et al. (2018) BMC Psych

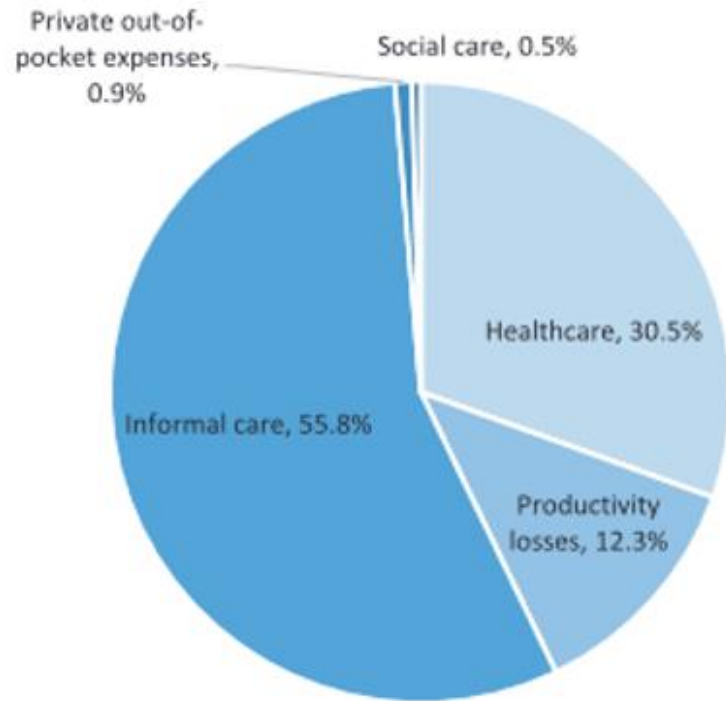
Helter et al. (2022) BJPsych Open

<https://public-health.meduniwien.ac.at/unsere-abteilungen/abteilung-fuer-gesundheitsoekonomie/forschung/downloads/oxcap-mh/>

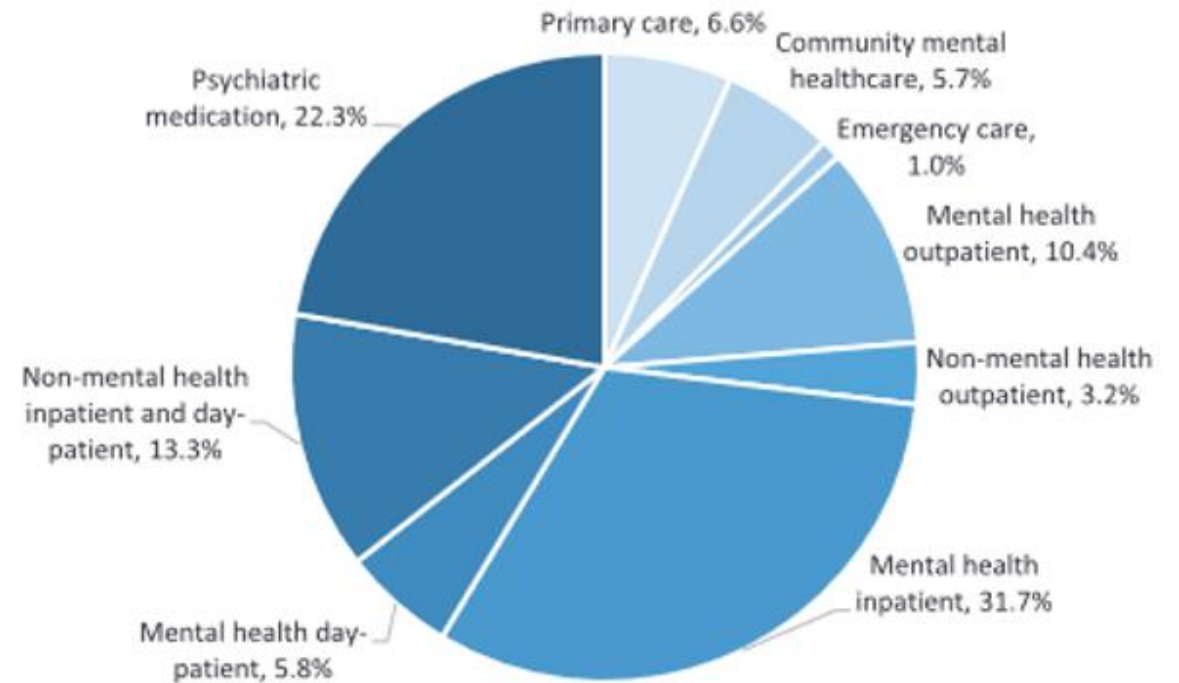
# Costs assessment: Bipolar disorders (UK)

(Simon et al. 2021, Brain and Behaviour)

