MENTOR
Building Mental Health and Well-being Together

Joint Action
MENTAL HEALTH TOGETHER

Version	4.0
Author	Senate of Bremen - Department of mental health and drug addiction and Italian Ministry of health
Task	5.3 - Involvement and joint ownership by people with lived experience (PLE) in mental health policies
Date of deliverable	31-07-2025
Type of the deliverable	Report

Co-funded by the European Union

This Joint Action is co-funded by the Health Programme of the European Union under Grant Agreement No. 101162928

Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or European Health and Digital Executive Agency (HaDEA). Neither the European Union nor the granting authority can be held responsible for them.

Table of Contents

1 Document Properties

Project name	Mental Health Together
Project acronym	MENTOR
Project number	1011622928
Topic	Involvement of people with lived experience (PLE) in mental health policies
Document authors	Joerg Utschakowski, Senate of Bremen–Department of Mental Health and Drug Addiction Giuseppe Salamina, Italian Ministry of Health
Period covered (duration)	Joint Action, first year

1.1 Document revision history

Version	Date	Contributors	Comments
1.0	04-2025	University of Padua, Medical School of Brandenburg (MHB)	First draft
2.0	22-07-2025	University of Padua, Medical School of Brandenburg (MHB)	Second draft
3.0	17-11-2025	University of Padua, Senate of Bremen, ASL of Turin	Workshop chapter and strategy chapter added
4.0	n.a.	University of Padua, Senate of Bremen, ASL of Turin	Workshop evaluation reworked, survey part on Italy specified, strategy chapter deleted

1.2 Statement of originality

The content of this document is original and was developed by task 5.3 MENTOR coordinators. They have been supported by the University of Padua, who contributed in the preparation of the survey questionnaire, in collecting and analysing the information and in writing the report, and by the team of the Brandenburg University, who prepared the research section of the survey questionnaire. The two external contributions were financed by an additional fund offered by the Italian Ministry of Health, who decided to further support the implementation of Task 5.3 (grant agreement nb. (CUP) C93C23007900001 with the University of Padua and the University of Brandenburg, as sub-contractor).

1.3 Abbreviations and Acronyms

EU	European Union
JA	Joint Action
GP	General Practitioner
MENTOR	Mental Health Together
PLE	People with Lived Experience
WP	Work package

List of abbreviations – WP5.3 participants and role		
SB	Senate of Bremen - Germany	coordination
ISS	Italian National Institute of Health, Rome, Italy	coordination
MHB	Medical School of Brandenburg, Berlin, Germany	external contribution
UNIPD	University of Padua, Italy	external contribution
SHSO-MHS	State Health Services Organisation- Directorate of Mental Health Services, Cyprus	full implementation
MOSA	Ministry of Social Affairs,Tallin, Estonia	full implementation
THL	Finnish Institute of Health and Welfare, Helsinki, Finland	training & pilot
NNGYK	National Centre for Public Health and Pharmacy, Budapest, Hungary	training & pilot
NUHI	Landspitali National University Hospital, Reykjavik, Iceland	full implementation
NPVC	National Centre of Mental Health, Riga, Latvia	training & pilot
NCMHFAD	National Centre for Mental Health and the Fight Against Drugs, Bucarest, Romania	full implementation
BIOSISTEMAK	Asociación Instituto De Investigación En Sistemas De Salud-Biosistemak, Basque Country, Spain	full implementation
IDIVAL	Fundacion Instituto de Investigacion Marques de Valdecilla, Cantabria, Spain	training & pilot
PHC	Public Health Center of the MOH of Ukraine	full implementation
SMS	Servicio Murciano de Salud, Murcia, Spain	observer
FFIS	Fundacion para la Formacion e Investigacion Sanitarias de la Region de Murcia, Spain	observer

2. About the MENTOR Project

The MENTOR project (Mental Health Together) aims to promote mental health through dialogue, collaboration, and the meaningful inclusion of people with lived experience (PLE) across care, prevention, and policy-making contexts. The project operates at multiple levels, ranging from institutional governance to everyday clinical practices, with the objective of fostering systemic, sustainable, and recovery-oriented change within European mental health systems.

A core element of MENTOR's approach is the integration of evidence-based practices with the capacity to adapt project actions to local contexts, acknowledging the diversity of organisational, cultural, and institutional frameworks across participating countries.

Overall Objectives of the Project

The strategic objectives guiding the project are multiple and interrelated:

- To effectively disseminating project's activities and outcomes among the various stakeholders involved.
- To promote the sustainability and adoption of MENTOR's results within European mental health systems.
- To strengthen mental health competencies by enhancing literacy and developing tools and policy recommendations that can reach even the most vulnerable groups, actively combating stigma.
- To facilitate access to innovative, evidence-based practices, particularly in the areas of prevention, wellbeing promotion, and the monitoring of mental health conditions within communities.
- To improve systems for monitoring and early diagnosis, ensuring that decisions are based on reliable and up-to-date data.
- To address social inequalities, with particular attention to the needs of people living with mental health conditions.
- To support the "Mental Health in All Policies (MHIAP)" approach, encouraging its adoption at both national and regional levels.
- To identify effective interventions for the promotion and prevention of mental health across different population groups.

- To support recovery-oriented, inclusive, and participatory practices that value lived experience and foster empowerment.
- To implement personalised and integrated models of care that respond to people's specific needs, taking into account the complexity of their life trajectories.

2.1 Purpose of This Document

This document is an integral part of the activities of the Joint Action *Mental Health Together* and focuses specifically on **Task 5.3**, which addresses the involvement of People with Lived Experience in mental health policies and services.

The document has two main objectives:

- to present the results of a comparative survey conducted in the countries participating in Task 5.3, describing the organisation of mental health systems and the current forms of PLE involvement;
- to analyse and evaluate the international workshops implemented within Task 5.3, aimed at sharing experiences and good practices related to participation, peer support, and co-production.

The document is structured accordingly. Chapter 3 presents the survey methodology and results, while Chapter 4 focuses on the evaluation of the workshops. Together, these components provide an empirical basis to inform future training activities, pilot interventions, and policy recommendations within the framework of Task 5.3.

2.2 Task 5.3: Involvement of People with Lived Experience

2.2.1 Task Description

Task 5.3, *"Involvement and Co-Participation of People with Lived Experience (PLE) in Mental Health Policies"*, consists of a set of integrated actions aimed at promoting meaningful and sustainable participatory processes within mental health systems across different national contexts.

The task acknowledges that participating countries differ substantially in terms of institutional frameworks, cultural traditions, and levels of experience in involving PLEs. While some contexts are characterised by established practices of peer support, advocacy, and co-production, others are at an early stage, with limited recognition of experiential knowledge.

Against this background, Task 5.3 pursues a twofold objective: on the one hand, to identify the conditions that support effective PLE involvement, including training, preparation, and institutional recognition; on the other hand, to foster operational alliances between PLEs, professionals, and policymakers, supporting the co-development of shared procedures and collaborative practices.

Within this perspective, PLE involvement is not conceived as symbolic or merely testimonial, but as a concrete contribution to the design, delivery, and evaluation of mental health services, with the aim of developing more responsive and flexible policies grounded in lived experience.

2.2.2 Structure of Task 5.3

Task 5.3 is organized into three operational phases spread over the three-year duration of the project, each encompassing specific activities and progressive objectives. This working framework allows for the gradual development of skills and strategies, leveraging both existing best practices and the creation of new participatory models.

Year 1 – Task 5.3.1: Valorisation of Best Practices

The first year of activities focused on exploring and valorising existing experiences across the various partner countries. A systematic collection of best practices has been carried out through a standardized questionnaire, collecting information on guidelines, regulations, and strategies for involving People with Lived Experience (PLE).

The collected information has been analyzed and shared during five international online workshops, which addressed key topics such as EX-IN training, peer advocacy, Empowerment Colleges, and co-production practices in service delivery. The analysis of the collected material enabled a categorization of experiences, highlighting effective strategies, recurring barriers, and favorable conditions for implementation.

