Survey THCS Mapping of research priorities and strategies to utilize research for informing policy making

Introduction

What is this survey about?

This survey is open until the end of April 2024. It is intended to serve the following goals:

1. To identify challenges and problems in health and care systems and services that should be researched. Your views will help national and European research funding agencies to prioritise key research questions for future research.
2. To identify the needs, gaps and opportunities in transferring innovations across settings and regions.
3. To identify the needs, gaps and opportunities in utilizing research to inform policy making in particular from a policy makers' perspective.

Why is this important?

Countries in Europe are all facing many challenges in how to best organise and finance health and care services to meet the diverse and changing health needs of an ageing population. There is much to gain from collaborative research at European level, to help find solutions and inform decision making on health services and systems.

Who can respond?

The survey is open to anyone. We are interested in the views of researchers, policymakers, patients, carers, health and social care workers, and any interested member of the public. Some of the questions on policy making are especially targeted toward policy makers, but also others are invited to respond.

Will my responses be identifiable?

No. All responses are treated anonymously, although we will ask some general information about your background.

How long does this survey take?

Approximately 20 minutes, but this also depends on the amount of input you would wish to provide and which questions you would wish to answer. It will be possible to only answer a few questions or to fill in the full survey.

Can I respond in my own language?

We would encourage you to respond in English. We will however do our best to also consider responses in languages other than English.

Thank you in advance for your time, support and contributions.

For more information on the project, please go to the website of the [THCS partnership](#).

Survey

1. Please **indicate the topics** and accompanying questions in the survey you would like to complete (multiple answers are possible). *Note. Additional questions for each topic area will appear below depending on your choice.*

- ☑ Research priorities
- ☑ Transfer of innovations
- ☑ Use of research in policy making

Research priorities

2. What are the **most important challenges** for the health and care system in your country that you would like to see addressed via European level research? *Please consider current and anticipated challenges, as we also want to know about long term challenges. Please be as specific as possible and formulate the challenge as a question.*

Our society is facing a new public health threat. Feelings of anxiety and depression, often coupled with persistent feelings of sadness or hopelessness, have grown to levels where virtually no one can ignore what is happening. The crisis is indeed personal, not political. There are, in fact, only two kinds of families in Europe: those struggling with mental illness and those not struggling with mental illness yet. According to OECD, 50% of us will be affected at some point. Mental health deterioration is recognized by World Economic Forum as a significant global risk to societies and economies. In many countries, mental disorders are becoming the leading cause of sick leave and disability-related early retirement and cost our economies €600 billion every year. Life expectancy for people with severe mental illnesses is about 20-25 years shorter than that of the general population.

While existing treatments like antidepressants offer some relief, their efficacy is limited for millions. Up to 50% of patients experience treatment resistance or partial response.

Worryingly, innovation in mental health has stagnated for decades. In the past three years, Europe has approved only 1 new psychiatric treatment, compared to 68 in oncology. The need for more therapeutic options is urgent and will bend the curve only when we move from a focus on reducing symptoms to a focus on recovery.

In this context, psychedelic treatments are emerging as a promising new class of treatments for mental health conditions, including addictions, as evidenced by the growing, rigorous, and compelling body of research.

While no treatment is without risks, research indicates that psychedelic medicines, when used in controlled and supportive settings, are generally safe both physiologically and psychologically. Classical psychedelics are non-toxic and non-addictive.

The EU has 29 clinical trials with psychedelic compounds for various brain disorders (https://www.ema.europa.eu/en/documents/presentation/presentation-european-regulatory-perspective-psychedelic-drugs-psychiatry-m-haberkamp_en.pdf). This year, €6.5 million from EU funding was allocated to a 4-year clinical trial, focusing on psychedelic therapy for psychological distress in palliative care patients (https://palliativeprojects.eu/psypal/). In April 2024, the European Medicines Agency held a workshop to advance the development of psychedelics for unmet medical needs (https://www.ema.europa.eu/en/events/ema-multi-stakeholder-workshop-psychedelics-towards-eu-regulatory-framework). Internationally, in 2023 Australia regulated the medical use of psychedelics for PTSD and depression, and the US is poised to approve its first psychedelic therapy in 2024 as a prescription medicine. Unfortunately, psychedelic drug developers focus on the US market, no approvals are in sight in the EU. To catalyse innovation, a shift is needed towards a more supportive regulatory framework.

Can we consider the following tools to stimulate innovation in novel mental health treatments:
Incentives such as regulatory protection
Enhanced EMA support including trough PRIME
Accelerated assessments, conditional market approvals, adaptive pathways
More predictable reimbursement environment
Creation of a European Hub for Mental Health R&D
Create research partnerships between the EU and Member States
Embrace RWE to bolster pre- and post-authorisation evidence generation and evaluations.