Relative size of main cost categories



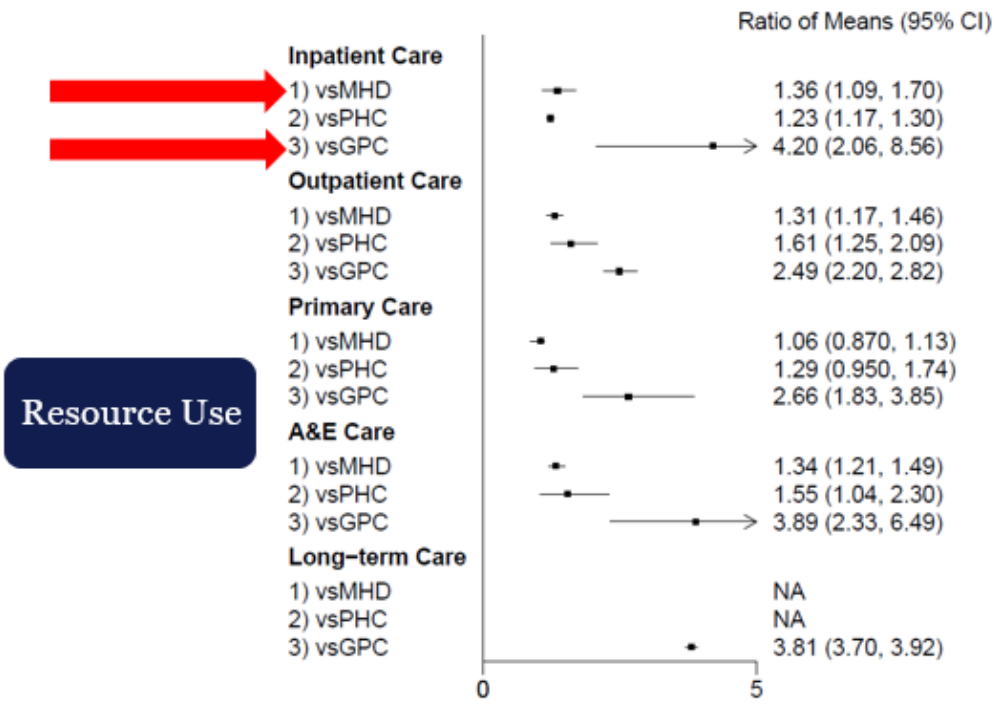
Relative size of main healthcare cost categories



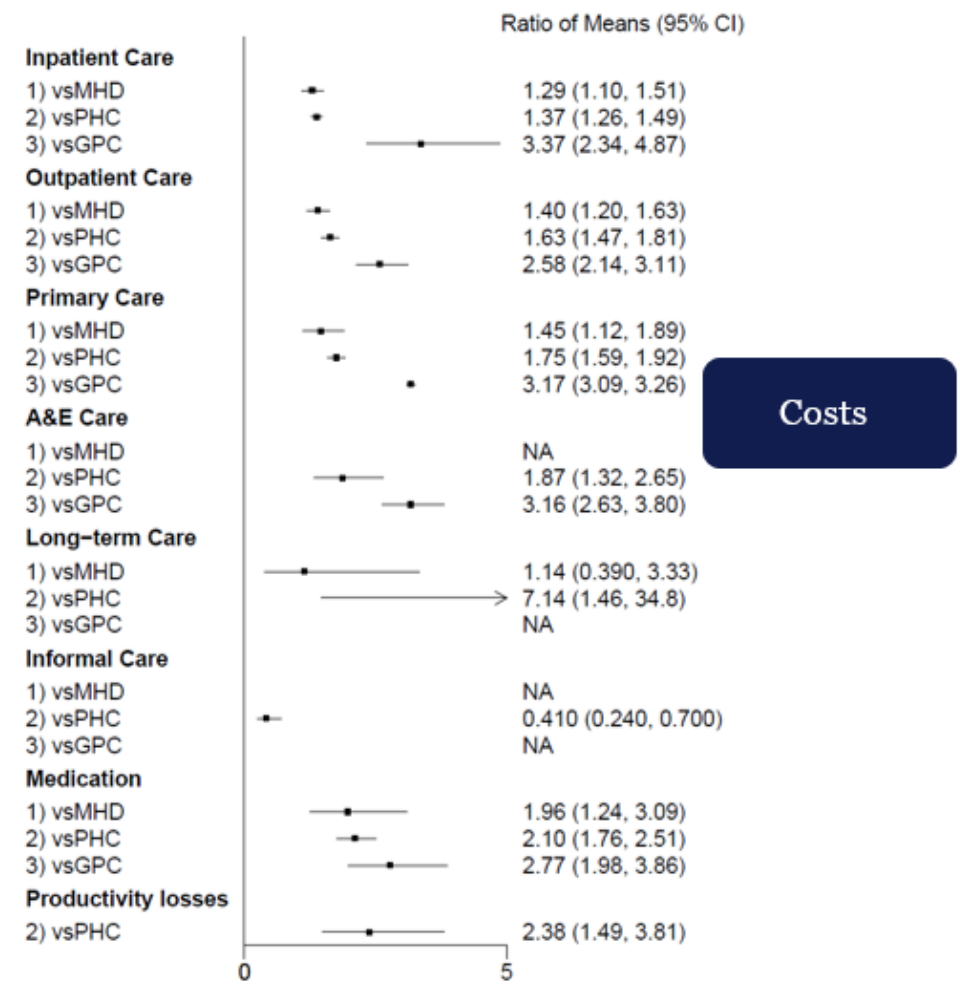


# Excess cost of physical co-morbidities

(Simon et al. 2023, Eur Neuropsychopharm.)