This phase has produced a significant project output: the document “Strategies for the Involvement of PLE at Different Levels,” jointly drafted by German and Italian coordinators and discussed within the partnership. At the same time, in Germany, a monitoring project has started to evaluate a recovery-oriented approach in eight psychiatric clinics, aiming to observe the integration of PLE in daily practice.

Year 2 – Task 5.3.2: Training and Tools for Peer Support

The second year focuses on developing training and evaluation tools aimed at supporting and legitimising the role of PLEs within mental health services. Also, individually tailored strategies for PLE involvement will be developed and implemented in the partner countries.

A key element of this phase is the introduction of the concept of *WE-Knowledge*—a shared and co-constructed form of experiential knowledge among peers—as the foundation for a new epistemology of care.

Training modules will be selected from established and recognised programmes, while new, context-specific modules will be developed through *Train the Trainer* workshops, in which PLE will be actively involved in both design and delivery of training sessions.

The quality and impact of the training and implementation initiatives will be assessed through a participatory evaluation process using focus groups and qualitative questionnaires. The findings from this phase will inform the development of a recommendation paper aimed at improving services, directed at both policymakers and mental health professionals.

Meanwhile, in Bavaria, continuous monitoring activities for a hospital network, where the peer-support approach will be implemented, are executed , including opportunities for training placements and participation in online conferences - demonstrating the ongoing engagement and vitality of the German partnership in peer-based involvement.

Year 3 – Task 5.3.3: National Strategy for De-stigmatisation

The final phase of Task 5.3 focuses on developing national guidelines for the de-stigmatisation of mental health issues. This strategy is the outcome of a collaborative process that will bring together insights gained from local contexts and the recommendations emerging at the European level.

The activities in this phase will include the promotion of knowledge exchange between professionals and People with Lived Experience, as well as the formalisation of protocols and collaborative procedures to ensure meaningful participation in both therapeutic and organisational pathways.

The final recommendations will be structured around two main pillars:

- **Support for social inclusion**, with particular attention to the transition from adolescent to adult mental health services.

- **Improvement of mental health systems**, through the systematic recognition of the voice, knowledge, and expertise of PLE as a cross-cutting resource in all phases of the care pathway.
- **Promotion** of good mental health and wellbeing, such as prevention of suicide and depression

2.3 Task set-up

Task 5.3 has an extensive geographical coverage across Europe, involving 10 countries and numerous institutions: Germany (SB), Italy (ISS), Cyprus (SHSO-MHS), Estonia (MOSA), Finland (THL), Iceland (NUHI), Latvia (NPVC), Spain (BIOSISTEMAK and IDIVAL), Ukraine (PHC), Hungary (NNGYK) and Romania (NCMHFAD).

Cyprus

2.3 Contacts

2.3.1 Coordinators contact

Name of the contact	Role in the project	E-mail
Jörg Utschakowski	task co-leader	joerg.utschakowski@gesundheit.bremen.de
Giuseppe Salamina	task co-leader	g.salamina@sanita.it

2.3.2 Main contributors of the Task 5.3

Jörg Utschakowski and Giuseppe Salamina, responsibles of task 5.3, have coordinated the organisation of the survey, the preparation of the questionnaire for the collection of the information; they have supervised the analysis of data collected and the preparation of this document.

The University of Padua and the Brandenburg Medical School (Berlin), participated in the definition of the questionnaire. University of Padua collected and analysed the information provided by partners and participated in the preparation of the report.

2.3.3 Acknowledgments

We sincerely thank all the representatives of local and national entities who took the time to respond to the survey. Their valuable input and collaboration were essential in making this report possible

.

3. Involvement of PLE in mental health policies within task 5.3 participating countries.

3.1 Methodologies and process

3.1.1 Design, Development, and Dissemination of the Survey

A structured questionnaire was developed to collect comparative information on the organisation of mental health services and the involvement of PLE in the countries participating in Task 5.3. The primary aim was to capture national specificities in service organisation, recovery-oriented policies, and participatory practices, while allowing for cross-country comparison.

The first draft of the questionnaire was prepared by the research team of the University of Padua (UNIPD) following discussions within the Task 5.3 project team. After an internal review process, the questionnaire was submitted to five external experts with expertise in mental health, participatory approaches, and social research. Their feedback contributed to refining the methodological, terminological, and structural aspects of the tool.

Online meetings with national partners were organised to support survey implementation, clarify the objectives of data collection, and promote a shared understanding of the methodological framework. The survey was disseminated in November 2024 through personalised email invitations, with data collection concluding at the end of February 2025.

The questionnaire was structured into several thematic sections:

- **Mental Health System – Key Descriptive Elements:** This section collects data on the organisation of mental health services, integration with addiction services, local service networks, models of access, and the presence of user and family associations.
- **User/Survivor-Led, Collaborative and Participatory Research:** This section maps out research initiatives led by users or conducted in partnership with them and requests useful contact details.
- **Legislative Framework and Socio-Cultural Context:** This section investigates national laws, guidelines, socio-economic factors, and barriers that influence the inclusion of PLEs.

- **Good Practices:** Respondents are invited to describe significant experiences of PLE involvement in service delivery.
- **Training:** This section gathers information about training opportunities available for PLEs, mental health professionals, or other stakeholders, including details about content, duration, and costs.
- **Contracts:** This section explores the forms of remuneration, types of employment contracts, and funding sources available for PLEs.
- **Evaluation and Monitoring:** Respondents are asked to indicate which tools are used to assess the effectiveness of PLE participation and how the results are applied.
- **Publications and Research:** This section collects references to studies and literature that document the impact of PLE involvement.

Data analysis was primarily qualitative, focusing on open-ended responses in order to capture meanings, approaches, and contextual differences across countries. This approach supported a nuanced interpretation of strengths, challenges, and potential pathways for enhancing meaningful PLE involvement in European mental health systems.

3.2 Results

This section presents an overview of the survey findings, based on the responses provided by partner institutions participating in Task 5.3. The results describe both national and, where available, regional contexts, and provide a comparative picture of current approaches to the involvement of People with Lived Experience in mental health systems.

3.3 Participants and respondents

The survey included participants from eleven countries or regions: Germany, Italy, Cyprus, Estonia, Finland, Iceland, Romania, Hungary, Latvia, and two regions of Spain - the Basque Country and Cantabria

Name	Country	Institution	Short name	Position*
Giuseppe Salamina	Italy	Italian National Institute of Health	ISS	BEN
Jörg Utschakowski	Germany	Senate of Bremen	SB	AE
A Paradesiotou	Cyprus	State Health Services Organisation – Directorate of Mental Health Services	SHSO-MHS	BEN
Maris Jõgeva	Estonia	Ministry of Social Affairs	MOSA	BEN
Minni Timberg	Estonia	n.a.	n.a.	n.a.
Pia Solin	Finland	Finnish Institute of Health and Welfare	THL	BEN
Nanna Briem	Iceland	Landspitali National University Hospital	NUHI	AE
Nína Eck	Iceland	n.a.	n.a.	n.a.
Sandra Sif Gunnarsdóttir	Iceland	n.a.	n.a.	n.a.
Catalina Constantin	Romania	National Centre for Mental Health and the Fight Against Drugs	NCMHFAD	BEN
Juan de la Torre	Basque Country	Instituto de Investigación en Sistemas de Salud	BIOSISTEMAK	BEN

Name	Country	Institution	Short name	Position*
Lola Verdoy	Basque Country	n.a.	n.a.	n.a.
Csizmadia Péter	Hungary	National Centre for Public Health and Pharmacy	NNGYK	BEN
Marta Krivade	Latvia	National Centre of Mental Health	NPVC	BEN
Baiba Livina	Latvia	n.a.	n.a.	n.a.
Liene Sile	Latvia	n.a.	n.a.	n.a.
Rosa Ayesa Cantabria	n.a.	Fundación Instituto de Investigación Marqués de Valdecilla	IDIVAL	AE
Olena Bidovanets	Ukraine	Public Health Center of the MOH of Ukraine	PHC	BEN
Marja Rosol	Ukraine	n.a.	n.a.	n.a.

