ROAMER

A Roadmap for Mental Health Research in Europe

Funded BY FP7/2007-2013nº282586

A Road Map for Mental Health Research in Europe

Grant Agreement no. 282586

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Developing mental health and well-being research priorities for Europe

Josep Maria Haro Abad

Coordinator of ROAMER

Til Wykes

ROAMER writing package lead

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OBJECTIVE

Coordinated and comprehensive

ROADMAP

IN MENTAL HEALTH AND WELLBEING RESEARCH

to promote and integrate

the biological, clinical, social and public health aspects

3 year project that started in Oct 2011, ends end of March 2014

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The ROAMER project
What we have done

- Biomedical research and neurosciences
- Psychological therapies and treatments
- Social and economic aspects
- Public mental health
- Well-being
- Clinical research and integration (developmental and geographical)
- Infrastructures, funding and capacity building

Analysis of State of the Art

Detection of Gaps and Advances

Criteria for priorities:

1. Efficacy/effectiveness
2. Impact/deliverability/ economic benefits
3. Answerability/feasibility
4. European research strength

- About 270 people in multidisciplinary work groups
- Surveys with 108 national stakeholder associations
- Scientific Advisory Board
- Stakeholder Advisory Board
- Funding Institutions Council

INTEGRATION

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The ROAMER Project

Scope

Includes mental and behavioural disorders (ICD-10):

- ✓ Schizophrenia and other non-affective psychosis
- ✓ Mood (affective) disorders, such as Depression, bipolar disorder
- ✓ Neurotic, stress-related and somatoform disorders; such as Generalized anxiety or panic disorders
- ✓ Childhood behavioural and developmental disorders, such as autism or ADHD
- ✓ Personality disorders
- ✓ Intellectual disability
- ✓ Alcohol and substance use disorders
- ✓ Unespecified mental disorders

Except for organic mental disorders, such as:

- ✗ Alzheimer's disease and other dementias

Same classification as used in the Global burden of disease attributable to mental and substance use disorders: findings from the Global Burden of Disease Study 2010 ; Whiteford, Harvey A et al. The Lancet , Volume 382 , Issue 9904 , 1575 - 1586

Participation in ROAMER

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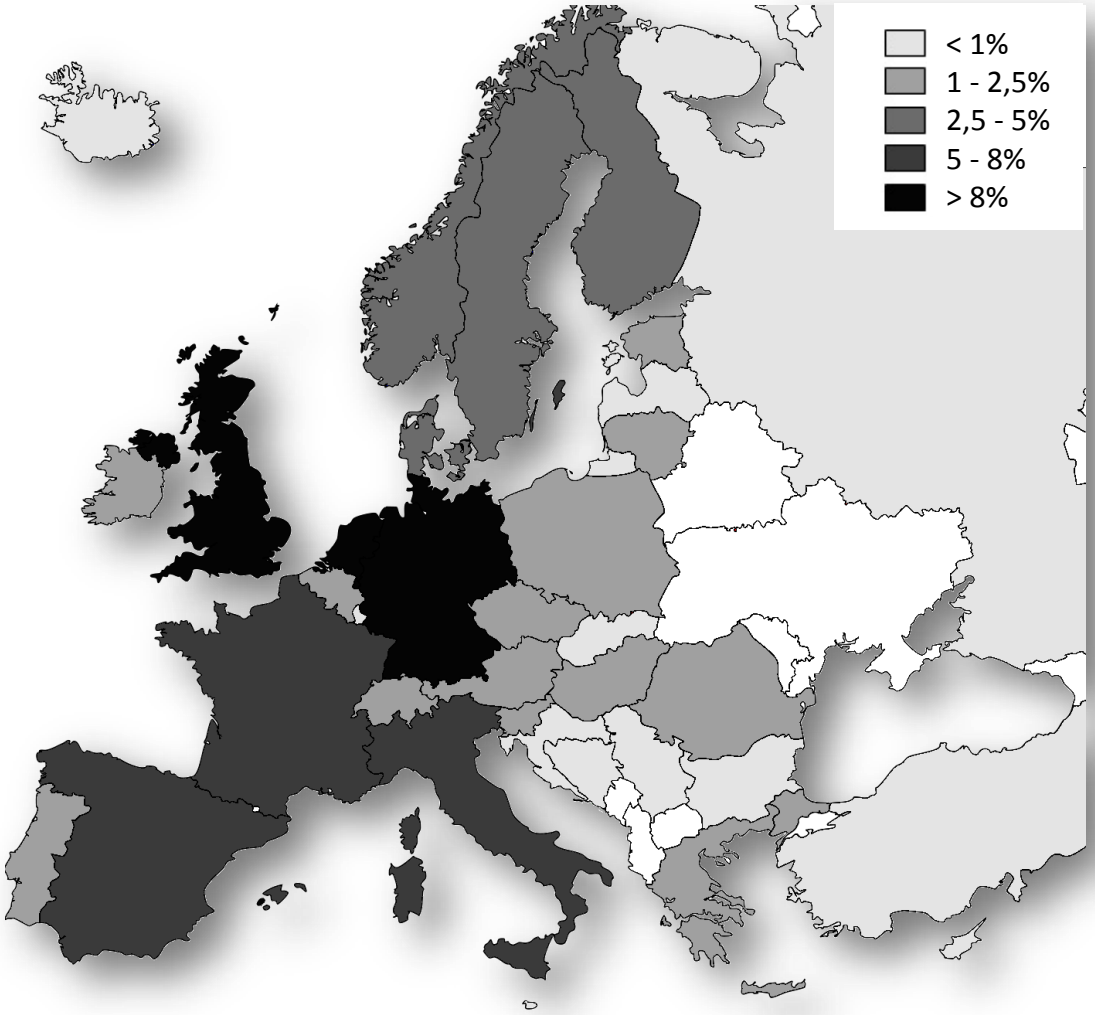

Stakeholder groups:

- **>600 researchers**
- **>250 associations**
- **30 policy makers and funders**
- **9 industries**

Other participants:

3% from abroad (USA, Australia, Canada)

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Stakeholder Advisory Board

- Global Alliance of Mental Illness Advocacy Networks - Europe (GAMIAN-Europe)
- EuroHealthNet
- European Psychiatric Association (EPA)
- European Brain Council (EBC)
- European Federation of Assoc. of Families of People with Mental Illness (EUFAMI)
- European Federation of Psychologists' Associations (EFPA)
- European Health Management Association (EHMA)
- European Joint Action for Mental Health and well-being
- European Public Health Alliance (EPHA)
- European Public Health Association (EUPHA)
- European Society for Child and Adolescent Psychiatry (ESCAP)
- Federation of European Neuroscience Societies (FENS)
- Union Européenne des Médecins Spécialistes (UEMS) - Section of Psychiatry
- WONCA World Working Party on Mental Health
- World Health Organization (WHO) – European Office for Mental Health
- Mental Health Europe (MHE)
- European Social Network (ESN)
- European Council of Neuropsychopharmacology (ECNP)
- International Union for Health Promotion and Education

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Scientific Advisory Board

Member	Area of knowledge	Country
Jean Addington	Young adults and adolescents. Psychosis & Schizophrenia	Canada
Peter Allebeck	Public Health	Sweden
Gerrit Glas	Mental Health and Philosophy	Netherlands
Guy Goodwin	Mood disorders	UK
Rachel Jenkins	Mental Health Policy	UK
John Kane	Pharmacotherapy, organization network clinical research (RAISE)	USA
Ron Kessler	Epidemiology	USA
Martin Knapp	Economics	UK
David Kupfer	Nosology	USA
Stefan Leucht	Statistics meta-analyses, psychopharmacol., clinical trials, Cochrane library	Germany
Don Linszen	Psychosis and Schizophrenia	Netherlands
Oscar Marin	Neurodevelopment and Animal Models	Spain
Patrick McGorry	Prevention	Australia
RobinMurray	Clinical psychiatry and Schizophrenia	UK
Michael Owen	Genetics	UK
Harold Pincus	Public Health	USA
Shekhar Saxena	International view	WHO
Emily Simonoff	Child and adolescent psychiatry	UK
Claudia Stein	Research evidence for health policy, well-being	EU
Gabriela Stoppe	Old age psychiatry	Switzerland