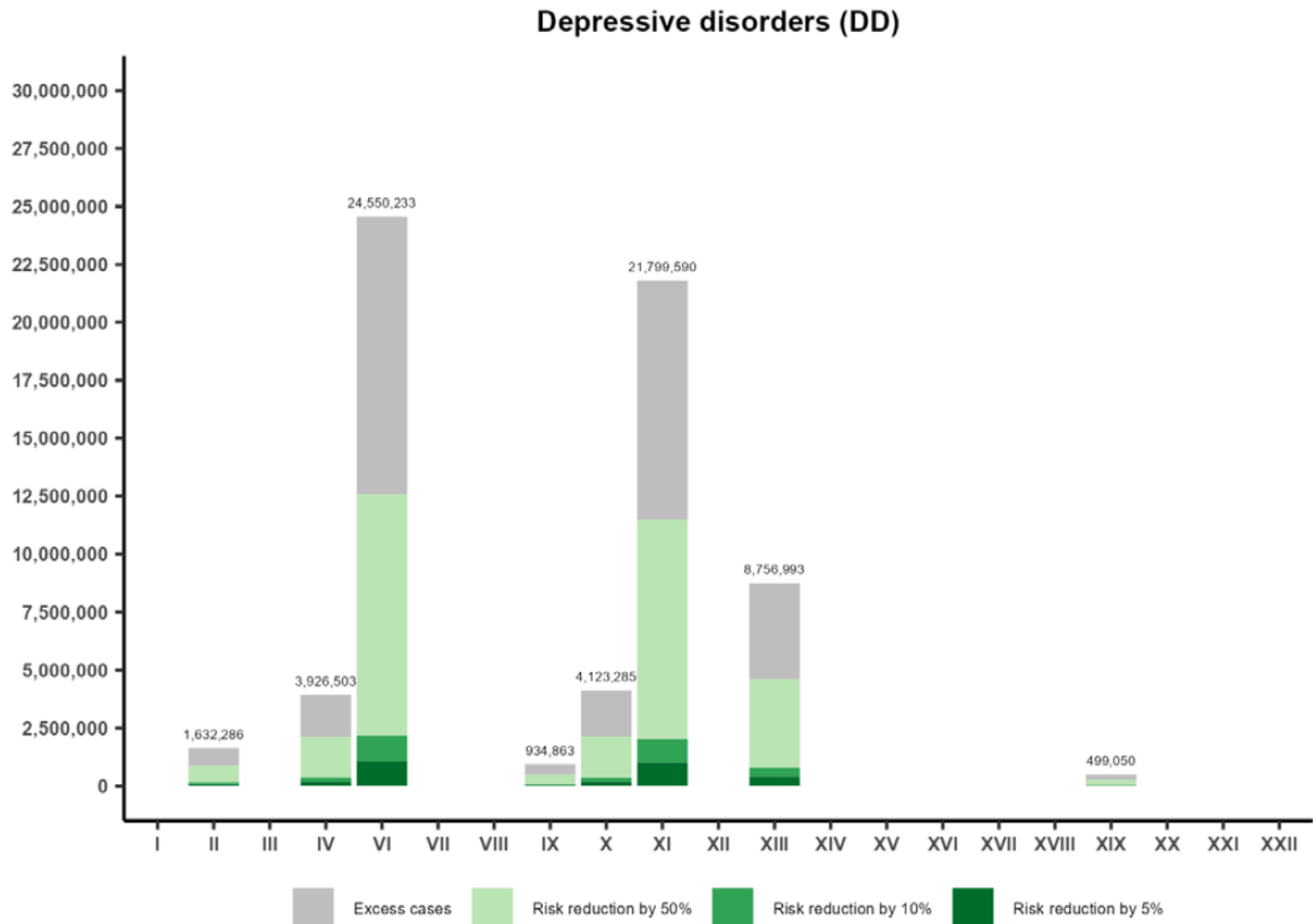


vsMHD: Individuals with given mental health disorder only  
 vsPHC: Individuals with given physical health condition(s) only  
 vsGPC: Matched general population controls



# Comorbid physical health burden in Europe

(Wienand et al. 2024, BMJ Mental Health)



# Incomparable costs: Day care centre

(Browning et al. 2021, Neuropsychopharm. | PREDICT EE, forthcoming)

Country	UK	DE	NL	ES
Name of item	Day care centre	Tageszentrum	Dagopvang	Centro de dia
Unit cost	£37	€8	€276, €67, €302, €460	n/a
Definition	PSSRU	n/a	n/a	n/a
Unit of measurement	per client attendance	per hour per therapy place	per day	n/a
Year	2018	2014	2014	n/a
Issue	-	Translation problem → Tagesstätte vs. Tageszentrum	none seems to match with UK/DE form as setting differs, translation problem	Expert advise needed