* BEN=beneficiary; AE=affiliated entity

SURVEY

PART 1. Overview of PLE Involvement

The inclusion of PLE in addiction and mental health services is an evolving phenomenon across Europe. The data collected reveal a highly diverse landscape, in which established models, emerging practices and fragmented or non-institutionalised situations coexist.

Survey questionnaire: questions 1 to 7

This section provides a detailed overview of the current situation in several countries, focusing on the following aspects: the existence of a formally recognised professional profile for PLE and how long it has been in place. The name or title used for this profile; the roles currently performed by PLE, for example in clinical or psychosocial work, training and education, and research; and, where available, a rough estimate of the number of PLE involved in each sector.

Cyprus does not have an official acronym or formalized profile for PLEs. However, PLE activity has been documented for approximately 15 years in addiction and 5 years in mental health. Although the numbers are small, their involvement spans multiple areas: two PLEs in both clinical and training roles for each field, and one involved in mental health research.

Estonia has formally recognized the PLE professional profile since 2014, using various terms (experience counsellor, expert by experience, etc.). To operate, PLEs must undergo basic training and be affiliated with a team or co-vision group. There are currently 400 registered experience counsellors, 95 of whom are directly involved in social rehabilitation services, including mental health.

In **Finland** a dedicated training program for PLEs has been offered by KoKoA, covering both addiction and mental health services since 2012,. PLEs have had a consolidated presence for about 16 years. It is estimated that over 100 individuals are currently active in various roles. In 2012, an association for trained peer support experts, KoKoA ry, was established, which has promoted the training and activities of peer support experts. For further information, please visit these websites:

https://thl.fi/aiheet/mielenterveys/mielenterveyspalvelut/kokemusasiantuntijuus-ja-vertaistuki

https://www.kokemusasiantuntijat.fi/

https://mielen.fi/kokemusasiantuntijatoiminta/

Currently, peer support experts are utilized in various roles, such as clinical work, training, research, and service development.

Germany features two main informal PLE profiles: EX-IN Genesungsbegleiter, trained recovery counsellors with EX-IN accreditation, and Suchthelfer, peer supporters working in addiction services. Despite the lack of formal legal recognition, EX-IN is widely accepted in practice. PLEs have been active for 50 years in addiction and 20 in mental health. Approximately 900 individuals work in clinical and psychosocial roles, and over 200 in training.

In **Hungary**, peer support/peer help work has been around since the 1990s. Peer helpers are employed by some NGOs, but they are not present in health services.

In **Iceland,** the acronyms used to identify PLEs are: Jafningi (Peer supporter), Notendafulltrúi (User advocate), Einstaklingur með lifða reynslu (Person with lived experience) and Fyrrum notendur geðheilbrigðisþjónustu (Previous users of MH services). Although there is no formal professional profile, training is provided through the Intentional Peer Support (IPS) model. PLEs have been active in mental health services for 16 years. In the field of addictions, 65 individuals are currently involved, although the duration of their engagement is not clearly specified. Of these, 20 work in clinical and psychosocial roles within mental health, and 65 within addiction services.

In **Italy,** PLEs are referred to as UFE (Utente Familiare Esperto) and ESP (Esperto in Supporto tra Pari). Although not formally recognized at the national level, PLE involvement is substantial. Around 500 ESPs are estimated to work in addiction services and 300 in mental health in clinical roles, with approximately 30 also involved in training. No data are available regarding research activities.

Latvia recognizes people with lived experience under the term CIP (Cilvēki ar izdzīvoto pieredzi), but there is no systematic training in place. Inclusion in services dates back to 1990 in addiction and to 2021 in mental health. Currently, there are no reliable estimates of the number of active PLEs or the scope of their roles.

In **Romania**, two acronyms are used to identify PLEs: CEP (Consilier prin experiență proprie) and PET (Persoană cu experiență trăită). These roles are not yet formally recognized, and no standardized training or structured employment system is in place.

In **Spain (Basque Country)** there is no formal professional profile for PLEs, nor a systematic inclusion process. Recognition is based on personal or family experience. Without official registries, it is impossible to quantify PLE participation in services.

In **Spain (Cantabria)** PLEs have been involved in addiction services for 45 years and in mental health for 4 years. Their involvement remains limited and uneven: only one

PLE is reported in clinical roles for addiction, while in mental health, participation is mainly focused on training (8 individuals involved). No engagement is currently reported in research or clinical mental health roles.

The results show that the inclusion of People with Lived Experience (PLE) in addiction and mental health services in Europe is a heterogeneous and evolving process, with very different levels of institutionalisation, professionalisation and recognition. Some countries have made significant progress in formally recognising the professional role of PLE. In contrast, in other countries, the roles of PLEs are still marginal, fragmented or informal, often supported by local or individual initiatives rather than systemic strategies. The data also indicate a prevalent presence of PLEs in clinical or psychosocial roles, with some involvement in training and, more rarely, in research. The history of the inclusion of PLEs also varies significantly, ranging from decades of experience in some countries to very recent contexts. This suggests that duration is not necessarily indicative of greater institutionalisation but may also reflect local or sectoral initiatives that have not yet found structural integration.

Country	Acronym	Definition in country language	English translation
Cyprus	n.a.	n.a.	n.a.
Estonia	n.a.	Kogemusnõustaja *	Experience counsellor
Finland	Koke	Kokemusasiantuntija	Expert by experience
Germany	n.a.	Genesungsbegleitung	Recovery companion
Hungary	n.a.	n.a.	n.a.
Iceland	n.a.	Jafningi	Peer supporter
Italy	ESP	Esperto in supporto tra pari	Peer support expert
Latvia	CIP	Cilvēki ar izdzīvoto pieredzi	People with lived experience
Romania	CEP	Consilier prin experiență proprie	Adviser by experience
Basque Country	n.a.	n.a.	n.a.
Cantabria	n.a.	n.a.	n.a.
Ukraine	n.a.	n.a.	n.a.

* Estonian definition for peer worker with a formal qualification

Country	Another acronym	Another definition in country language	English translation
Cyprus	n.a.	n.a.	n.a.
Estonia	n.a.	Haiguskogemusega inimene	Person with illness experience
Finland	n.a.	Vertaistukiasiantuntija	Peer support expert
Germany	n.a.	Suchthelfer	Addiction support worker
Hungary	n.a.	n.a.	n.a.
Iceland	n.a.	Notendafulltrúi	User advocate
Italy	UFE	utente e famigliare esperto	Expert user or family member
Latvia	n.a.	n.a.	n.a.
Romania	PET	persoană cu experiență trăită	Person with lived experience
Basque Country	n.a.	n.a.	n.a.
Cantabria	n.a.	n.a.	n.a.
Ukraine	n.a.	n.a.	n.a.

Country	Peer work profile officially recognized	Official definition of peer worker	Years of presence in mental health services	Years of presence in addiction services	Number of peers in mental health field	Number of peers in addiction field	PLE involved in training (mental health)	PLE involved in training (addiction)
Cyprus	No	n.a.	5	15	few	few	n.a.	n.a.
Estonia	Yes	Kogemusnõustaja	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
Finland	Yes	n.a.	16	16	>100	>100	>100	n.a.
Germany	No	n.a.	20	50	400	500	150	75
Hungary	No	n.a.	0	35	n.a.	n.a.	n.a.	n.a.
Iceland	No	n.a.	16	65	20	65	10	n.a.
Italy	No	n.a.	20	40	200	400	10	20
Latvia	n.a.	n.a.	5	35	n.a.	n.a.	0	0
Romania	No	n.a.	0	0	n.a.	n.a.	0	n.a.
Basque Country	No	n.a.	0	0	n.a.	n.a.	n.a.	n.a.
Cantabria	n.a.	n.a.	4	45	0	10	8	0
Ukraine	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.

Note. n.a. = not available / not reported; PLE = people with lived experience.