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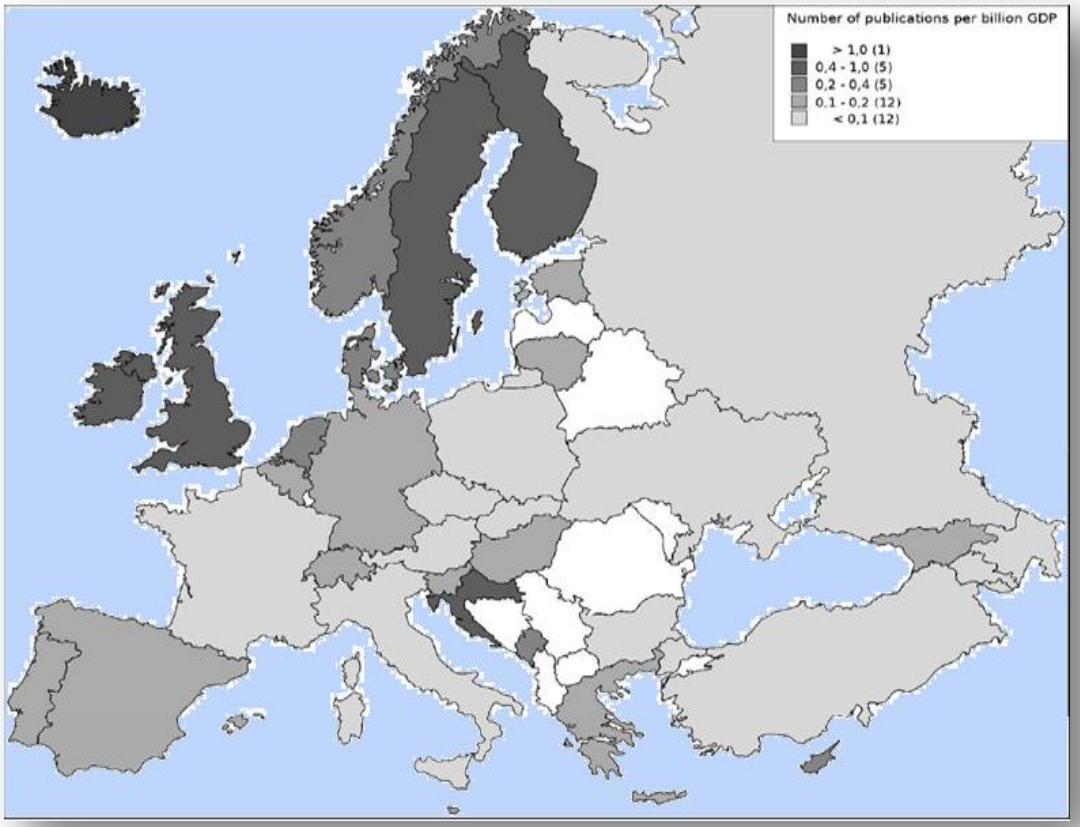
Systematic Literature Mapping

Public Mental Health

Geographic distribution of publications (weighted by GDP)



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Period: 2007-2011

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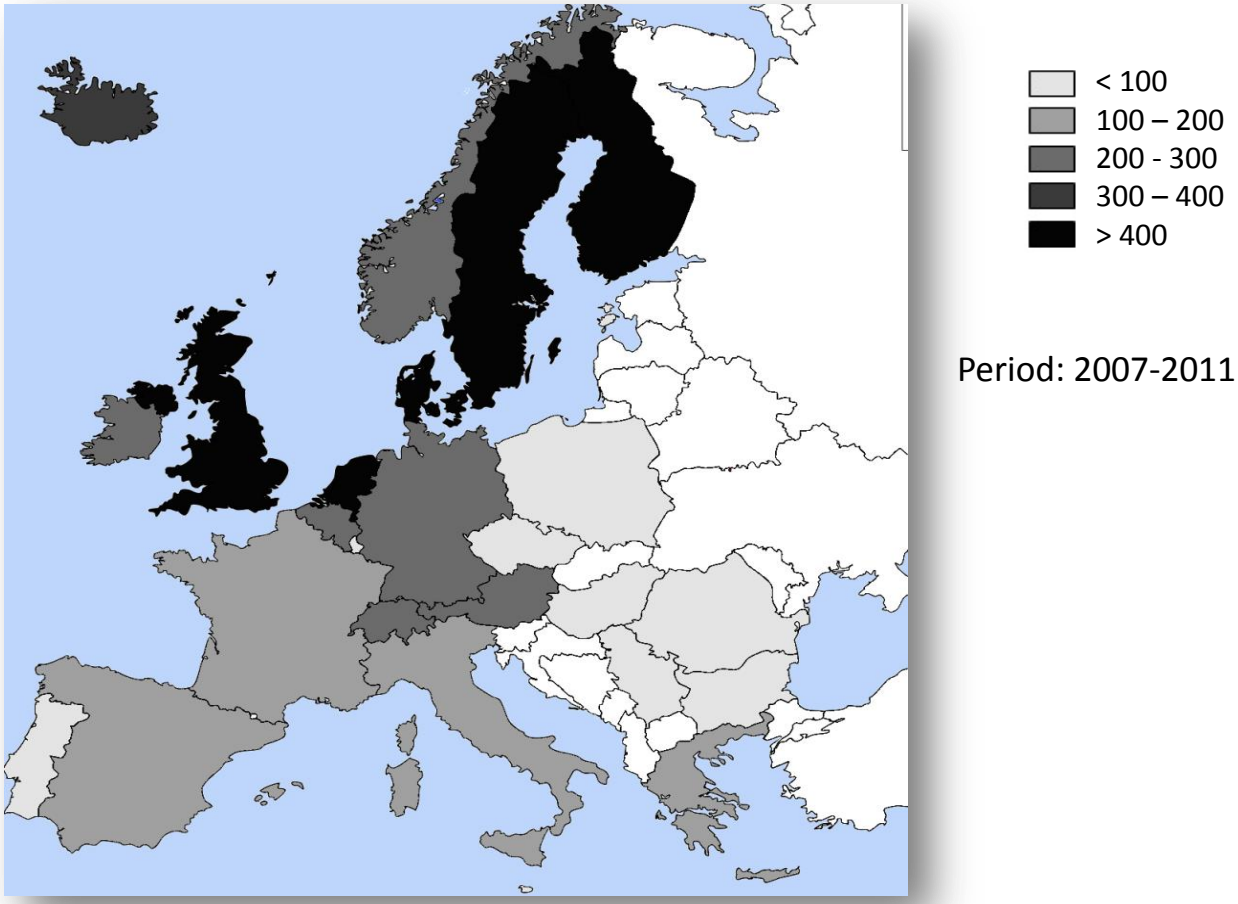
Systematic Literature Mapping

Randomized Clinical Trials

Geographic distribution of RCT-related publications (weighted by GDP)



Period: 2007-2011

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National funding for MH research

National public and non-profit funding for mental health research

in euros for year 2011

	Total amount allocated for mental health research (M€)	% of health research budget allocated to mental health	Funding per capita for mental health research (€ / inhabitant)
Spain	16.8	5.6	0.4
Finland	10.2	9.7	1.9
France	84.8	4.1	1.3
UK	95.3	7.0	1.5

GDP per capita in 2011

Spain : $ 31 118 Finland : $ 48 695 France : $ 42 578 United-Kingdom : $ 38 927

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Establishing Research Priorities

1) Expert opinion / subjective methods
2) Valuing the burden of disease
3) Valuing the impact on patient clinical status /quality of life
4) Valuing the economic impact
5) Combination of criteria (including feasibility)

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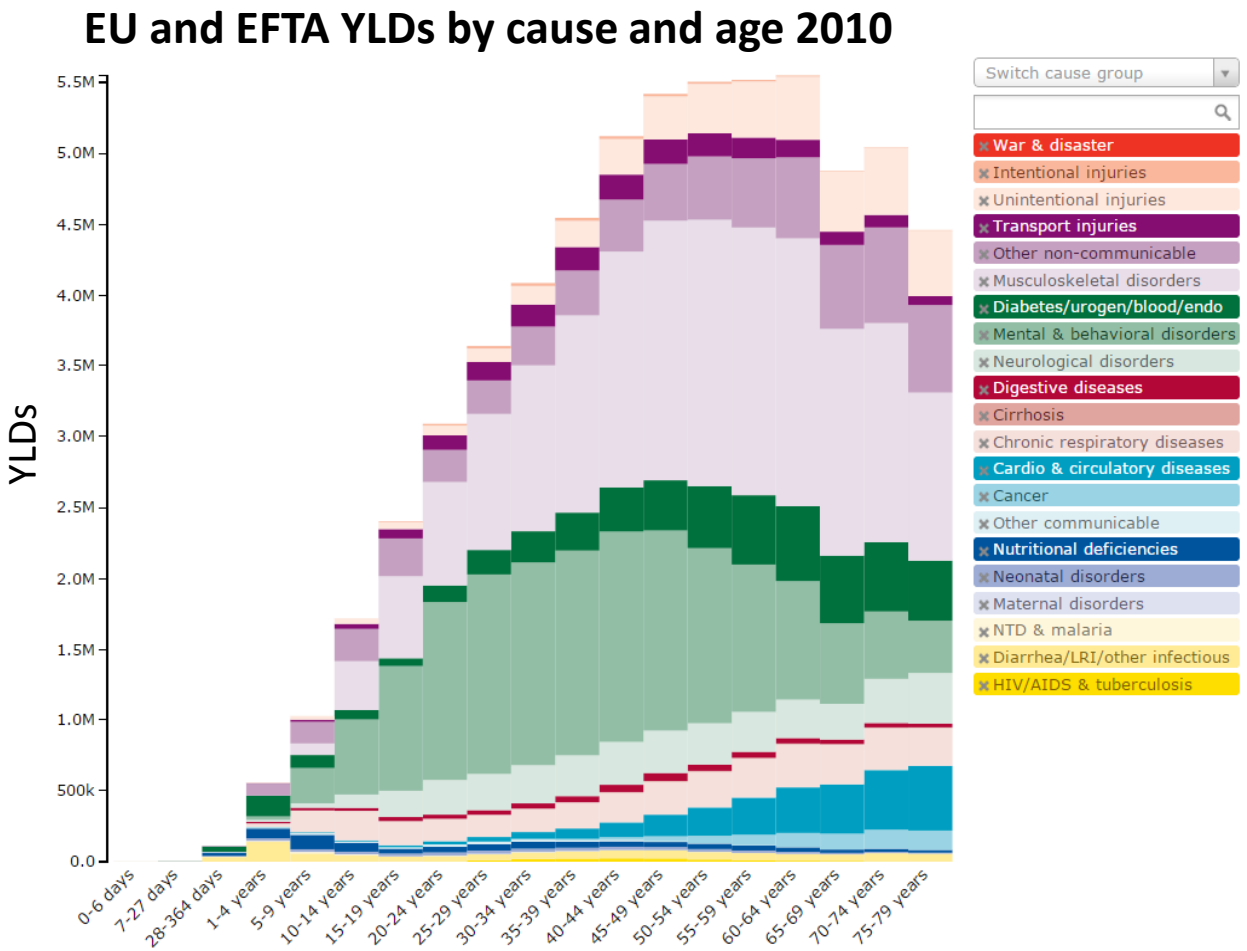
Burden of Disease