3. Below you will find a list of thematic areas. Could you indicate which topic areas you believe would need more attention in future European level research?

Life-course
- ☐ Child and adolescent health
- ☐ Ageing
- ☐ Women's and men's health, gender and health
- ☐ Sexual and reproductive health
- ☑ Other

Please specify which other topics relating to the life-course you have in mind

> Mental health

Non Communicable Diseases (NCDs)
- ☐ NCD prevention
- ☑ NCD management
- ☐ Self-management
- ☐ Multimorbidity
- ☑ Integrated care
- ☐ Inequalities in epidemiology, prevention and management of NCDs
- ☑ Specific disease areas
- ☐ Other topics relating to NCDs

Please specify which other specific disease areas you have in mind

> Mental health conditions; substance use disorders

Communicable diseases
- ☐ Antimicrobial Resistance (AMR)
- ☐ Immunizations
- ☐ Vaccination
- ☐ Inequalities in epidemiology, prevention and management of communicable diseases
- ☐ Other

Strengthening health systems
- ☑ Health and care financing
- ☐ Environmental sustainability of health and care systems
- ☐ Health information systems
- ☐ Medicines, vaccines and health products
- ☑ Health workforce
- ☐ Health system reforms
- ☑ Equitable access to care
- ☑ Integrated care provision
- ☑ Person centeredness and involvement
- ☐ Health education, support for self-management and health literacy

- ☐ Health in All Policies
- ☐ Digital/ICT/AI/Big data/Robotics
- ☐ Other

Health emergencies

- ☐ Preparedness for and response to public health threats
- ☐ Adaptive capacity and resilience to health risks
- ☐ Other namely (see field below)

Determinants of health

- ☑ Socio-economic determinants (including education, employment, income and living conditions)
- ☑ Commercial determinants (i.e. actions by corporate actors that affect health)
- ☑ Environmental determinants (including air, water, sanitation, chemicals, radiation)
- ☑ Healthy cities and regions
- ☑ Migration and health
- ☑ Climate change
- ☐ Other, namely (please specify below)

4. You are invited to provide **more details** to support your answer(s) on any of the questions above in the open text field below. This also applies if you wish to mention other priority areas than those listed so far.

Transfer of innovations across settings and regions

5. What would you consider to be the most important **barriers in the transfer of innovations**?
- ☑ Lack of innovations that address the most prominent problems in my country/region
- ☐ Lack of funding to transfer innovations
- ☑ Lack of knowledge on methodologies to support the transfer of innovations
- ☐ Lack of knowledge on the core features and elements of innovations
- ☐ Other

6. What kind of information regarding a solution developed elsewhere, might be the most valuable when **adapting and implementing it** in your own country or region?
- ☐ Information on the implementation costs
- ☐ Information on the conditions that contributed to its success
- ☐ Information on the impact and effects achieved by the solution in the original context
- ☐ Other

7. Are there **policies, best practices, promising approaches and innovative actions** that you would recommend as they have the potential to effectively address health policy priorities? *Please list up to three suggestions. It is also of added value if you could add a short clarification on why these suggestions rank high, potentially including relevant links, including whether the action has been evaluated or piloted, or else why it should be tried as a novel option with high impact.*

	Effective policies, best practices, promising approaches or innovative actions	Rationale and/or references
1	The approval of psychedelic therapies in Europe might be a matter of time. To facilitate their adoption, we will need to support the transition from clinical trials to national healthcare settings: Mechanism are needed for structured collaboration to build an infrastructure and expertise for safe and equitable access to psychedelic therapies. A pan-European multidisciplinary advisory body or commission on novel therapies is needed to combat the mental health crisis. It could establish a comprehensive framework for psychedelic care models, addressing standards of care, training and licensing, ethical guidelines, safety standards, etc. This synergistic approach would unify Member States efforts, rather than have countries addressing one by one the same issues.	
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Use of research in policy-making

*The next questions 8 to 15 address the needs, gaps and opportunities in utilizing research to inform policy making **from a policy makers' perspective**. The questions are mostly intended for respondents involved in policy making, but other respondents are also invited to fill them in. If you are not involved in policy making, you can also skip question 8 to 15 and move to the section on 'Background information'.*

8. On a scale from 1 to 5, how easy do you believe it is for policy makers to:

	1 (very easy)	2	3	4	5 (very difficult)	N/A
Access research evidence or academic expertise relevant for policy making?	○	○	○	○	○	○
Understand research evidence relevant for policy making?	○	○	○	○	○	○
Assess the quality and validity of research evidence before incorporating it into policy decisions?	○	○	○	○	○	○
Apply research evidence relevant for policy making?	○	○	○	○	○	○
Evaluate the effectiveness or impact of policies / strategies / regulations?	○	○	○	○	○	○

9. Are you involved in a formal collaboration (contract, partnership etc.) between policy makers and universities / research organizations?