PART 2 Mental Health System: few descriptive elements

Survey questionnaire: questions 8 to 14

The aim of this paragraph is to provide a detailed description of how the mental health system is organised in each participating country. This analysis is essential to understand where PLEs can play a role within each system or whether they are already involved. This section explores various aspects of the organisation and provision of mental health services in different countries. It begins by examining which bodies are responsible for providing hospital care for mental disorders, as well as the current situation regarding admissions to psychiatric hospitals. The section also looks at the range of mental health services and rehabilitation activities available in each country, with a particular focus on the existence of residential rehabilitation services. Another important aspect is the collaboration of mental health services with other public or private organisations in the provision of care and support. Finally, it investigates which services are responsible for providing assistance, help and support to people suffering from problems related to alcohol, illegal drug use and behavioural addictions, such as gambling, eating disorders or Internet addiction. Finally, the section examines which services are responsible for providing mental health care and support to young people under the age of 18. The data paint a varied picture of mental health facilities in Europe.

In **Cyprus**, there are both stand-alone psychiatric hospitals and psychiatric wards in general hospitals.

Estonia presents a particular situation: there are no autonomous psychiatric hospitals, but there are psychiatric wards in general hospitals. It is interesting to note that the larger hospitals have psychiatric clinics or mental health centres, while the smaller ones have simple psychiatric wards.

In **Finland**, psychiatric hospital care is provided by both stand alone psychiatric hospitals and psychiatric wards within general hospitals.

In **Germany**, a variety of structures similar to those in other countries can be found, with autonomous psychiatric hospitals, psychiatric wards in general hospitals, and private psychiatric clinics.

In **Hungary**, services are available through social insurance in stand-alone psychiatric institutions or through the psychiatric wards of clinics and county hospitals. Private care is provided by stand-alone institutions.

Iceland seems to have a more centralised system in this respect, with only psychiatric wards present within general hospitals.

In **Italy**, psychiatric care seems to be more integrated into the general healthcare system, with the presence of psychiatric wards in general hospitals and private psychiatric clinics.

In **Latvia**, hospital care for mental health conditions is provided through stand-alone psychiatric hospitals, psychiatric wards within general hospitals, and private psychiatric clinics. Mental health services include outpatient clinics and a home visit team for patients unable to visit doctors.

In **Romania**, the provision of psychiatric care includes stand-alone psychiatric hospitals, psychiatric wards in general hospitals and also private psychiatric clinics.

Moving on to **Spain**, in **Cantabria**, there are autonomous psychiatric hospitals, psychiatric wards in general hospitals and also private psychiatric clinics.

In the **Basque Country**, on the other hand, we find long-term hospitals specialised in mental health care, as well as autonomous psychiatric hospitals, psychiatric wards in general hospitals and private psychiatric clinics. In summary, data show that most of the countries considered offer psychiatric care both through specialised wards within general hospitals, potentially favouring integration with other branches of medicine, and through autonomous psychiatric hospitals, which could offer an environment more specifically oriented towards mental health care. The presence of private psychiatric clinics is another constant in many of the countries mentioned, suggesting a role for the private sector in the provision of these services.

The exceptions, such as **Estonia**, which has no autonomous psychiatric hospitals, highlight the different approaches to the organisation of mental health services in the various European contexts.

The **structure and functioning of mental health systems** across the examined countries present diverse approaches to hospitalization, available services, and rehabilitation activities.

In **Cyprus**, voluntary and forced hospitalization have a maximum duration of 1 month, with an average stay of 43 days. Services include outpatient clinics and community-based teams, with rehabilitation focusing on addiction treatment, occupational therapy, day centers, and community mental health services, including residential rehabilitation.

In **Estonia**, , with an average stay of 18.7 days in 2023. Services include outpatient clinics, crisis resolution teams (CRT), and community-based teams (CBT), offering social rehabilitation, occupational therapy, supervised employment, community-based services, and day-care centers.

In **Finland**, there is no limit on the duration of hospitalization, with an average stay of 15 days. Services include outpatient clinics, crisis resolution teams, ACT, and community-based teams. Rehabilitation activities encompass psychotherapy, work activities, housing services, rehabilitative day activities, and psychosocial support.

In **Germany**, voluntary hospitalization has no limit (average 25 days), while forced hospitalization is limited (judge reviews after 1 year, usually ≤6 weeks). Services include outpatient clinics, crisis resolution teams (CRT), and community-based teams (CBT), providing psychosocial rehabilitation, vocational rehabilitation, day care and employment programs, residential homes and assisted living, and specialized rehabilitation for addiction.

In **Hungary**, parts of community psychiatric care and rehabilitation are Community psychiatric care; Acute and chronic day hospitals; Day clubs; 24-hour mobile crisis service and crisis broker; Sheltered housing; Work rehabilitation services; GP and specialist consultation service.

In **Iceland**, there are no limits on voluntary hospitalization, but limits exist for forced hospitalization, with an average stay of 10 days. Available services include outpatient clinics and assertive community treatment, with rehabilitation activities guided by sports scientists, artistic expression, music, Individual Placement and Support (IPS), and individual options within and beyond the mental health system.

In **Italy**, the limit for both voluntary and forced admissions is 15 days, with an average stay of 12 days. Services include outpatient clinics. Rehabilitation activities include residential rehabilitation, both public and private.

In **Latvia**, voluntary hospitalization is limited to 30 days and forced hospitalization to 2 months, with an average stay of 25 days. Services include outpatient clinics and a home visit team. Rehabilitation activities involve ergotherapy, social worker consultations, art therapy, and nutrition specialist consultations, alongside public residential options.

In **Romania**, there is no general limit; compulsory admission is 48 hours without court approval, during which the patient is assessed by a specialist, and up to 30 days with court approval, with possible extension upon further judicial review. Services include outpatient clinics.

In **Spain (Basque Country)**, there is no hospitalization limit; the average stay is 15–30 days. Services include outpatient clinics, crisis resolution teams (CRT), assertive community treatment (ACT), and community-based teams (CBT). Residential (public) rehabilitation supports recovery and reintegration. Rehabilitation activities include

individual and group therapies (psychotherapy, supportive therapy), psycho-educational workshops, psychosocial rehabilitation (social skills, daily living, work), occupational and therapeutic activities, support and self-help groups, family interventions, specific programs for specific disorders and monitoring/follow-up.

In **Spain (Cantabria)**, hospitalization has no limit, with an average of 34.9 days. Services offered are outpatient clinics, crisis resolution teams (CRT), and community-based teams (CBT). Service includes residential rehabilitation focuses on cognitive, occupational, psychosocial, and laboral rehabilitation.

The data show a diverse landscape in how European countries regulate psychiatric hospitalization and structure rehabilitation services. Some countries, such as **Italy and Cyprus**, apply strict limits to hospital stays, while others—**Finland, Germany, and Spain**, for instance—allow more flexibility, often with relatively short average durations. Rehabilitation offerings also vary significantly. Countries like **Finland, Germany**, and the **Basque Country** provide broad, integrated services, including vocational support, housing, and community-based care, reflecting a strong commitment to recovery-oriented models. Others, like**, Hungary**, offer a growing range of rehabilitative interventions—such as art therapy, occupational programs, and counselling—but these are often less integrated or more limited in reach. Crisis response services (CRT, ACT, CBT) are widespread in **Germany, Finland, Estonia, and Spain**, indicating a shift toward managing mental health needs in the community. In contrast, **Italy and Romania** show more traditional models, with less emphasis on crisis resolution outside of hospitals. In sum, the comparison highlights both convergence—towards shorter hospital stays and more comprehensive community-based care—and persistent gaps in implementation.

Collaboration between various entities within the mental health system. *Survey questionnaire: questions 15 to 16*

In **Cyprus**, collaboration involves municipalities: prevention activities. Social sector: cooperation with social workers from the Ministry of Social Welfare. Schools: prevention and counselling. Well-organised national educational psychology service. Associations/NGOs: social services, community residential facilities. Families: psycho-education. Access is direct/open; patients who are beneficiaries of the General Health System have free access, with or without a doctor's prescription, depending on the service. Non-beneficiaries have free access to emergency psychiatric services only.

Estonia reports collaboration in mental health services: municipalities, social sector, schools, associations/NGOs, families, private clinics. Direct access, review plans, introduction of e-consultation.