Years lived with disability (YLD)

Mental disorders 11.8% of total DALY's

17.0% cardiovascular
17.7% cancer



Global Burden of Disease,2010

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Impact on patient status and economic return

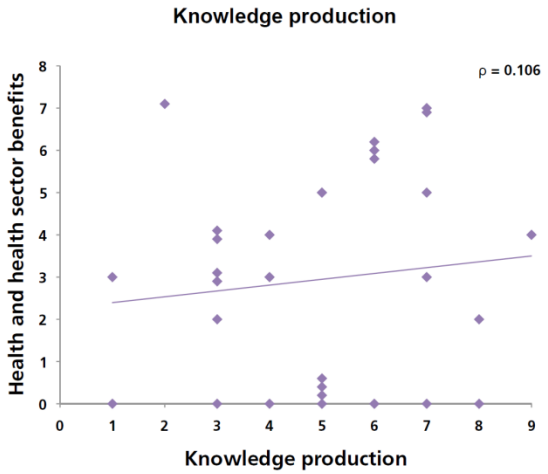
RAND CORPORATION

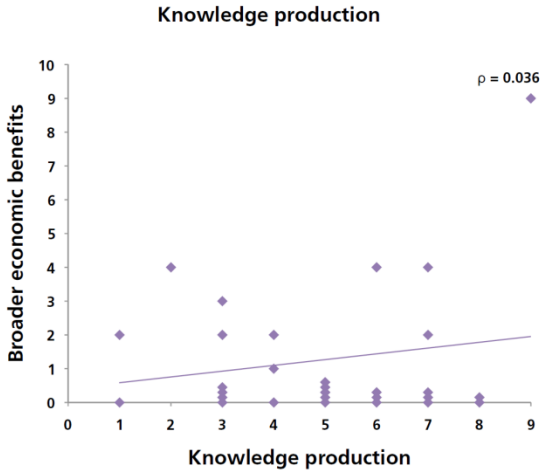
Project Retrosight

Understanding the returns from cardiovascular and stroke research

Medical Research: What's it worth?

Estimating the economic benefits from medical research in the UK





For each **€1** invested by the taxpayer or charity donor in cardiovascular disease and mental health research, a stream of benefits is produced equivalent to earning €0.39 and **€0.37** respectively **per year in perpetuity**.

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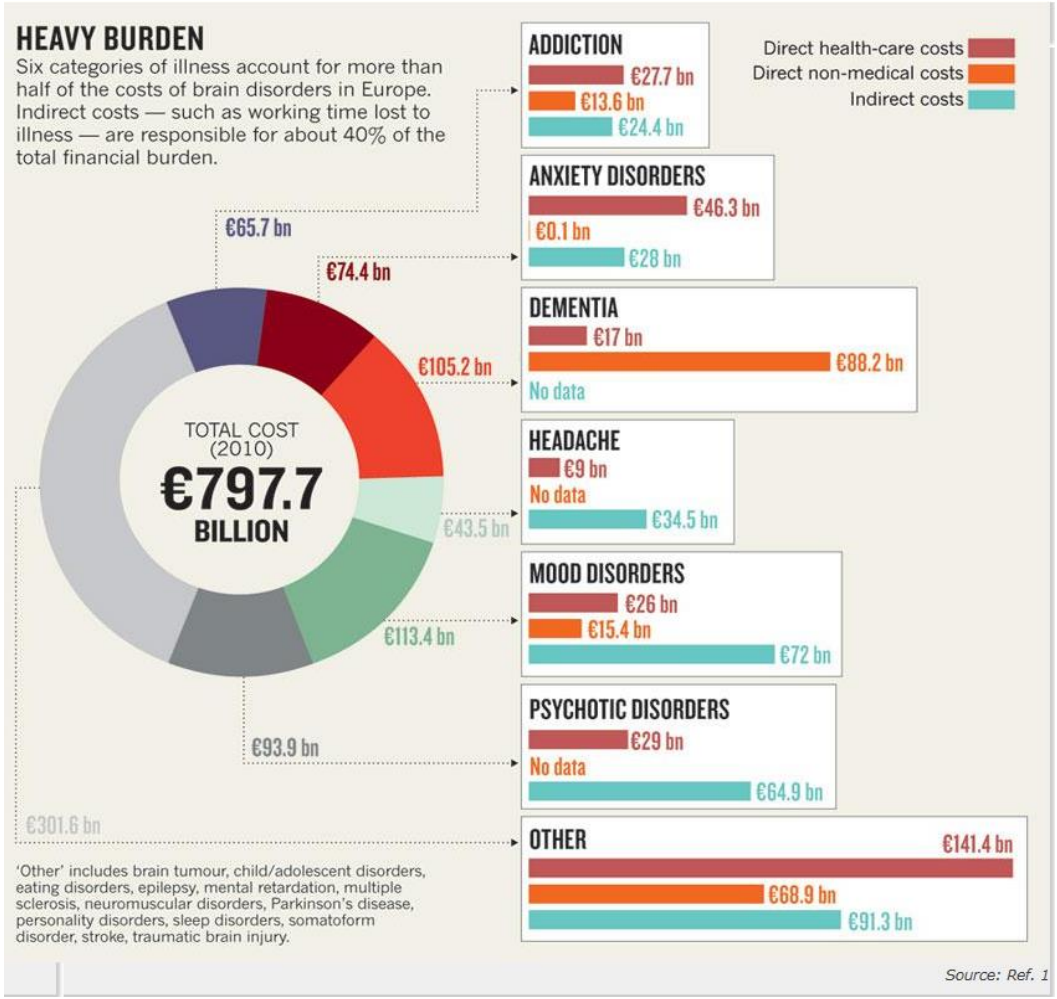
Economic Impact

High economic cost of mental disorders in Europe:



Direct + Indirect Costs =

€692.5 billion

(excluding dementia and comorbidity)

Gustavsson, A. *et al.* Eur. Neuropsychopharmacol. 21, 718-779 (2011) and Smith K. (Nature, 2011)

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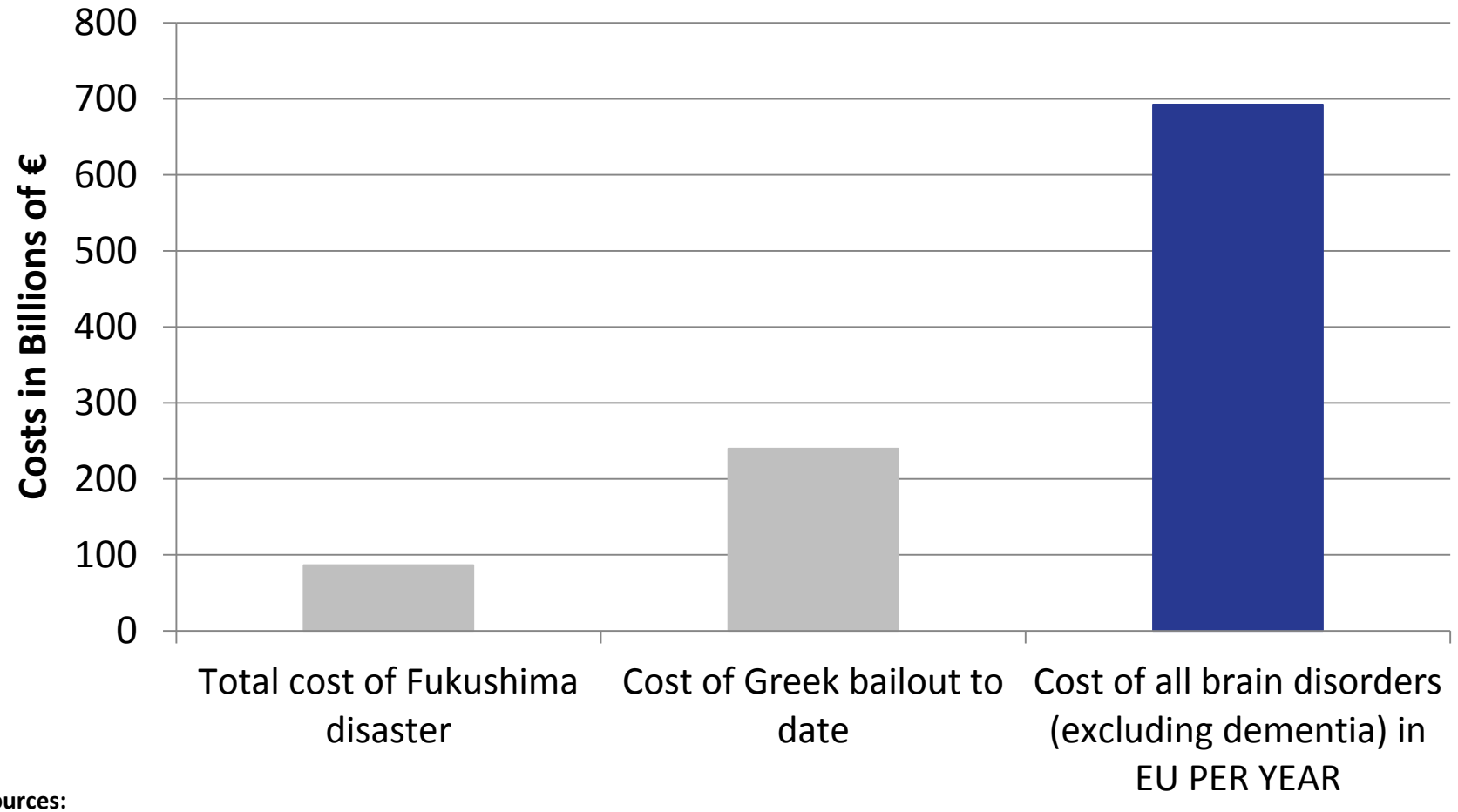
Perspective on Costs



Sources:

http://rt.com/news/183052-japan-fukushima-costs-study/

http://www.reuters.com/article/2014/10/15/markets-bonds-euro-idUSL6N0SA3IH20141015

Gustavsson, A., Svensson, M., Jacobi, F., Allgulander, C., Alonso, J., Beghi, E., … Olesen, J. (2011). Cost of disorders of the brain in Europe 2010. *European Neuropsychopharmacology*, *21*(10), 718–79.