○ Yes
◉ No

10. In your experience, what are the **main barriers or challenges in incorporating research evidence into policy development**, across the stages of agenda setting, policy development, policy implementation and evaluation?

	Agenda setting	Policy development	Implementation	Evaluation
Lack of relevant **research findings**	◉	○	○	○
Lack of research findings in a **usable format**	○	○	◉	○
Lack of time to seek out **research resources**	◉	○	○	○
Lack of knowledge on **how to incorporate research**	○	○	◉	○
Lack of **institutional mechanisms**	○	◉	○	○

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Lack of **support** from my institution's leadership	○	○	○	○
Lack of **contacts/networks**	○	○	○	○
Other	○	○	○	○

11. Can you give an example of an evidence-informed policy and explain **how** the evidence was used in the development of this policy?

> In 2023, the Australia's medical regulator TGA approved the use of psychedelics to treat some mental health conditions, making the country one of the first in the world to "officially recognise MDMA and psilocybin as medicines". From July 1 2023, authorised psychiatrists are allowed to prescribe MDMA to treat post-traumatic stress disorder (PTSD). They will are also allowed to prescribe psilocybin for treatment-resistant depression.
>
> The TGA said the decision addressed the "lack of options" for people with some mental illnesses that did not respond to other treatments. It stressed that the drugs had only been approved for use under controlled medical settings by authorised psychiatrists. All other uses of psilocybin and MDMA remain prohibited. The TGA said the decision to allow the treatment was made because for some patients, the benefits of being treated with these substances under a psychiatrist's supervision outweighed the risks. "Clinical trials have shown promise when they (MDMA and psilocybin) are used in combination with psychotherapy conducted in strictly controlled medical settings," the regulatory body said.

12. What would facilitate the use of research evidence in policy development?
   - ☑ More time and/or resources
   - ☐ User friendly online repositories of scientific evidence
   - ☐ Research briefs
   - ☑ Communities of practice
   - ☑ International best practices
   - ☐ Other

13. Are there any mechanisms or platforms in place in your country to **support ongoing engagement** between researchers and policy makers? If so, please specify:

14. In your opinion, **what role should researchers play** during the policy making process?

15. What are the **key incentives** or rewards that motivate policy makers to incorporate research evidence into their decision-making processes?

> Economic evaluations

Background information

16. In which **country** are you based / working? *(In case you are based at an international organisation, you can also write the name of your organisation or else write 'international level')*

> Psychedelic Access and Research European Alliance EU-level

17. What is your **age**?
- ○ Under 35 years old
- ○ 35-44 years old
- ○ 45-54 years old
- ○ 55-64 years old
- ○ 65 years old or above

18. What is your **gender**?
- ● Male
- ○ Female
- ○ Neither
- ○ Prefer not to say

20. In answering this questionnaire, is your **perspective** the one of a (please choose the most appropriate):
- ○ Researcher
- ○ Health or social care professional
- ○ Policy-maker
- ○ Citizen / member of the general public
- ○ Representative of a research funding organisation
- ○ Manager in a health or social care organisation
- ○ Health insurer / financer of care
- ○ Representative of an organisation of patients / carers / citizens
- ● Representative of another type of NGO
- ○ Other

Please specify

>

21. What is your **professional background**?
- ☐ Medicine / Nursing / Allied healthcare work / Social work
- ☑ Public health
- ☑ Health Policy
- ☐ Economics
- ☐ Prefer not to say
- ☐ Social Sciences
- ☐ Other

22. How many **years of experience** do you have working in health systems?
- ○ Less than 1 year
- ○

○ 1-5 years

○ 6-10 years

◉ 11-15 years

○ More than 15 years

23. Please indicate at which **type of organisation** you are based:

☐ Funding body

☐ Local / regional government

☐ National government

☐ International body

☐ University or research institute

☐ Public Health institute

☐ Industry

☑ Non-governmental organisation

☐ Healthcare provider

☐ Not applicable

☐ Other

24. What is your **current position/role**?

> Founder and Executive Director

25. In what **phase(s) of policy making** are you involved? *(multiple answers possible)*

☑ Agenda setting

☑ Policy development

☑ Implementation

☐ Assessment

☐ Not applicable

26. Do you have any closing reflections on the topics addressed in this survey?

Thank you for your contribution.

Would you like to be involved in the activities of the European Partnership on Transforming Health and Care Systems (THCS) initiative? For example: offer technical support to the project team, participate in a focus group or thematic workshops. If so, please express your interest by sending an email to: info@thcspartnership.eu.

Contact

[Contact Form](#)