In **Finland**, collaboration occurs with municipalities, the social sector, NGOs/associations, and private services, with open/direct access to a composed system including primary health care, specialized care, crisis services, private services, and services for children and adolescents.

Germany highlights collaboration with the social sector, schools, associations/NGOs, and families. Access to treatment and nursing care is open but requires a GP or specialist prescription and is covered by health insurance. Rehabilitation services are funded by the welfare system and require a special certificate, usually issued by doctors and/or social workers.

In **Hungary** psychiatric and addiction care has developed essentially within the health care system. The development of psychiatric nursing homes began in the 1960s, essentially providing a form of outpatient care, a form that still exists in the health care system today and works closely with the social care system.

Iceland also sees collaboration with municipalities, associations/NGOs, and schools, with access being direct/open or requiring referral, particularly for secondary and tertiary mental health care. There are also Community based team (CBT). Collaboration extends to the social sector and families, and includes the involvement of Individual Placement and Support (IPS) teams, which facilitate access to employment or education opportunities. User advocates in secondary mental health services are involved in activities such as advocacy, education, self-help groups, and direct support, while peers in tertiary services (NUHI) operate according to the IPS philosophy and do not hold positions of authority.

Italy indicates direct/open access and requires a referral procedure. Highlights collaboration with Municipalities: collaboration with the social sector; social sector: rehabilitation; schools: mental health promotion, prevention, information, fight against stigma; associations/NGOs: externalisation of self-help rehabilitation activities, peer support; families: mental health promotion, prevention, information, fight against stigma.

In **Latvia**, collaboration exists but is unsystematic, involving municipalities, the social sector, schools, associations/NGOs, and families. In Latvia, access to mental health services is direct and open.

Romania's public health system requires a referral from a General Practitioner for free psychiatric and psychological services, except for emergencies. Collaboration involves municipalities, the social sector, schools, associations/NGOs, and families.

Spain (BP) reports active collaboration with public and private entities, including municipalities and the social sector coordinating social care, and schools following referral protocols for children, with access requiring referral from primary care professionals.

Spain (Cantabria) involves municipalities, the social sector, schools, associations/NGOs, and families, requiring a referral procedure.

Collaboration across sectors is declared a priority in all examined mental health systems, yet its implementation varies widely. In countries like **Finland** or the **Basque Country,** collaboration is structurally embedded and policy-driven. Elsewhere, such as **Latvia or Romania**, it is often informal, fragmented, or dependent on local initiatives—raising doubts about its long-term sustainability. Access mechanisms also reflect deeper institutional cultures. Open-access systems (e.g., **Estonia, Iceland**) promote low-threshold care, while referral-based models (e.g., **Italy, Spain, Romania**) suggest more hierarchical, regulated logics. These may protect system integrity, but risk excluding those with limited access to primary care. A key tension lies in the relationship between clinical and social actors. While cooperation with families, schools, and NGOs is widespread, it is not always equitable. Third-sector organisations often bring flexibility and innovation, but their role remains peripheral or poorly formalised within public systems.

Mental health services for alcohol, drugs, behavioral addictions and for young people

Survey questionnaire: questions 17 to 32

The integration of services for alcohol, drugs, and behavioral addictions within the mental health system and the role of PLEs in these areas also vary.

In **Cyprus** the Drug and Alcohol Detoxification and Rehabilitation Unit (THEMEA) is part of the mental health service with PLEs and interest in further development. The Mental Health Services of the State Health Services Organization (SHSO) handle alcohol and drug addiction with PLEs and interest in development, but no PLEs are involved in behavioral addiction services, despite integration.

In **Estonia** there are PLEs in alcohol and drug addiction and behavioural addictions.

Finland has partially integrated services, with PLEs active in peer support and interest in expanding their role.

Germany reports services sometimes integrated (mostly separate systems), PLE are always present.

In **Iceland**, SÁÁ and Samhjálp handle addiction treatment, sometimes integrated with mental health services, and PLEs are present. Behavioral addiction services are integrated with the mental health system, but PLE presence is unknown, although there is interest in development.

Italy reports sometimes integrated services for alcohol and drugs, and integrated for behavioural addictions. PLEs are only present in drug addictions.

In **Latvia** there are no PLEs in the field of addiction.

In **Romania** there are no PLEs in addictions, but there is interest in implementing them.

In **Spain, (Basque Country)**, Osakidetza, the Basque public healthcare provider, offers integrated treatment for alcohol dependence, but currently, there are no PLEs involved. There are "mediators or guides with their own experience" in the field of alcoholism within Osakidetza, based on the peer support model. However, there is interest in incorporating peer support in the future. Other entities provide support but not treatment, and private services are available, including peer mediators with lived experience in alcoholism. Regarding illicit drug addiction, integrated care is provided with active involvement of PLEs, and there is significant interest in expanding peer support, which is recognized as essential for recovery. Private clinics also offer support in this area. Finally, behavioral addictions are addressed through integrated care, with PLEs already involved in providing support, contributing to treatment and recovery for patients.

In **Spain (Cantabria),** Alcohol Dependence is managed through early care, specialized care, and Alcoholics Anonymous, fully integrated into mental health services. PLEs are already active in peer support, with interest in expanding their role. Drug addiction are managed by the Addictive Behaviors Unit of the Cantabria Health Service, but separate from mental health services. There is no peer support, and there are no plans for future development in this area. Behavioral Addictions are addressed by the Cantabrian Health Service and associations like Proyecto Hombre, ACAT, and AMAT, fully integrated into mental health services. No PLEs are currently involved.

The integration of addiction services into mental health systems, and the role of PLEs within them, varies widely across Europe, reflecting deeper differences in institutional culture, policy history, and professional boundaries. In some countries, particularly for

drug-related care, there is growing alignment between mental health and addiction services, often accompanied by the involvement of PLEs. However, this is not uniform: alcohol and behavioural addictions—despite being formally included in mental health systems—often lack peer support, revealing a gap between structural integration and cultural recognition.

The survey paints a varied picture of the organisation of services dedicated to the **mental health for young people.** In several countries, there seems to be a trend towards integrating these services within the general mental health system.

For example, in **Cyprus**, child services are an integral part of mental health services.

In **Estonia**, services for young people are part of the mental health system, and there are some examples of informal activities, mostly provided by civil society organisations with components of peer support for young people aged less than 18 years.

In **Finland**, psychiatric clinics, child welfare services, and school and student health services are increasingly integrated with mental health services, especially within the framework of regional wellbeing services counties. However, the level of integration may vary across regions.

In **Germany**, Youth mental health services (under 18) is provided by children and adolescent psychiatry, part of mental health services. No peer support programs for youths under 18 currently exist, although some adults with past experience work in the field.

Iceland, the NUHI child and adolescent mental health department and municipal mental health services have the capacity to treat and diagnose young people, suggesting an integration.

In **Italy**, the Neuropsychiatry (NPI) service-responsible for delivering mental health support to young people aged less than 18 years of age - appears to be integrated only in some cases.

In **Latvia**, mental health treatment and support for young people under 18 is provided by the health care service, which is integrated with mental health services. However, there is currently no experience of peer support specifically for this age group.

In **Romania**, services responsible for delivering mental health treatment support in young people aged less than 18 years of age are part of mental health services.

In **Spain (Basque Country)**, child services are integrated, and the presence of existing peer support is reported.

As for **Spain (Cantabria)**, while child services are integrated into the mental health system, there is no current structured PLE involvement, although there is interest in developing it in the future. Across Europe, there is a clear trend toward integrating youth mental health services within the general mental health system. While structural integration is advancing, peer involvement (PLEs) in youth services remains limited.