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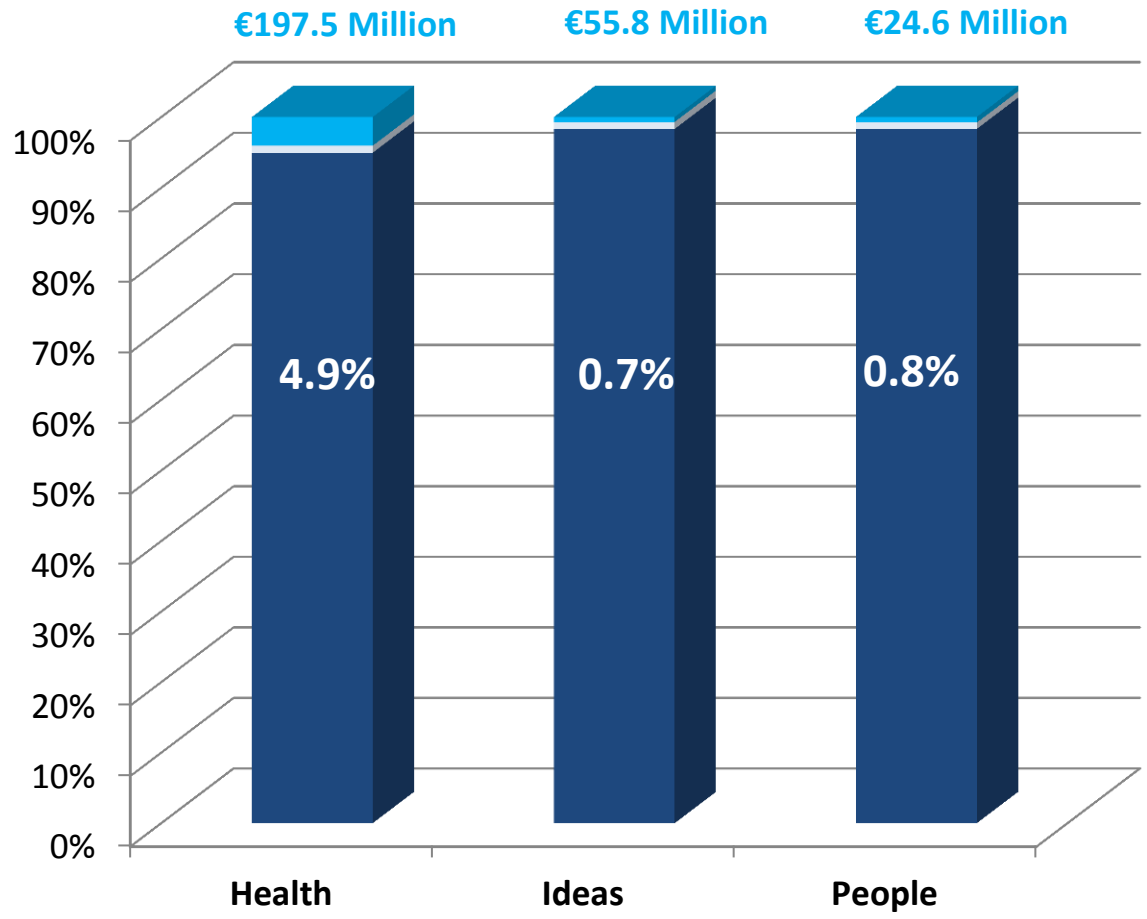
European Funding for MH Research

Funding strategies: FP7's investments



Mental disorders 11.8% of total DALY's

17.0% cardiovascular
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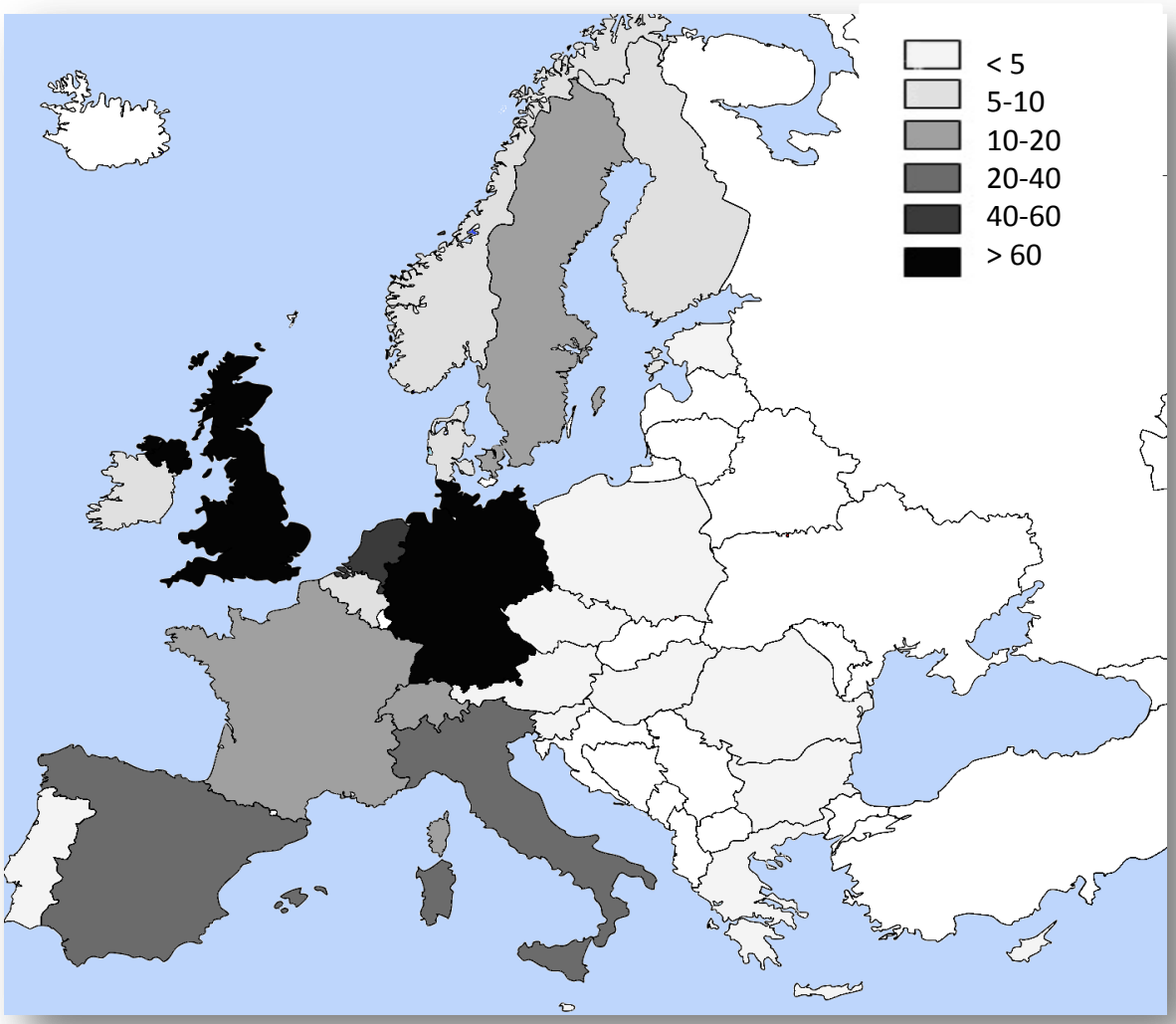
European Funding for MH Research

Mental health research (specific) FP7 Funding per country (Million €)



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Integrating Priorities

- There should be **more research into preventative measures, resilience factors, and buffer interventions** for positive mental health and well-being, as part of a wider focus on positive mental health and well-being. Do that tend to thy positive impacts on mental health and well-being as well as societal (e.g. economic crises) and personal factors (e.g. lifestyle and behaviour change). Novel interventions research (e.g. eHealth and self-management of disorders) will elucidate these factors and their relationship to each other – for instance relationships between psychopathology and subjective well-being.

Research into preventative measures and resilience, as part of a wider focus on positive mental health and well-being

- Promotion of basic psychological research aiming to identify the basic mechanisms involved in the initiation and maintenance of behaviour relevant for health
- Promotion of psychological (behavioural) research regarding change of health-related behaviours
- Timely research is needed on different aspects of the impact of current and past economic shocks (e.g. booms, recessions) on mental health and well-being. Do that tend to thy positive impacts on mental health and well-being as well as negative impacts? What factors cushion individuals from the most adverse impacts of crises?
- To perform and sustain long-term prospective cohort studies to investigate the determinants of mental health and well-being and to study risk and protective factors for mental disorders and suicidal behaviour.
- Increase evidence of population well-being interventions impacting mental health outcomes.
- Establish evidence on the impact and cost-effectiveness of clinical interventions to improve, protect and promote subjective well-being.
- Check and broaden evidence on the effects of subjective well-being on prevention of mental disorders and recovery.