© DHE/MUW

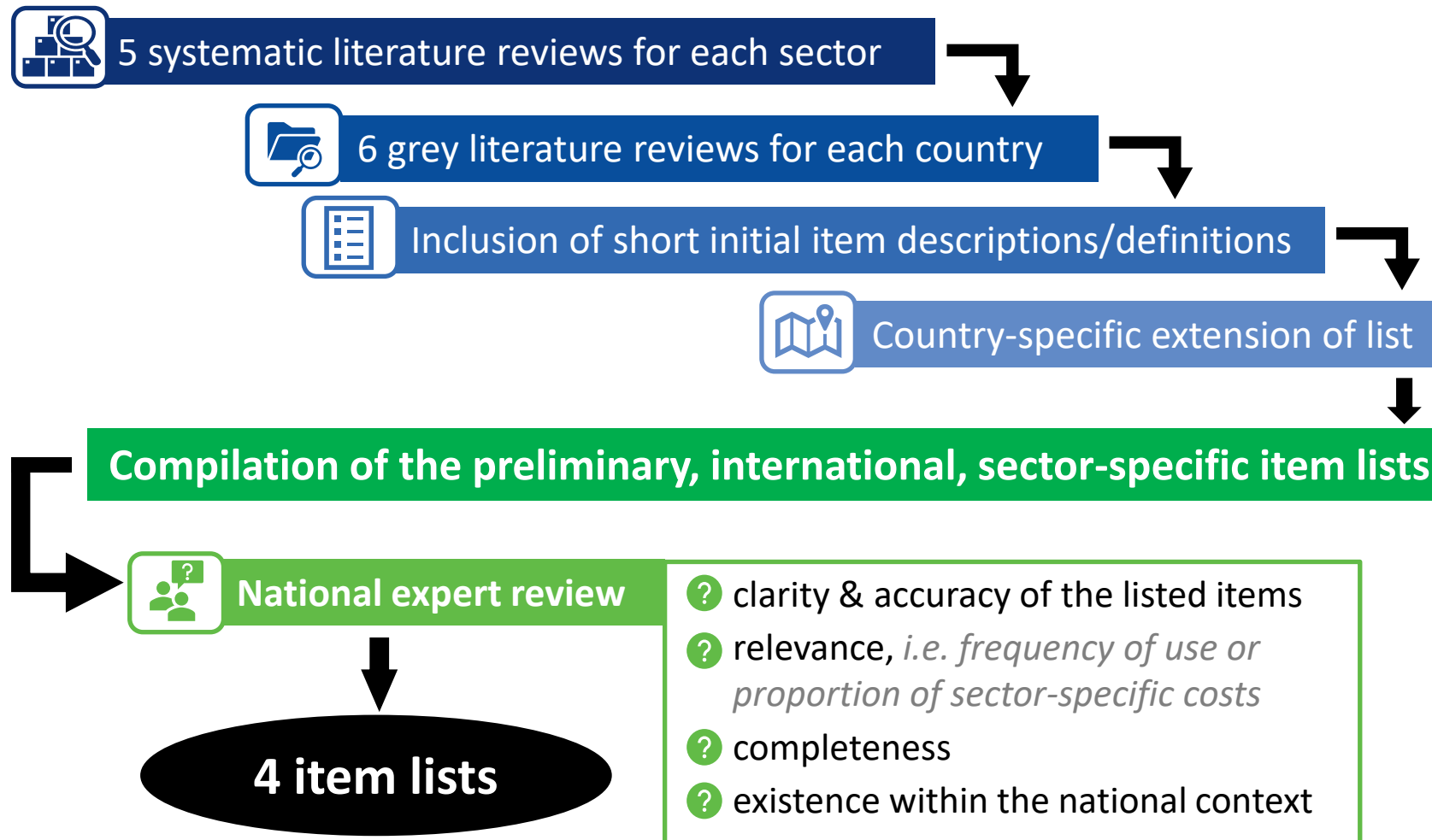
# H2020 PECUNIA Project (2018-2021)

- Multi-sectoral, multi-person, multi-country approach
- Aims:
  1. To improve the comparability and feasibility of health economic assessments
  2. To harmonize costing and outcome methods
  3. To develop new tools to support future harmonized methods



# Identification of services

(Fischer et al. 2022, PLOS ONE)



# Disambiguation of services

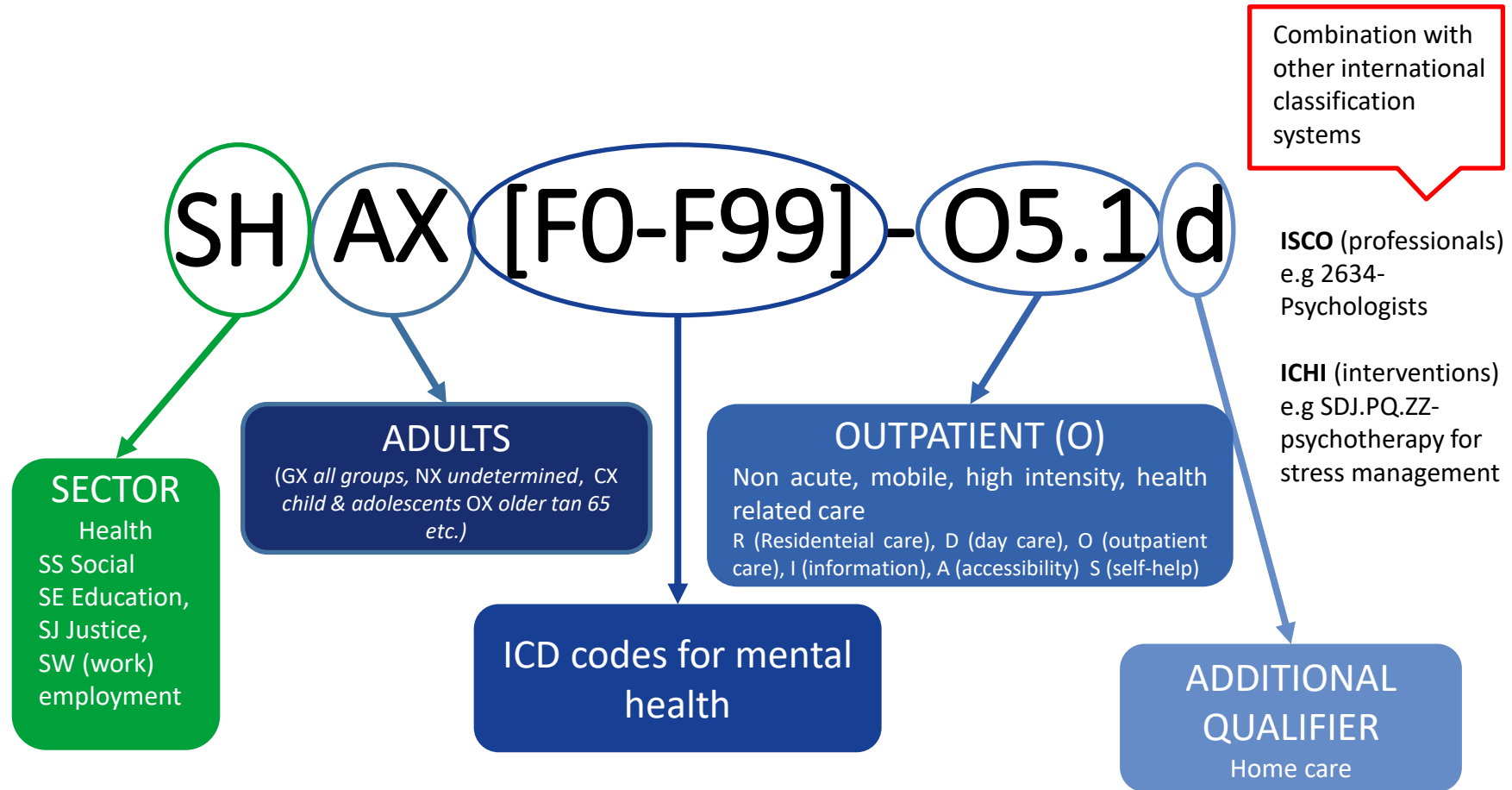
(Gutierrez-Colosia et al. 2022, EpiPsychSci)