In the following chart, the web-sites giving information about:

presence of user associations and self-help groups across different countries or associations including both users and family members;
availability of self-help groups at national and local levels;
types of rehabilitation activities;
collaboration between mental health services and other public or private entities;
access to mental health care;
involvement of people with lived experience (PLEs) in areas such as alcohol dependence, substance use disorders, behavioural addictions, and mental health support for individuals under the age of 18.

are listed for each country

Country	Web resources
Estonia	• RV301: Hospital beds, hospitalised, discharges, bed days and rate per 100 000 inhabitants by bed speciality (current classification). PxWeb • Psychosocial crisis support | Palunabi) • Tallinn Mental Health Center • Projektist - Depressioonivaba Tallinn • About Us | Lootuse küla • LUNEST – Eesti psühhotroopsete ainete tarvitajate ühing “LUNEST” • www.lunest.ee • eluS – Toetus pärast lähedase enesetappu • https://www.epill.ee/ • Alkohoolikute Täiskasvanud Lapsed – Al-Anoni Pererühmad • In English | AA Estonia • Sõltuvusprobleemide tugigrupp naistele - Rehabikeskus OÜ • Tugigrupid lähedastele - Dementsuse Kompetentsikeskus • https://taastumisekool.ee/et/teenused/duo-tugigrupid/duo-tugigrupp-psuehhoosi-haigestunud-inimeste-laehedastele/Infoleht_DUO%20tugigrupp%202024.pd
Finland	• https://stm.fi/en/mental-health-services • https://thl.fi/en/topics/mental-health/mental-health-services • https://mieli.fi/en/mental-ill-health/how-to-seek-help/mental-health-services/ • https://thl.fi/en/topics/alcohol-tobacco-and-addictions/substance-abuse-treatment • https://paihdelinkki.fi/en/where-to-find-help/substance-abuse-treatment-services/peer-support-groups-and-help-by-telephone/ • https://paihdelinkki.fi/en/where-to-find-help/substance-abuse-treatment-services/what-should-i-do-if-i-have-problems-with-substance-abuse/

Country	Web resources
	• https://www.mll.fi/en/home-page/mll-peer-support-program/ • https://mieli.fi/en/ • https://finfami.fi/in-english/ • https://www.monimuotoisetperheet.fi/in-english/ • https://sateenkaariperheet.fi/en/
Germany	• Startseite - BPE Online • https://www.netzg.org/startseite • Der BApK: Bundesverband der Angehörigen psychisch Kranker • www.expa-trialog.de • Deutsche Depressionsliga e. V. • www.anonyme • www.netzwerk-selbsthilfe.de
Iceland	• https://gedhjalp.is/ • https://hugarafl.is/ • https://www.matthildurskadamin • nkun.is/ • https://rotin.is/ • https://hringsja.is/ • https://klubburinngeysir.is/ • https://gedhjalp.is/urraedi/vin-athvarf/ • https://hugarafl.is/ • https://gedhjalp.is/ • https://hugarafl.is/ • https://gedhjalp.is/thjonusta/
Latvia	• https://samariesi.lv/lv/jaunumi/zubites-latvijas-samariesu-apvienibas-izveidots-dienas-aprupes-centrs-personam-ar-demenci • www.butblakus.lv • https://www.apeirons.lv • https://www.autisms.lv • https://www.facebook.com/udhsbiedriba • https://aa.org.lv/lv/ • https://na-latvija.lv • https://as.org.lv • https://www.pab.org.lv • http://asariga.wordpress.lv • https://www.coda.org.lv
Spain **(Basque Country)**	• https://www.saludmentaleuskadi.net/ • https://orekabide.org/ • https://www.avifes.org/ • https://asafes.org/ • https://www.agifes.org/ • https://www.saludmentaleuskadi.net/ • https://orekabide.org/
Spain (Cantabria)	• https://www.ampros.org/ • https://www.ascasam.org/ • https://www.afacayle.es/afa-medina-del-campo/ • https://www.escuelacantabradesalud.es/adaner-cantabria

Country	Web resources
	• https://grupoenvera.org/ • https://amica.es/es/ • https://www.apcantabria.es/inicio • https://www.alcoholicos-anonimos.org/v_portal/apartados/apartado.asp • https://www.ascasam.org/ • https://www.afacayle.es/afa-medina-del-campo/ • https://grupoenvera.org/ • https://amica.es/es/ • https://www.cocemfecantabria.org/ • https://www.ascasam.org/ • https://www.afacayle.es/afa-medina-del-campo/ • https://www.escuelacantabradesalud.es/ • https://www.alcoholicos-anonimos.org/v_portal/apartados/apartado.asp • https://proyectohombre.es/
Romania	• https://copilsifamilie.ro/ • https://autismromania.ro/ • https://anpd.gov.ro/web/ • https://www.echilibru.org/ • https://www.lrsm.org.ro/category/proiecte • https://mentalhealthforromania.org/en/ • https://www.estuar.org/

PART 3 Research

The survey has collected information regarding the institutional conditions governing research on mental health users and survivors, with a particular focus on collaborative and participatory research in the countries involved in the MENTOR project.

In **Finland**, User/Survivor Research of Mental Health Services and Collaborative and Participatory Research are found. Key contributors include the Finnish Institute for Health and Welfare (THL), the University of Oulu, and projects like FINSCI, Universities such as Åbo Akademi and Laurea University of Applied Sciences.

Iceland presents collaborative research and survivor-led/guided research.

In **Germany**, there are approximately 35 PLEs in mental health research, 2 user-led research projects, and 15 collaborative projects; in addition, there are many participatory roles and participation in some national research programmes. No data is available on addiction research in Germany.

From the limited references to research provided by only a few countries, it is clear that the participation of PLEs in this field remains marginal or poorly documented — indicating an area that has yet to be fully developed and valued.

For further information, please visit these websites or research papers:

Country	• Websites & Articles
Estonia	• Empowering Informal Caregivers of People with Dementia Through Support Groups: A Participatory Action Research Study | ETERA - e-terast tärkab mõt
Germany	• https://www.imppeer.de/ • https://www.mhb-fontane.de/en/mental-health • Hoghe J, Walther C. Förderliche Rahmenbedingungen für diePartizipation von Genesungsbegleiter_innen in der sozialpsychiatrischen Regelversorgung. In: Köttig M, Röh D, Hrsg. Soziale Arbeit in der Demokratie – Demokratieförderung in der Sozialen Arbeit. Verlag Barbara Budrich; 2019: 162–170 • Heumann K, Utschakowski J, Mahlke C et al. Implementierung von Peer-Arbeit. Nervenheilkunde 2015; 34: 275–278. https://doi.org/10.1055/s-0038-1627581