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ROAMER Goals

Public health interventions for promoting mental health and well-being

New, safe and effective treatments and services and social interventions

Reduce burden on society – indirect costs

Reduced treatment costs – direct costs

European level competitiveness

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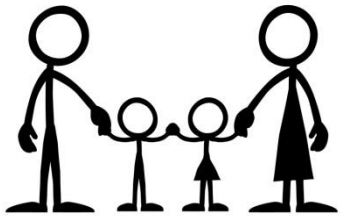
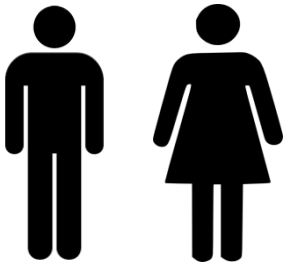
Levels of Mental Health

Societal level

Family level



Individual level



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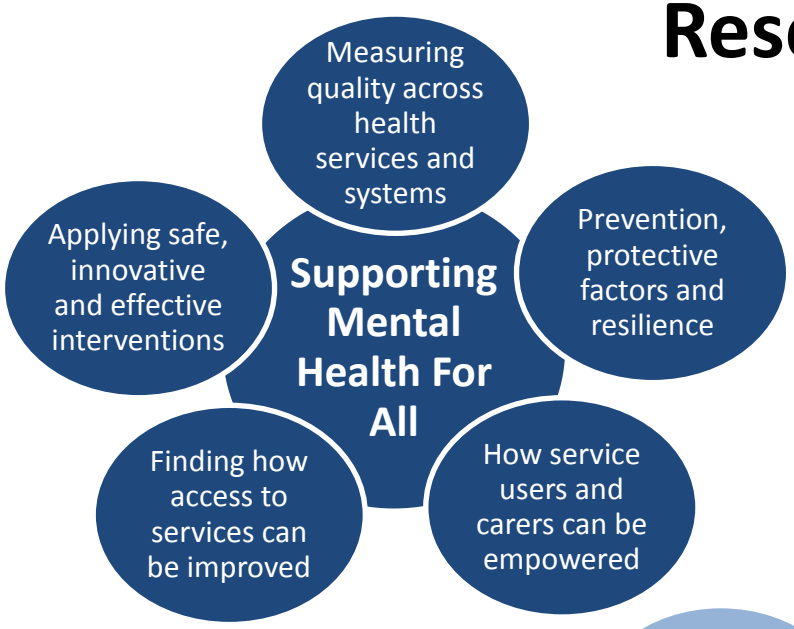
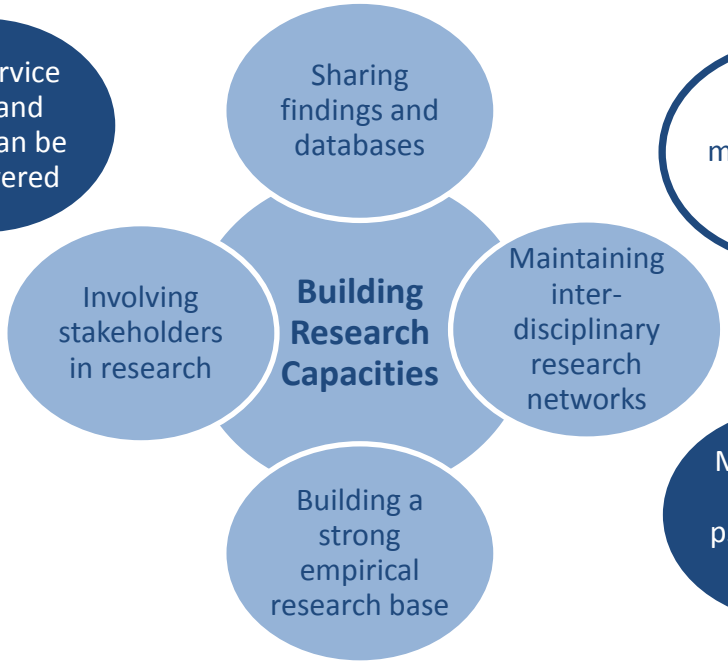
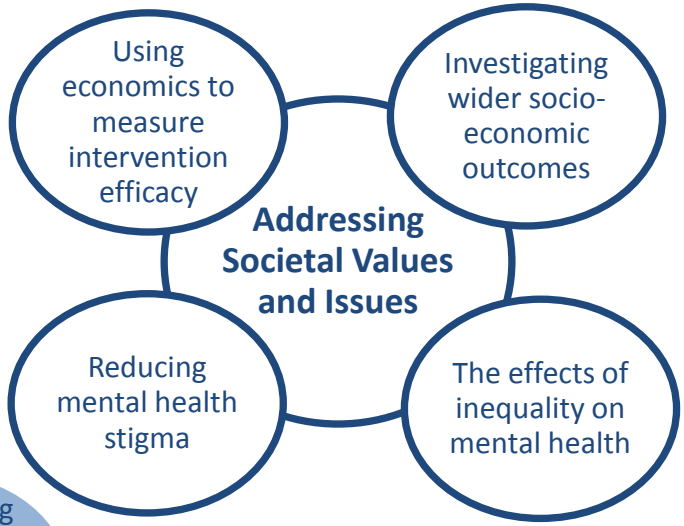
WHY European competitive advantage

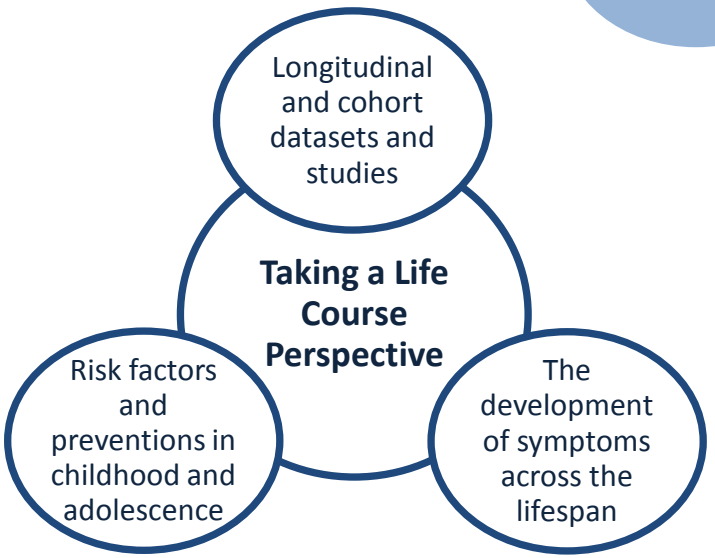
- Excellent Science in Europe
- Research potential of new and longitudinal data sets
- Stable healthcare systems providing universal care
- Ability to track individuals through healthcare
- Health and welfare systems differ across countries allowing natural experiments

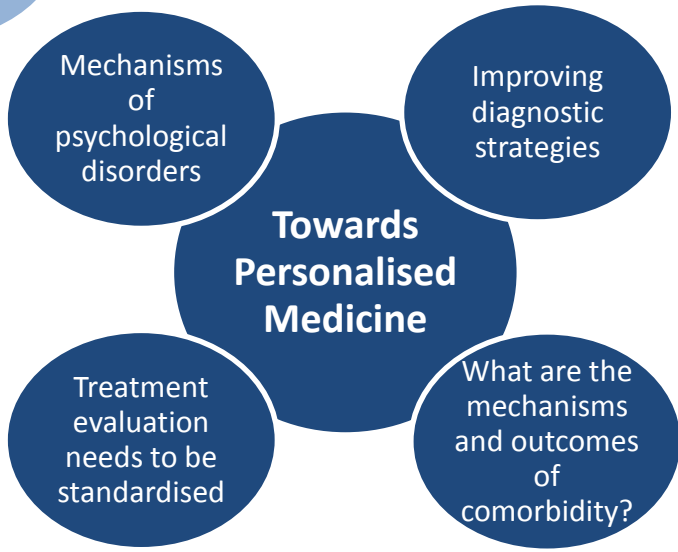
Research is needed into…











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High Level Priorities

1. Research into **mental disorder prevention, mental health promotion** and other interventions in **children, adolescents and young people**
2. Focus on the **development and causal mechanisms** of mental health symptoms, syndromes and well-being across the lifespan (including older populations)
3. Developing and maintaining international and interdisciplinary **research networks and shared databases**
4. **Developing and implementing better interventions** using new scientific and technological advances
5. **Reducing stigma and empowering service users and carers** in decisions about mental health research
6. **Health and social systems research** that addresses quality of care and takes account of **socio-cultural and socio-economic contexts** and approaches

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High Level Priorities

1. Research into **mental disorder prevention, mental health promotion** and other interventions in **children, adolescents and young people**

For example:

- Performing and sustain **long-term prospective cohort studies** on the determinants of mental health and well-being and to study risk and protective factors for mental disorders

- Developing pharmacological and psychological **treatments for children and adolescents**

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High Level Priorities

For example:

- Determining what the **social and biological factors underlie risk or resilience factors** for mental disorders across the life span

- Studying **what brain abnormalities predict future mental disorder** using longitudinal structural and functional neuroimaging

2. Focus on the **development and causal mechanisms** of mental health symptoms, syndromes and well-being across the lifespan (including older populations)

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High Level Priorities

3. Developing and maintaining international and interdisciplinary **research networks and shared databases**

For example:
Establishing access to European **mental health databases** across different studies with standardised mental health outcomes

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High Level Priorities

For example:
Understanding why some individuals do not respond to treatment by identifying relevant, and potentially developmentally specific, mediating and moderating variables of evidence-based psychotherapies for youths with mental disorders

4. **Developing and implementing better interventions** using new scientific and technological advances

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High Level Priorities

5. **Reducing stigma and empowering service users and carers** in decisions about mental health research

For example:
Studying the role of stigma in the wider context of inequalities (health inequalities, etc.) and implementing interventions to assess the place of stigma in public services

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High Level Priorities

For example:
Health-systems-level research on the cost-effectiveness of different ways of financing, regulating, organising and providing services to promote and protect mental health

6. **Health and social systems research** that addresses quality of care and takes account of **socio-cultural and socio-economic contexts** and approaches

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What Can You Do?