Items (N)	A final list of <b>56 items</b> were obtained from systematic review and grey literature review. 34 from the health sector and 22 from the social sector			
	Accurate	Confusing	Ambiguous	Vague
<b>Level 1. Unit of analysis</b>	50 items (89%)	6 items (11%) <i>e.g 'legal carer', 'outpatient health care contact'</i>		
<b>Level 2. Target population</b>	29 items (52%)	3 items (5%) <i>e.g homeless people/women and mental disorders</i>	4 items (7%) <i>e.g 'Child development centre for children and families'</i>	20 items (36%) <i>e.g 'rehabilitation facility for illness, injury or addiction'</i>
<b>Level 3. Definition</b>	23 items (41%)	6 items (11%) <i>e.g 'Outpatient health care at workplace, e.g. company physician, nurse</i>	12 items (21%) <i>e.g 'Polyclinic</i>	13 items (23%) <i>e.g rehabilitation facility</i>
<b>Total L1, L2, L3</b>	13 items (23%)	-	2 items	5 items



# Definition of services: DESDE coding system

(Castelpietra et al. 2020, BJPsych)



# Measurement of costs: PECUNIA RUM

(Pokhilenko et al. 2023, Appl Health Econ Health Policy)

- Multi-sectoral:
  - Place of living and overnight stays (Sec A)
  - Non-residential health and social care (Sec B)
  - Medication (Sec C)
  - Unpaid help (informal care) (Sec D)
  - Education (Sec E)
  - Employment and productivity (Sec F)
  - Safety and justice system (Sec G)
  - Out-of-pocket and other expenses (Sec H)
  - Final remarks (Sec I)
- Self-reported
- Flexible: modular
- User guide
- Free for non-commercial use

SECTION A: PLACE OF LIVING AND OVERNIGHT STAYS

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

A1 Where have you lived or stayed overnight (e.g. in hospital) in the past 3 months?	
<i>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.</i>	
1 Individual or shared flat or house	■ _____ nights
2 Family or friend's flat or house	■ _____ nights
3 Dormitory (e.g. boarding school, university residence)	■ _____ nights
4 Paid temporary accommodation (e.g. hotel)	■ _____ nights
5 Emergency shelter (e.g. temporary shelter for homeless)	■ _____ nights
6 Sheltered housing (e.g. housing with assistance, supported housing)	■ _____ nights
7 Nursing home (e.g. residential care home with nursing)	■ _____ nights
8 Other long-term residential care home	■ _____ nights
9 Therapeutic community home (e.g. temporary group residence for therapeutic purposes)	■ _____ nights
10 Hospital	
Type of hospital department/service (e.g. oncology, surgery, psychiatry): _____	■ _____ nights
Type of hospital department/service (e.g. oncology, surgery, psychiatry): _____	■ _____ nights
Type of hospital department/service (e.g. oncology, surgery, psychiatry): _____	■ _____ nights
11 Residential palliative care (e.g. hospice)	■ _____ nights
12 Place of detention (e.g. prison)	■ _____ nights
13 On the street	■ _____ nights
14 Other, please specify: _____	■ _____ nights



# Valuation of costs: PECUNIA RUC Templates

(Mayer et al., under review)

- Standardized and transparent methodology
- Reference Unit Costs (RUCs)
- Automated calculations
- Flexibility: primary and/or secondary input data
- User guide
- Free for non-commercial use

PECUNIA RUC Templates Version 1.0 / 2021 SERVICE-1 top-down micro-costing template PECUNIA © PECUNIA Consortium, 2021

**SERVICE-1 top-down micro-costing template**

Basic instructions and data sources:  
 SERVICE-1 top-down micro-costing template for the reference unit cost calculation per setting-specific direct client contact minute based on a top-down micro-costing approach to be filled in by the user based on  
 a) published secondary data (not older than 10 years) OR  
 b) primary data from service provider collected with the "SERVICE-1 data collection sheet".