- Ruppelt F, Mahlke C, Heumann K et al. Peer-Stadt Hamburg? Doppelte Peer-Beratung an der Schnittstelle ambulant-stationär. Nervenheilkunde 2015; 34: 259–262
- Mahlke C, Schulz G, Sielaff G et al. Einsatzmöglichkeiten von Peerbegleitung in der psychiatrischen Versorgung. Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz 2019; 62: 214–221
- Hoghe J, Röseler L, Limmer R, Walther C, Schütz A. Work-related stress among peer workers in social psychiatry: stressors, resources and their relationship to health-related and motivational outcomes. 2022. https://doi.org/10.17605/OSF.IO/KYPND
- Brändli H. EX-IN – Erfahrungswissen in der Psychiatrie. Familiendynamik 2020; 45: 180–186. DOI: 10.21706/fd-45-3-180
- Eikmeier G, Lacroix A. Recovery und Inklusion: ein Erfahrungsbericht über 5 Jahre Genesungsbegleitung in der Psychiatrie. Gesundheitswesen 2018; 80: 101–104
- Freitag R. Experienced Involvement–EX-IN. Einbeziehung Psychiatrie Erfahrener. Sozialpsychiatrische Informationen 2011; 41: 30–32
- Braukmann J, Heimer A, Jordan M, Maetzel J, Schreiner M, Wansing G. Evaluation von Peer Counseling im Rheinland – Endbericht. Berlin, Düsseldorf, Kassel; 2017
- Förderkreis Borderline-Trialog e.V. DBT Peer Coach. Informationen zur Weiterbildung (08.01.2024). Im Internet: https://www.borderlinetrialog.de/dbtpeercoach;
- Puschner B, Repper J, Mahlke C et al. Using Peer Support in Developing Empowering Mental Health Services (UPSIDES): Background, Rationale and Methodology. Ann Glob Health 2019; 85: https://doi.org/10.5334/aogh.2435
- Utschakowski J, Sielaff G, Bock T, Winter A, Hrsg. Experten aus Erfahrung. Peerarbeit in der Psychiatrie. Köln: Psychiatrie; 2016
- Mücke B. Peers in der Berliner Krisenpension. Die Kerbe 2010; 38–40
- Schmidt M, Dimpker H. Genesungsbegleitung in der medizinischen und sozialen Rehabilitation: erste Praxiserfahrungen. Die Kerbe 2013
- Heumann K, Schmid C, Wilfer A et al. Kompetenzen und Rollen (-erwartungen) von Genesungsbegleitern in der psychiatrischen Versorgung – Ein partizipativer Forschungsbericht. Psychiat Prax 2019 o.S. DOI: 10.1055/a-0597-8188
- Schulz G, Afting Ijeh M. Können Genesungsbegleiter die Resilienz von psychiatrischen Organisationen und den dort tätigen Mitarbeitern erhöhen? Die Kerbe 2014; 25–28
- Heuer I, Schulz G, Bock T et al. Krise als Chance?! … Nervenheilkunde 2021; 40: 712–717
- von Peter, S., Göppert, L., Ziegenhagen, J., Beeker, T., Glück, R., Groth, B., Groß, U., Reinholdt, A., Boerma, R., Heißler, M., Habicht, J., & Schwarz, J. (2021). Supported employment, participation at work, and peer support: A qualitative, participatory case study report of the Geesthacht model. Frontiers in Psychiatry, 12, 634080. https://doi.org/10.3389/fpsyt.2021.634080
- Beeker, T., Glück, R. K., Ziegenhagen, J., Göppert, L., Jänchen, P., Krispin, H., Schwarz, J., & von Peter, S. (2021). Designed to clash? Reflecting on the practical, personal, and structural challenges of collaborative research in psychiatry. Frontiers in Psychiatry, 12, 701312. https://doi.org/10.3389/fpsyt.2021.701312
- von Peter, S., Krispin, H., Kato Glück, R., Ziegenhagen, J., Göppert, L., Jänchen, P., Schmid, C., Neumann, A., Baum, F., Soltmann, B., Heinze, M., Schwarz, J., Beeker, T., & Ignatyev, Y. (2022). Needs and experiences in Psychiatric Treatment (NEPT)- piloting a collaboratively generated, initial research tool to evaluate cross-sectoral mental health services. Frontiers in Psychiatry, 13, 781726. https://doi.org/10.3389/fpsyt.2022.781726

	• von Peter, S., Kraemer, U. M., Cubellis, L., Fehler, G., Ruiz-Pérez, G., Schmidt, D., Ziegenhagen, J., Kuesel, M., Ackers, S., Mahlke, C., Nugent, L., & Heuer, I. (2024). Implementing peer support work in mental health care in Germany: The methodological framework of the collaborative, participatory, mixed-methods study (ImpPeer-Psy5). Health Expectations: An International Journal of Public Participation in Health Care and Health Policy, 27(1), e13938. https://doi.org/10.1111/hex.13938
Iceland	• Jóhannesdóttir, Í. R., Fridjónsdóttir, H. S., & Klinke, M. E. (2025). Advance Directives in Mental Health Service: A Qualitative Study on Stakeholders' Perspectives. *Journal of Psychiatric and Mental Health Nursing*, *32*(3), 800–810. https://doi.org/10.1111/jpm.13157

PART 4. Socio-cultural context in mental health system

Survey questionnaire: questions 37 to 42

This part of the survey has explored in depth the regulatory framework and socio-cultural context that affect the participation and inclusion of people with lived experience (PLE) in mental health services. The analysis focuses on the activities in which PLE are currently involved and how these roles have been introduced and integrated into different care systems. Particular attention is paid to the existence of official documents – such as institutional recommendations, regulations or laws – that legitimise and promote the recognition of PLE, facilitating their entry into services in a structured and continuous manner.

In addition to regulatory aspects, the impact of socio-cultural, economic and political factors that have influenced the implementation or transformation of support services based on the contribution of PLEs in different national contexts is also examined. The survey also considers the main barriers – practical, symbolic or legislative – that hinder the effective implementation of inclusive strategies. Finally, it reflects on the existence of any areas or activities from which PLEs are excluded due to explicit legal or political restrictions that limit their active involvement in mental health services. The socio-cultural context significantly influences the integration and acceptance of PLEs within mental health systems, as reflected in integration efforts, official documents, and prevailing attitudes.

In **Cyprus** PLE activity is mostly informal, with no available policy documents. Stigma and stakeholder pressure influence their role. Legal restrictions explicitly prevent PLEs from working in clinical public sector settings, such as mental hospitals or community services.

In **Estonia**, people with lived experience (PLE) are involved in various areas of mental health services, especially as peer supporters, support group facilitators, educators, and speakers in anti-stigma initiatives. However, certain activities such as participatory research, supervision of other PLEs, and crisis intervention are still underdeveloped or absent. The role of the Kogemusnõustaja (experience counselor) is formally recognized and regulated by law. Official guidelines define the training requirements and areas where these professionals can operate. Despite this, the effective integration of PLEs is still hindered by cultural barriers, inadequate funding, lack of training, and resistance from within services.

In **Finland** PLEs are active in a wide range of areas including peer support, advocacy, proximity work, mentoring, co-design, and participatory research. The system is integrated across hospital districts, education, and research, with national-level strategic documents supporting their role. The strong welfare state enables involvement, although barriers such as complex bureaucracy and persistent stigma exist. Legal restrictions involve data protection and the need for professional qualifications.

Germany has one of the most structured systems, with national guidelines (EX-IN, DGSP) supporting PLE integration. Activities range from peer support to participatory research and mediation. Key factors influencing peer support implementation include social movements and activism, education and training availability, cultural evolution, inclusion policies, local initiatives, and international experience. Legislative changes, funding, welfare policies, and social stigma also play important roles, but barriers remain—especially cultural resistance and lack of political support.

In **Iceland** PLEs are widely involved in various activities, especially informal groups and recovery projects, supported by national policy documents. Factors such as inter-institutional collaboration and grassroots initiatives are key. Still, barriers like staff resistance, legal responsibility concerns, and insufficient training hinder their integration. There are no specific legal requirements for staff qualifications. PLEs are involved in peer support, advocacy and representation, collaboration with other services, team-based work, testimonial activities, participatory research, case management support, and mental health education.

In **Italy** PLEs participate in various services, including formal and informal support groups, school/community programs, and advisory boards. Influencing factors include grassroots activism, international exchanges, local or community initiatives, initiatives run by single individuals, availability of funding, education and training. However, cultural barriers, lack of training, and privacy laws pose significant limitations.

In **Latvia** PLE involvement is limited, especially in formal structures. There's no official recognition or strategic document. Activism and social movements are highly

influential, while funding and cultural barriers are significant challenges. Legal and technological constraints are moderate, but no legal restrictions for PLEs are reported.

In **Spain (Basque Country)** co-design and testimonial activities are present, but with unspecified frequency. Influential factors include inclusion policies and activism. Organizational barriers, lack of training, and limited political support are high obstacles. No legal framework is specified.

In **Spain (Cantabria)**, while PLEs are involved in formal and informal support groups and hospital collaboration, their participation in areas like advisory boards or community interventions is lacking. Influential contextual factors include cultural evolution and social movements. However, major barriers include cultural and organizational issues, lack of training and political support. No legal framework exists to support their role in personalized care planning. The results show that, although important for legitimising the role of PLEs, regulatory frameworks and official documents are not uniformly present in all national contexts. The socio-cultural context, which includes stigma and resistance, plays a crucial role in influencing the integration of PLEs and often represents a significant barrier. There are several factors that influence the implementation of PLE inclusion, such as activism, collaboration between institutions and funding, but also common barriers such as lack of training and limited political support. In the case of personalized treatment planning and case management, there is no legal support in Cantabria for PLE to collaborate.