The Members of the European Parliament, as representatives of the citizens:

- Have power of control over the Union's institutions
- May ensure equity in research funding distribution
- Can promote increasing involvement of service users in mental health research projects

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What Can You Do?

As researchers:

- Pursue research informed by the ROAMER research priorities
  - e.g. developmental mechanisms and risk factors, comorbidity, developing new interventions, systems-level research, including societal and wider contextual factors as measures
- Aim to develop and expand interdisciplinary and international research networks
- Pool information with other researchers and institutions
  - Moving towards fully open publications and data
- Build opportunities for direct involvement of service users (and other stakeholders) in research

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What Can You Do?

As policymakers:

- Read and disseminate freely available ROAMER materials
- Work with researchers (and stakeholders such as service users) to produce truly evidence-based policy
- Build research into any new mental health policies
    - Work with researchers to devise effective evaluations for policy trials
- Ensure opportunities and funding for new research following the ROAMER priorities

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What Can You Do?

As service users:

- Get involved in research
  - e.g. through organisations like SURE and GAMIAN
- Read and disseminate freely available ROAMER output
- Lobby policymakers to fund research into areas of service user interest
  - e.g. quality of care, systems research, new interventions, comorbidity, stigma
- Approach research institutions and funding bodies with your own research proposals

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What Can You Do?

As a funding body:

- Create funding calls based on the ROAMER priority areas
- Create more opportunities for interdisciplinary and international research projects
- Make the direct involvement of service users a requirement of funded mental health research projects
- Build continuations of funding into research
    - So successful projects can immediately continue into implementation

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And all the others involved

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EXTRA SLIDES

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THE GLOBAL BURDEN OF DISEASE: GENERATING EVIDENCE, GUIDING POLICY

2013

INSTITUTE FOR HEATLH METRICS AND EVALUATION UNIVERSITY OF WASHINGTON

Mental and behavioral disorders are the **primary drivers of disability worldwide** and caused over 40 million years of disability in 20- to 29-year-olds.

DALYS for mental and behavioural disorders increased from 1990 to 2010 by 37%

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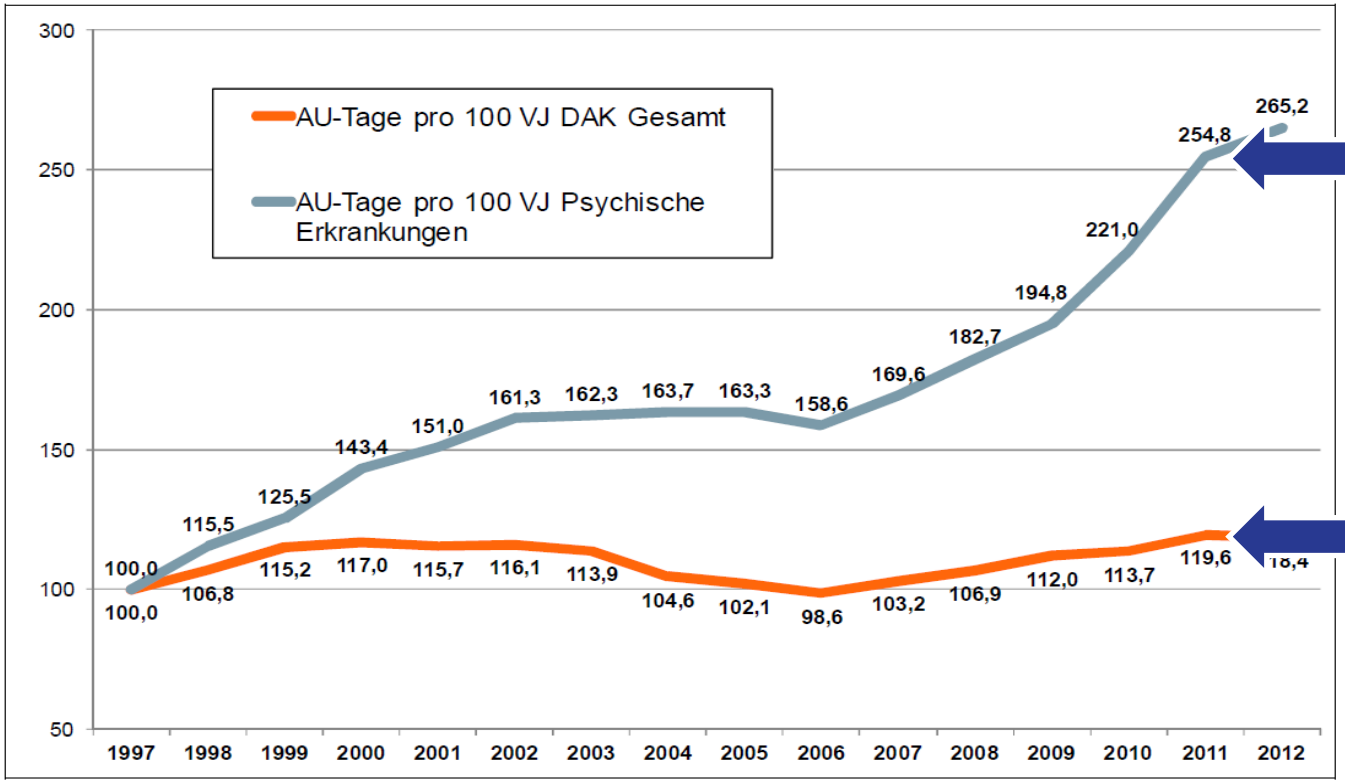
Higher Levels of Absenteeism

Abbildung 23: Entwicklung des Fehltagevolumens aufgrund psychischer Erkrankungen im Vergleich mit dem AU-Gesamtvolumen. Indexdarstellung 1997 = 100



Absence due to mental disorders *increases*

Total sick leave *stays constant*

Quelle: AU-Daten der DAK-Gesundheit 1997-2012

Source: DAK Gesundheit 2013

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Higher Levels of Absenteeism

Therefore best way to combat overall absenteeism and loss of productivity is to specifically target mental disorders

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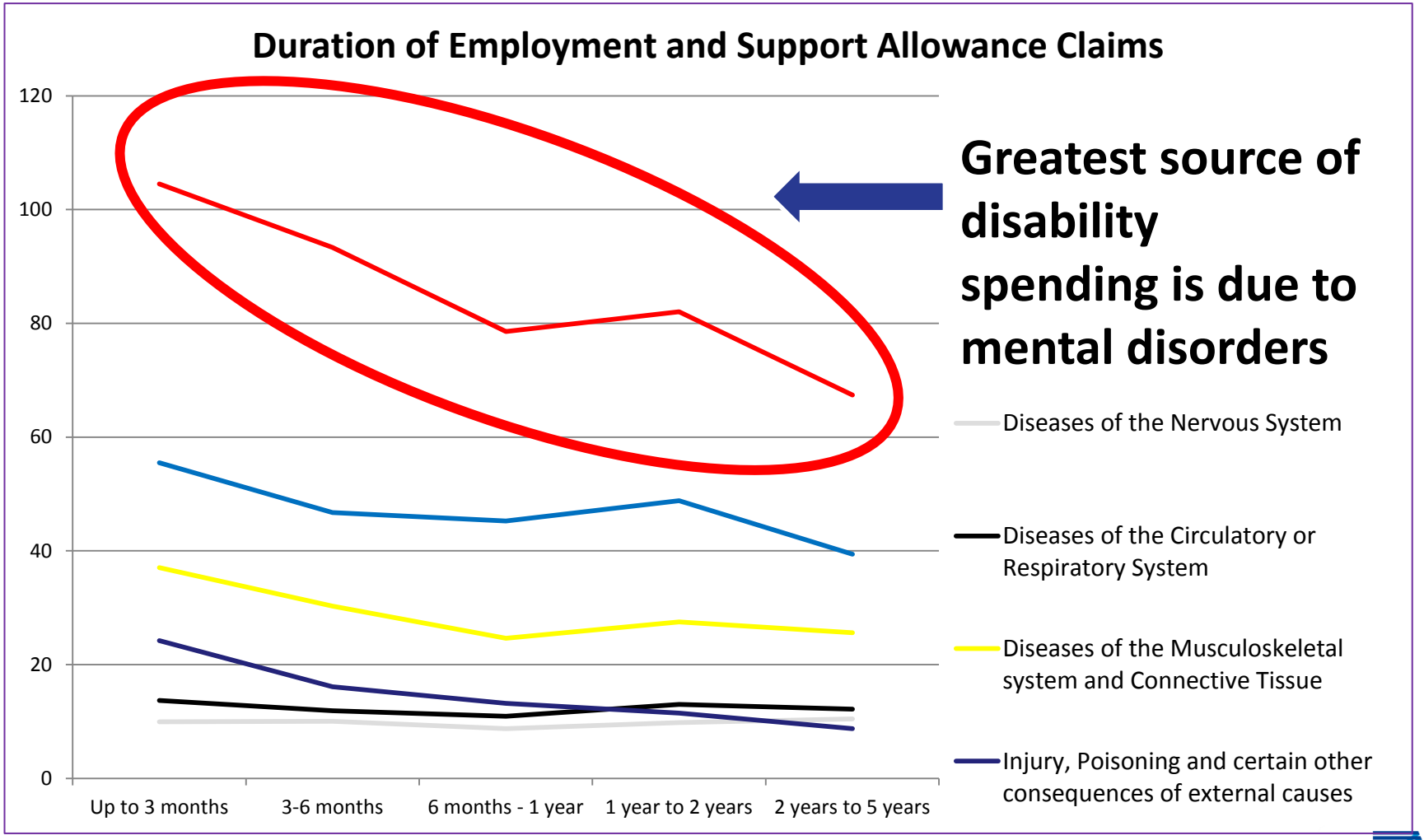
Disability Benefit Claims