User guide legend: dark blue = instructions, light green = data to be entered by user, dark green = prospective entry or automatic calculation, gold = not applicable (N/A)

**Module 1: Service description**  
 Module 1 summarizes selected service characteristics and establishes the connections between the costing template and the RUC

Reference (only) Name: \_\_\_\_\_  
 (e.g. general practitioner)

Unit of measurement: \_\_\_\_\_  
 (e.g. direct client contact per contact or per hour)

Other (please specify): \_\_\_\_\_

DESD PECCUNIA prototype code: \_\_\_\_\_ ESCO code: \_\_\_\_\_ ICHI code: \_\_\_\_\_  
 (if applicable)

Service definition: \_\_\_\_\_  
 Module 1 short description of the context the unit cost is calculated for

Opening hours (annual total): \_\_\_\_\_  
 (in the annual opening hours (in hours) of the service provider)

Setting: \_\_\_\_\_  
 (e.g. health care context from step-down list)

Funding source: \_\_\_\_\_  
 (e.g. institutional insurance/funding, primary/tertiary/quarternary, non-institutional insurance, other (please specify))

Valuation approach: top-down micro-costing approach

**Module 2: Basic unit cost information**  
 Module 2 collects basic information on the cost data inputs and references to be provided with the subsequent cost estimate.

Unit cost year: \_\_\_\_\_  
 (e.g. 2020)

Currency: \_\_\_\_\_  
 (e.g. Euro)

Country: \_\_\_\_\_  
 (e.g. Germany)

Data type: \_\_\_\_\_  
 (e.g. primary data collection and/or secondary data collection)

Data sources: \_\_\_\_\_  
 (e.g. search of data sources, publications, consulting, provider data collection sheet)

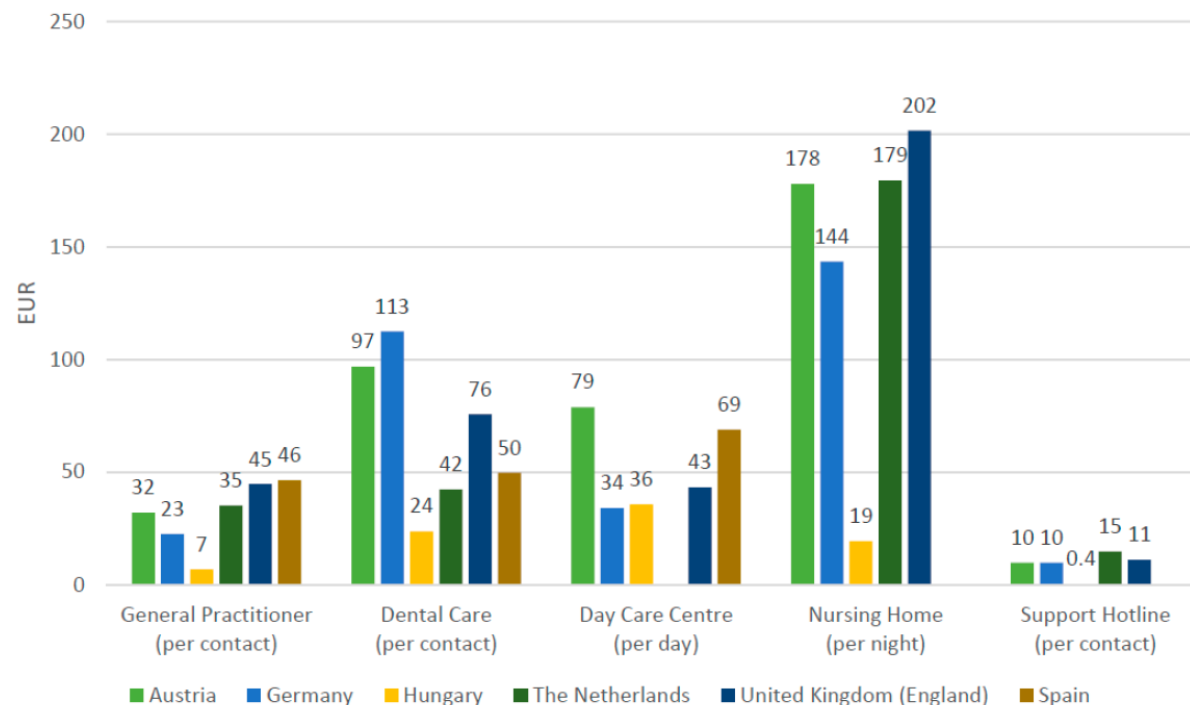
SAMPLE COPY - DO NOT USE

# Access to cost information: PECUNIA RUC Compendium

(Mayer et al. 2022, Int J Environ Res Public Health)

- Electronic library
- Harmonized RUCs
- Transparent meta-data
- User guide
- Free for non-commercial use

Reference unit cost estimates for the core set of health and social care services, per country




# Outcome assessment: PECUNIA PROM-MH Compendium

(Laszewska et al. 2021, BMJ Mental Health)

- 204 instruments for quality of life/well-being measurement in MH
- 47 meta-data categories
- 6 categories of usability in EEs
- Free access