Source: Department of Work and Pensions, 2012

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Disability Benefit Claims

Therefore best way to reduce expenditure on disability claims is to prevent the development of mental disorders

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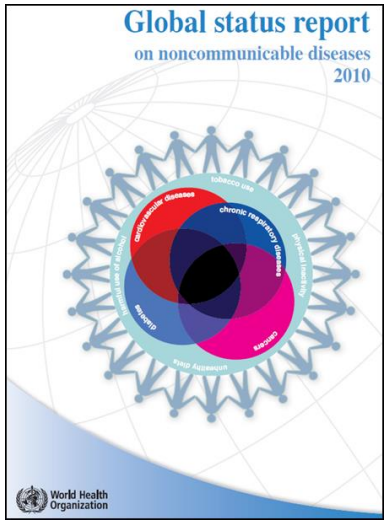
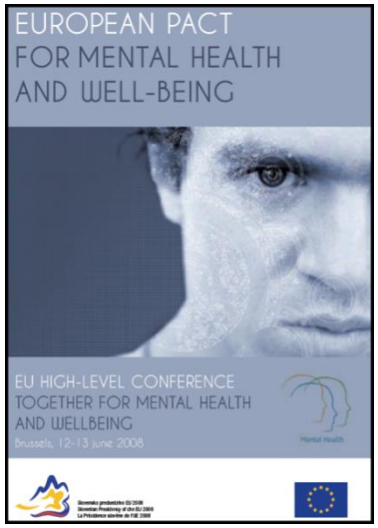
Input to ROAMER





Improving treatment for children with mental illness, like this girl in Somalia, is an urgent priority.

Grand challenges in global mental health

A consortium of researchers, advocates and clinicians announces here research priorities for improving the lives of people with mental illness around the world, and calls for urgent action and investment.

Schizophrenia, depression, epilepsy, dementia, alcohol dependence and other mental, neurological and substance-use (MNS) disorders constitute 13% of the global burden of disease (Table 1), surpassing both cardiovascular disease and cancer[1]. Depression is the third leading contributor to the global disease burden, and alcohol and illicit drug use account for more than 5% (ref. 2). Every seven seconds, someone develops dementia[3], costing the world up to US$609 billion in 2009 (ref. 4). By 2020, an estimated 1.5 million people will die each year by suicide, and between 15 and 30 million will make the attempt[5].

The absence of cures, and the dearth of preventive interventions for MNS disorders, in part reflects a limited understanding of the brain and its molecular and cellular mechanisms. Where there are effective treatments, they are frequently not available to those in greatest need. In 83% of low-income countries, there are no anti-Parkinsonian treatments in primary care; in 25% there are no anti-epileptic drugs[6]. Unequal distribution of human resources — between and within countries — further weakens access: the World Health Organization's European region has 200 times as many psychiatrists as in Africa[7]. Across all countries, investment in fundamental research into preventing and treating MNS disorders is disproportionately low relative to the disease burden[8].

To address this state of affairs, the Grand Challenges in Global Mental Health initiative has identified priorities for research in the next 10 years that will make an impact on the lives of people living with MNS disorders. The study was funded by the US National Institute of Mental Health (NIMH) in Bethesda, Maryland, supported by the Global Alliance for Chronic Diseases (GACD), headquartered in London. Answers to the questions posed will require a surge in discovery and delivery science. We use the term 'mental health' as a convenient label for MNS disorders. We exclude conditions with a vascular or infectious aetiology (such as stroke or cerebral malaria), because these fell within the scope of the two previous grand challenges initiatives — in global health and in chronic non-communicable diseases[9].

This initiative differs from previous priority-setting exercises for mental ▸

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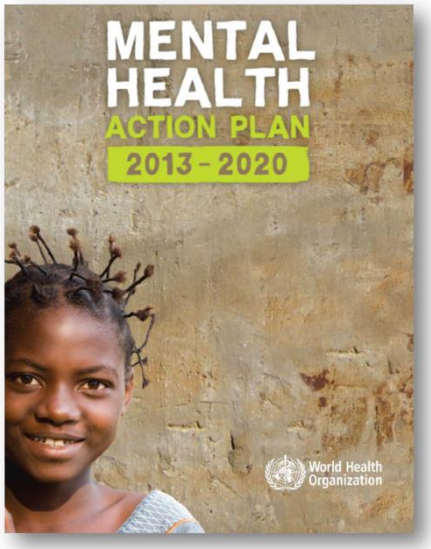

Health & Consumer Protection
Directorate-General

Brussels, 14.10.2005
COM(2005)484

Green Paper

Improving the mental health of the population: Towards a strategy on mental health for the European Union

European Parliament resolution of 19 February 2009 on Mental Health (2008/2209(INI))

The European Parliament ,

– having regard to the EU high-level conference 'Together for Mental Health and Well-Being' held in

– having regard to the Commission's Green Paper on 'Improving the mental health of the population

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Current European Focus

ADVICE FOR 2016/2017
OF THE HORIZON 2020 ADVISORY GROUP
FOR SOCIETAL CHALLENGE 1,
"HEALTH, DEMOGRAPHIC CHANGE AND WELLBEING"

July 2014

- Innovations making use of ICT
- Ageing and longitudinal development
- Personalising medicine and care
- Early development
- Research on health and care systems

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ADVICE FOR 2016/2017
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"HEALTH, DEMOGRAPHIC CHANGE AND WELLBEING"

July 2014

Also identifies over-arching issues in health research:

- Development across the lifespan
- Service user and citizen involvement
- Gender aspects of research
- Transnational collaboration using EU funds
- Evidence-based medicine and implementation science
- Innovation using technological advances
- Interdisciplinarity in research

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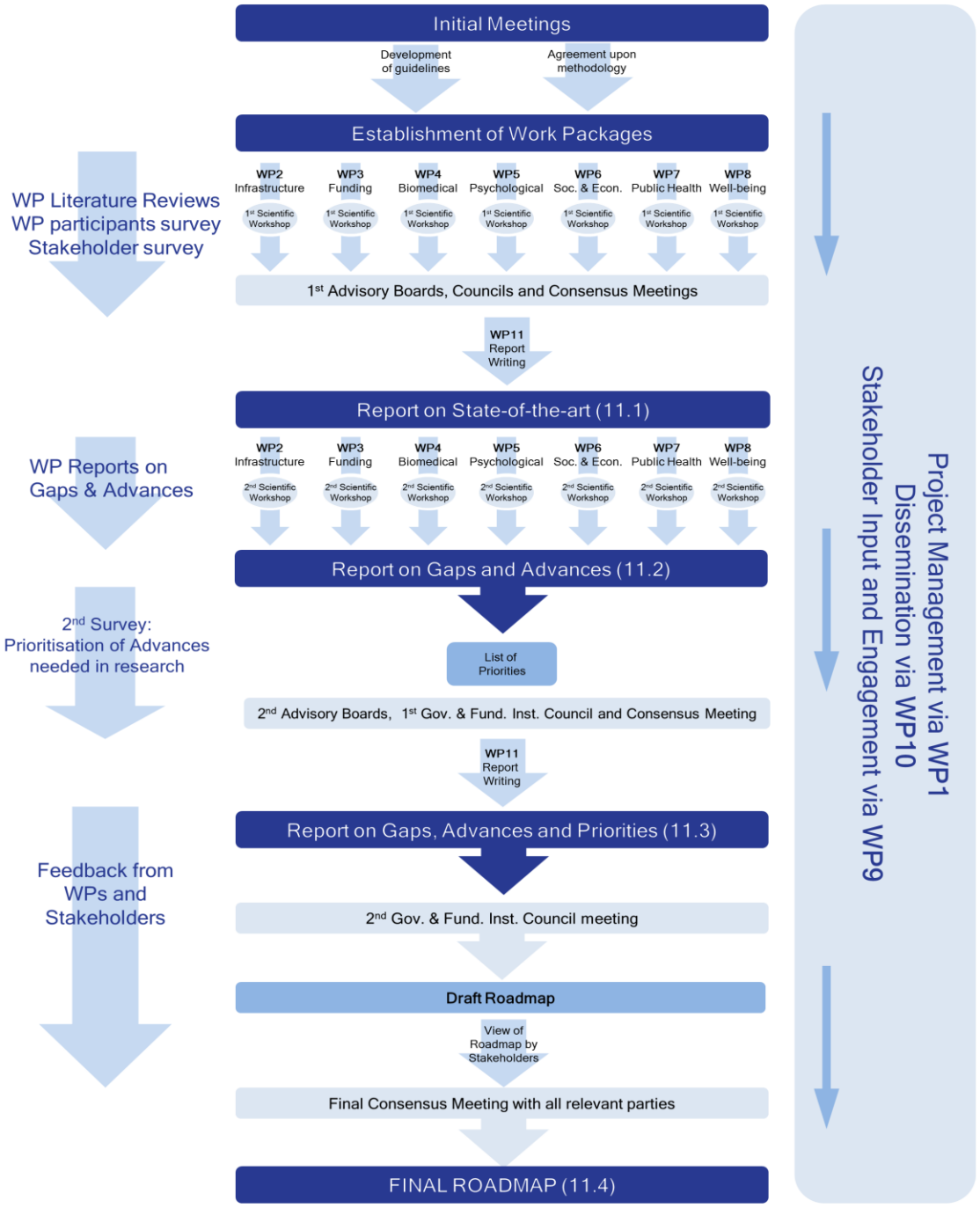