PECUNIA PROM-MH Compendium Version 1.0 / 2020

PECUNIA 		CENTER FOR PUBLIC HEALTH PUBLIC UNIVERSITY OF VIENNA Department of Health Economics	
<a href="#">Back to start</a>		<b>15D</b>	
<b>15D instrument of health-related quality of life</b>			
A generic, comprehensive (15-dimensional), self-administered instrument for measuring health-related quality of life among adults (age 16+ years)			
Date of meta-data: 3 Apr 2020		References	
<b>BASIC CHARACTERISTICS</b>		References	
Year of first publication	1993	Sjostrom M, Fuhrman M (1993) A fifteen-dimensional measure of health-related quality of life (15D) and its applications. In: Vliesser IM, Rosser RM, eds. Quality of life assessment: Key issues in the 1990s. Dordrecht: Kluwer Academic Publishers (pp 185-195)	
Country of origin (language)	Finland	<a href="http://www.15d.com/instrument.asp?InstrumentID=104154_english.pdf">http://www.15d.com/instrument.asp?InstrumentID=104154_english.pdf</a>	
Link to sample questionnaire			
Math category of outcome measurement	• QOL/Well-being		
Sub-category of outcome measurement	• HRQoL		
Generic/mental health specific	• Generic		
Target age group	• Adults		
No. of items	15		
Levels of answers	5		
Approximate time to complete	5 min		
Domains covered	Mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, social activities, mental function, discomfort, depression, distress, vitality and sexual activity		
Standard recall period	• Day of completion		
Person completing instrument	• Self-reported, proxy-reported, interviewer-administration		
Modes of administration	• Paper-based, Computer-based	<a href="http://www.15d-instrument.com/15d/">http://www.15d-instrument.com/15d/</a>	
Belongs to the family of instruments	15D		
Related instruments	• 15D		
Other language versions available	• Yes		
Approximate no. of known translations	32	<a href="http://www.15d-instrument.com/15d/">http://www.15d-instrument.com/15d/</a> Arabic, Bulgarian, Catalan, Chinese, Danish, Dutch, English, Estonian, Finnish, French, German, Greek, Hebrew, Hungarian, Indonesian, Italian, Japanese, Korean, Norwegian, Polish, Portuguese, Romanian, Serbian, Slovenian, Spanish, Swedish, Thai, Turkish, Vietnamese	
<b>SCORING</b>			
Answer scale	• Likert scale		
Level-sum scoring (raw-sum)	Not known		
Standardised scoring (z-score)	Not known		
Weighted preference-based scoring	Yes, The single index score (15D score) on a 0-100 scale		
Approximate number of preference-based value sets	3	Finland <a href="https://doi.org/10.13007/3338910002068">https://doi.org/10.13007/3338910002068</a> , Denmark <a href="https://www.15d.com/">https://www.15d.com/</a> , Norway <a href="https://doi.org/10.1007/s11138-018-2043-0">https://doi.org/10.1007/s11138-018-2043-0</a>	
Technique of validation	• VAS		
Availability of mapping studies	Yes	EQ-5D-5L, SF-36, HRQ-12, QWB, Hout-40, OAS-21, K10, D-39, Hout, Marlowe, AQOL-6, EQ-5D-5L, EQ-5D-3L	
Approximate number of mapping studies	13	<a href="https://doi.org/10.1177/0272989X18078127">https://doi.org/10.1177/0272989X18078127</a> , <a href="https://doi.org/10.1007/s40201-018-00167-z">https://doi.org/10.1007/s40201-018-00167-z</a>	
<b>VALIDATION IN MENTAL HEALTH</b>			
Validation in mental health domains	Not known		
Approximate number of mental health domains	Not known		
<b>APPLICATION IN MULTISECTORAL, MULTI-NATIONAL, MULTI-PERSON (ECONOMIC) EVALUATIONS</b>			
Availability of separate adult and child components	• No		
Availability of a proxy-completion option	• No		
Feasibility of assessing outcomes beyond health, i.e. capabilities or caregiver, family or social care outcome	• No		
Availability of multiple translations (two or more language versions of the instrument)	• Yes		
Availability of a preference-based value set	• No		
Availability of preference-based valuations in more than one country	• No		
<b>OTHER</b>			
Link to the manual	Not known		
Terms of use	Free use	<a href="http://www.15d-instrument.com/15d/">http://www.15d-instrument.com/15d/</a>	
Date of meta-data	3 Apr 2020		

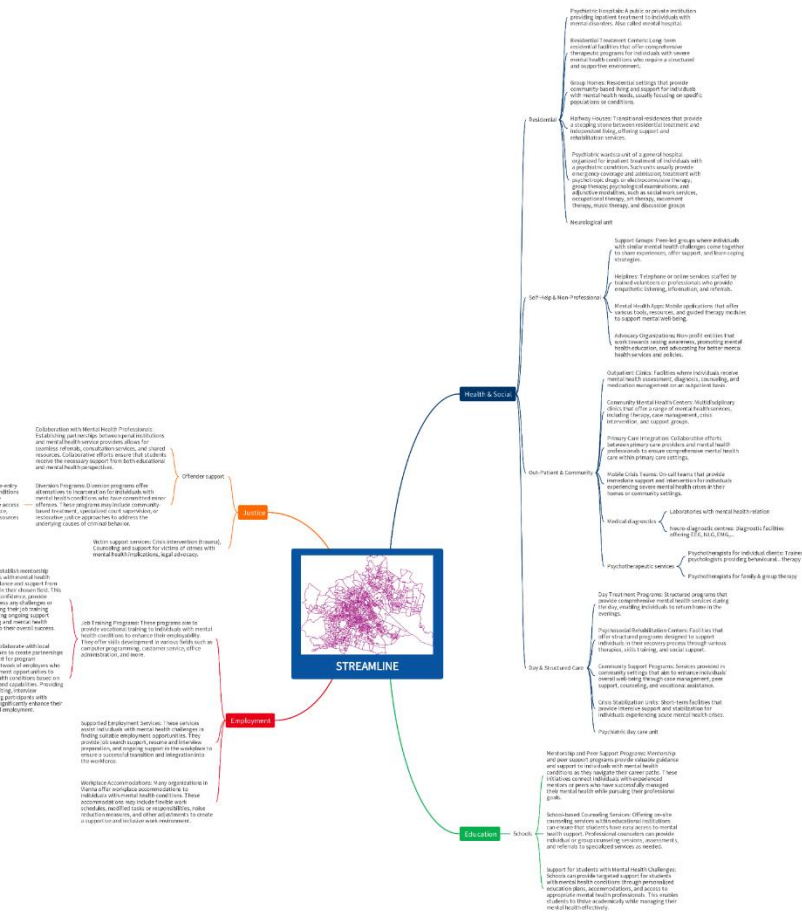
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<https://www.pecunia-project.eu/tools/prom-mh-compendium>