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EU Countries Represented

EU countries represented across ROAMER work packages:

Austria, Belgium, Croatia, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Netherlands, Norway, Poland, Portugal, Romania, Scotland, Serbia, Slovenia, Spain, Sweden, Switzerland, United Kingdom

PLUS pan-European, Australian, North American and Global representatives on advisory boards

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Generating Priorities

- Balance between a number of factors:
  - Likelihood of translation within the next ten years
  - Will use EU scientific expertise
- Involvement of scientific experts through production of priorities and in a survey
- Involvement of key stakeholders (who we know don't necessarily agree)
  - Service users
  - Clinicians
  - Industry

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The ROAMER roadmap

Continuous review by the Gov. & Fund. Institution Council, Stakeholder and Scientific Advisory Boards

Systematic identification of research advances needed in each area of knowledge

(consensus of WP experts)

Justification (common criteria*)

Integration among areas

Prioritisation

(Survey)

Final Priority list and Roadmap

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Generating Priorities

- Each work package generated a list of research priorities
  - Decided by consensus
  - Justified by work packages according to common criteria
- These were integrated into an over-arching set of priorities by WP11
  - Based on emergent common themes
- Priorities were then reviewed and revised by all work package leaders

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List of Priorities

- Final 20 priorities address a number of levels
  - From population and public health, to families, to the individual, to the cellular and molecular level
- All areas of research have equal importance
- They recognise the interdisciplinarity of mental health research
- Depend on the consensus decision-making of individual work packages

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Consensus Decision-Making

- Draft versions of this list of priorities were sent out to:
  - the ROAMER consortium
  - ROAMER Stakeholder Advisory Board
  - ROAMER Scientific Advisory Board

- These priorities were revised by consensus
  - Via correspondence
  - During a two-day conference in November 2013

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Prioritisation of Advances

Five main priority areas:

1. Supporting Mental Health for All
2. Responding to Societal Values and Issues
3. Life-course perspectives of mental health problems
4. Research Towards Personalised Medicine
5. Building Research Capacities

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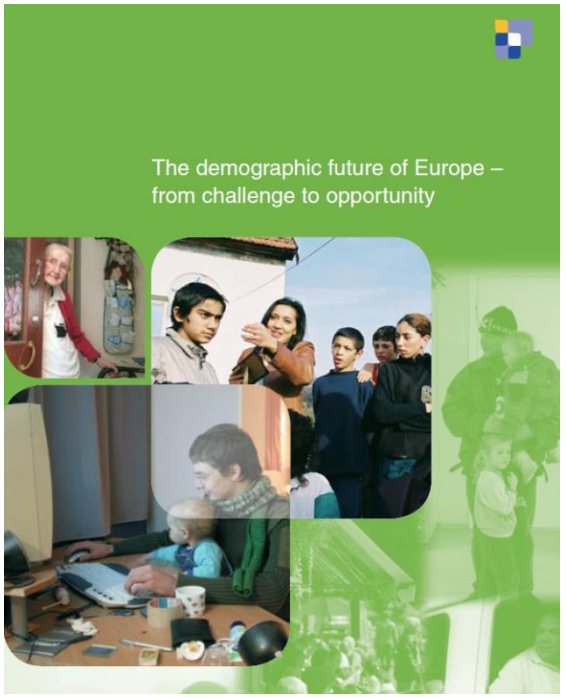
Impact

Europe 2020

Europe 2020 is the EU's growth strategy for the coming decade.
In a changing world, we want the EU to become a smart, sustainable and inclusive economy. These three mutually reinforcing priorities should help the EU and the Member States deliver high levels of employment, productivity and social cohesion.

Concretely, the Union has set five ambitious objectives - on employment, innovation, education, social inclusion and climate/energy - to be reached by 2020. Each Member State has adopted its own national targets in each of these areas. Concrete actions at EU and national levels underpin the strategy.

José Manuel Barroso
President of the European Commission



Research and Innovation performance in the EU

Innovation Union progress at country level

Innovation Union is the European Union strategy to create an innovation-friendly environment that makes it easier for great ideas to be turned into products and services that will bring our economy growth and jobs.

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Prioritisation
- EUROPEAN SURVEY -

2014 ROAMER's European Survey: 'Priorities for mental health research in Europe'

SECTION I. Prioritisation of advances needed in mental health research in Europe

Based on your knowledge and expertise, **please rate from 1** (the lowest) **to 10** (the highest) **the *relevance*[1] and the *feasibility in Europe*[2] of each advance needed in mental health research** listed below.

[1]***Relevance***: *likelihood that the advance results in an effective intervention to improve mental health*
[2]***Feasibility in Europe***: *likelihood that the advance can be achieved in Europe*

IMPORTANT: In case you are participating on behalf of an association/organisation, please make sure to provide your **collective view** rather than your individual opinion.

A. Supporting Mental Health for All

A1. Research into the quality of mental health services and systems across Europe. *

	1	2	3	4	5	6	7	8	9	10
Relevance	○	○	○	○	○	○	○	○	○	○
Feasibility in Europe	○	○	○	○	○	○	○	○	○	○

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Prioritisation
- EUROPEAN SURVEY -

Groups of respondents

Transparent selection

> 600 European researchers

> 40 European/national associations

- Persons with mental health problems, families, and carers
- Clinicians and other mental health service professionals

9 Industries
(e.g., EFPIA partners on the IMI grants)

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- EUROPEAN SURVEY -

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The ROAMER Roadmap

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Systematic identification of research advances needed in each area of knowledge

(consensus of WP experts)

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Prioritisation

(Survey)

Final Priority list and Roadmap

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Justifying Priorities

- In the final Roadmap, each integrated priority is justified according to common criteria:
  - Efficacy/effectiveness
  - Impact / deliverability / European economic benefits
  - Answerability/feasibility in Europe
  - European Research strengths

- These will be based on the justifications from individual work packages

- Will illustrate **how Europe is uniquely well placed** to address (and benefit from) the identified priorities

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High Level Priorities

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High Level Priorities

- All 20 priorities are included in the final ROAMER roadmap

- 6 of these 20 priorities have been highlighted
  - These are practical, targeted and actionable and build on a European legacy of excellent science to tackle societal challenges.

- Resolvable in next 5-10 years as part of coordinated European approaches to improve the mental health of European citizens

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High Level Priorities

1) Research into **mental disorder prevention, mental health promotion** and other interventions in **children, adolescents and young adults**

Relevant to:

- Policymakers and funding bodies in health, education, children's and young people's services
- Europe 2020 growth strategy objective 4: "*reducing school dropout rates to below 10%, with at least 40% of 30–34-year-olds completing tertiary education*"
- 'Youth on the Move' flagship initiative of Europe 2020

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High Level Priorities

2) Focus on the **development and causal mechanisms** of mental health symptoms, syndromes and well-being across the lifespan (including older populations)

Relevant to:

- Policymakers and funding bodies in healthcare, public health, education, employment, ageing
- Demographic change and the ageing European population
- Horizon 2020 Open Data Research Pilot

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High Level Priorities

3) Developing and maintaining international and interdisciplinary **research networks and shared databases**

Relevant to:

- Policymakers and funding bodies in health, innovation/industry, higher education
- Pharmaceutical and biochemical industries, and participants in the Innovative Medicine Initiative
- Horizon 2020 Open Data Research Pilot
- 'Youth on the Move' flagship initiative of the Europe 2020 growth strategy

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High Level Priorities

4) **Developing and implementing better interventions** using new scientific and technological advances

Relevant to:

- Policymakers and funding bodies in health, innovation/industry, higher education, technology and communications
- Pharmaceutical and biochemical industries, and participants in the Innovative Medicine Initiative
- 'Innovation Union' flagship initiative of the Europe 2020 growth strategy
- 'A digital agenda for Europe' flagship initiative of Europe 2020

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High Level Priorities

5) **Reducing stigma and empowering service users and carers** in decisions about mental health research

Relevant to:

- Policymakers and funding bodies in healthcare, public health, community engagement, employment
- Europe 2020 growth strategy objective 5: *"ensuring 20 million fewer people are at risk of poverty or social exclusion"*
- *'European platform against poverty'* flagship initiative of the Europe 2020 growth strategy

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High Level Priorities

6) **Health and social systems research** that addresses quality of care and takes account of **socio-cultural and socio-economic contexts** and approaches

Relevant to:

- Policymakers and funding bodies in healthcare, public health, economic equality, geographic equality
- Europe 2020 growth strategy objective 5: *"ensuring 20 million fewer people are at risk of poverty or social exclusion"*
- *'European platform against poverty'* flagship initiative of Europe 2020

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A Roadmap for Mental Health Research in Europe

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