# STREAMLINE Project (2023-2025):

- MH services mapping and costing in Vienna for future health services planning and financing
- Tasks:
  1. Multi-sectoral (H&SC, Ed, Empl, Just) and multi-person (Ch, Adol, Adult) identification of services
  2. Coding of main service types
  3. Reference Unit Cost development
  4. Development of policy recommendations



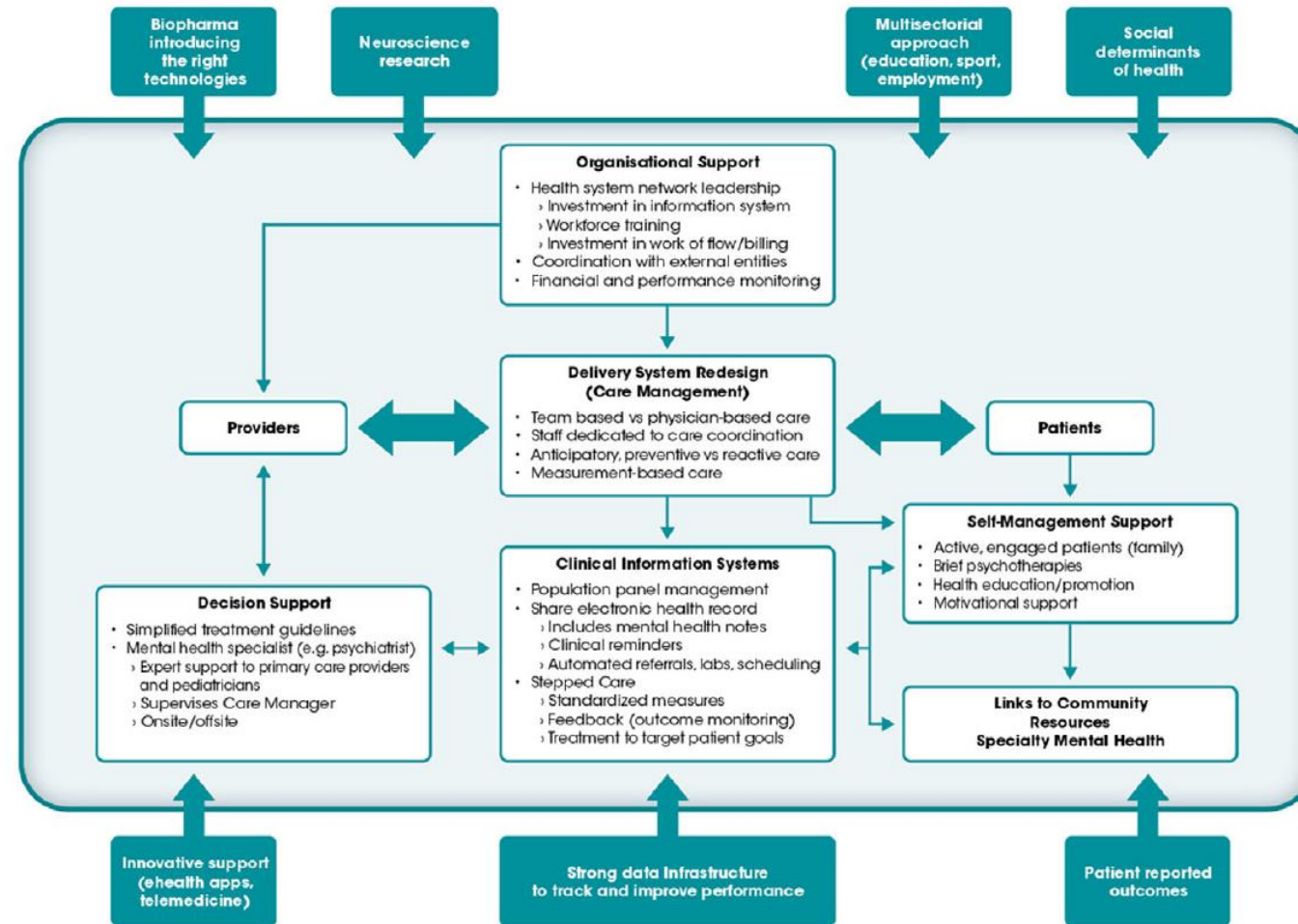
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<https://public-health.meduniwien.ac.at/unsere-abteilungen/abteilung-fuer-gesundheitsoekonomie/forschung/projekte/laufende-projekte/streamline/>

# Summary

- New harmonized and compatible value assessment framework, cost and outcome tools now exist (PECUNIA) with ongoing piloting in Vienna (STREAMLINE)
- Main limitations in value assessment remains:
  - Limited data availability
  - Limited promotion, prevention, early intervention and integrated care considerations
  - Limited life course approaches
  - Limited flexibility for emerging trends (e-health, COVID, youth MH)
  - Limited opportunities for implementation (fragmentation)

# Policy implications: Enabling ecosystem

(Simon et al. Eur Psych 2023)



# Thank you!

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# Questions & Answers