For further information, please visit these websites:

Country	• Websites
Estonia	• https://www.riigiteataja.ee/akt/110072018007 • https://kogemused.ee/wp-content/uploads/2017/05/kogemusnoustamise_teenuse_juhis.pdf
Finland	• https://www.hel.fi/en/decision-making/get-involved/support-and-collaboration/experts-by-experience-in-health-and-social-services • https://mielen.fi/experts-by-experience-program/
Germany	• 2023-03-EX-IN-D-Satzungsneufassung-FINAL.pdf • EX-IN Deutschland • DGSP e.V.

Iceland	• https://www.althingi.is/altext/153/s/1329.html

PART 5. Best Practices

Survey questionnaire: questions 43 to 44

This section reports any significant activities (good practices) that were indicated in the questionnaire regarding the involvement of PLEs in mental health services. It also reports any guidelines developed for peer support in communities or mental health services.

In **Estonia**, there are Policy & Advocacy initiatives through the Union of People with Mental Disorders and the Public Foundation. There are also Peer Support Programmes such as LUNEST, SÜTIK, and DUO Support Groups. University of Tartu participates in the "Partnership Experiential Knowledge" international project aimed at integrating lived experience into higher education. In the field of Innovation & Treatment, the 'MÄRT' Project is active, focusing on the holistic treatment of mood and anxiety disorders. There are no official guidelines, but key materials are available, such as a guide to community cooperation for the elderly and people with special needs, and a study on family support communities.

In **Finland**, there is a national strategy, institutional projects, and the development of a toolkit for peer support group facilitators (developed by Finnish Association for Mental Health (Mieli)), which serves as a guide for organizing peer support groups, along with national recommendations. For example, the National Mental Health Strategy and Suicide Prevention Program 2020–2030 emphasizes the importance of peer support experts and their involvement in mental health services. Additionally, the National Institute for Health and Welfare (THL) has developed several projects that support the integration of peer support experts into services.

In **Germany**, there is the EX-IN training and the Empowerment College. There are no official guidelines at the national level, but several key documents are available that provide guidance.

In **Iceland**, there is a description of the work for peers within the hospital (attached, but not in the text provided).

In **Italy**, the ‘CARTA NAZIONALE ESP’ is mentioned.

In **Latvia**, the Minnesota model for addiction treatment is mentioned.

In **Spain (Basque Country)**, the existence of mental health and addiction practices aimed at improving recovery, reducing stigma, and promoting patient engagement is highlighted. For further information, please visit these websites:

Country	Websites
Estonia	• LUNEST – Eesti psühhotroopsete ainete tarvitajate ühing “LUNEST” • https://www.lootusefond.ee/en/ • Partnership Experiential Knowledge • https://heakool.ee/eng/ • https://drive.google.com/file/d/1bJYkOdqle1YqSNf-eBLNnc38sFxi1FwO/view?pli=1 • https://tai.ee/et/sotsiaaltoo/vaimse-tervise-raskustega-inimeste-lahedaste-toetuskogukonna-kujundamise-voimalused?utm_source=chatgpt.com
Finland	• https://julkaisut.valtioneuvosto.fi/bitstream/handle/10024/162234/STM_2020_15.pdf • Korkeila J. (2021). Organization of Community Psychiatric Services in Finland. *Consortium psychiatricum*, *2*(1), 55–64. https://doi.org/10.17816/CP64 • https://thl.fi/en/research-and-development/research-and-projects/national-mental-health-strategy-2020-2030 • https://mentalhealthsupport.eu/library/finnish-clubhouse-coalition/
Germany	• Empowerment College • EX-IN Germany: www.ex-in.de • DGSP - German Society for Social Psychiatry: www.dgsp.de • BZgA: www.bzga.de

PART 6. Training

Survey questionnaire: questions 45 to 46

This section presents any training programmes for PLE or training courses on the inclusion of PLE aimed at mental health service providers or other professionals in participating countries. In terms of training, the European landscape remains highly diverse.

In **Cyprus**, no structured training or available information is reported.

In **Estonia**, training programs are well developed and offered to PLEs with experience in mental health and/or addiction, as well as to family members and mental health professionals. However, several challenges exist: the quality of training varies, and there's a lack of a coordinated training system and quality control.

In **Finland**, structured programs are in place to support the professional inclusion of PLEs through formal training.

In **Germany**, training programs are well developed and offered to PLEs with experience in mental health and/or addiction, as well as to family members and mental health professionals.

In **Hungary** there is an official training course for addiction counselors who can follow former drug users, and there is an NGO (in the field of addiction) that organises training courses for PLEs.

In **Iceland**, training is available and primarily based on the Intentional Peer Support (IPS) model, targeting individuals with lived experience in mental health.

In **Italy**, training is offered to PLEs with experience in both mental health and addiction, as well as to family members, but such programs are not yet standardized at the national level.

In **Latvia**, no structured training or available information is reported.

In **Spain (Basque Country)** and **Spain (Cantabria)**, there are no active programs. The data collected therefore highlights the urgent need to develop structured, recognised and accessible training courses in the various participating countries. All practices are not formalized but managed through internal dynamics within individual services.

For further information, please visit these websites:

Country	• Websites
Estonia	• DUO-tugigrupi-juhendaja-koolitus_oppekava_-2023.pdf • https://loovruum.voog.com/taustast • Õppekava_Kogemusnõustaja baaskoolitus.docx • https://loovruum.voog.com/koolitused/knk-praktiline-info • https://www.leoskikoolitus.ee/kogemusnoustajate-valjaope • https://epry.ee/wp-content/uploads/2025/03/CARe-rakendaja-koolituse-oppekava_2024_2025-2.pdf
Germany	• www.ex-in.de • EX-IN Angehörigenbegleitung – EX-IN Hamburg e.V.
Iceland	• https://www.intentionalpeersupport.org/trainings/?v=b8a74b2fbcbb#CTAnchor

PART 7. Job opportunities for PLEs

Survey questionnaire: questions 47 to 55

This section provides an overview of the forms of remuneration provided for activities carried out by persons with lived experience (PLE) within mental health services, where applicable. The average hourly remuneration, expressed in euros, received by PLEs is examined, as well as the average number of hours worked per week by those employed on a contract basis. In addition, the professional qualifications required to access these roles are analysed.

Further focus is given to the presence of any sources of funding to cover the costs of training PLEs and remunerating their activities. Finally, the main forms of financial support used to fund contracts are investigated, highlighting any institutional mechanisms or specific programmes in place in the different national contexts. The contractual arrangements for PLEs vary significantly between countries. They range from no official contract and no payment in Cyprus, to permanent and fixed-term contracts, occasional collaborations, freelance work, and partnerships with NGOs in countries such as Estonia, Germany, Iceland, and Italy.

In **Cyprus**, there is no official contract and no payment.

In **Estonia**, PLEs may be employed through fixed-term or permanent contracts, freelance work, or NGO partnerships. Payments and working arrangements are variable and often project-based.

In **Finland**, monetary compensation and non-monetary benefits are both offered. Payment methods include hourly rates, fixed compensation, reimbursement of expenses, or gift vouchers. Working hours range between 15 to 25 hours. Required qualifications include lived experience. Funding sources include public funds, municipal budgets, NGO funding, internal service budgets, and dedicated project funds (e.g. European and national calls). For further information, please visit these websites:

https://stm.fi/en/mental-health-services
https://julkaisut.valtioneuvosto.fi/bitstream/handle/10024/70241/Es200611eng.

pdf?sequence=1

In **Germany**, PLEs can work through fixed-term or permanent contracts, freelance arrangements, or collaborations with NGOs. A specific hourly wage is often provided (e.g. 15 euros/hour). Working hours can be around 25 hours per week. Required qualifications typically include EX-IN training. Funding comes from public and project-based sources, as well as internal budgets.

In **Hungary** there are no formal contracts or employment arrangements in either the addiction or mental health fields. PLEs are employed by some NGOs in the addiction field, but their employment status is unknown.

In **Iceland**, PLEs are involved through permanent or fixed-term contracts, freelance work, or partnerships with associations. Working hours typically range from 15 to 25 hours with an hourly wage of approximately 25 euros per hour. Compensation is provided, and donations are also mentioned as a funding source, alongside public and project-based funding.

In **Italy**, PLEs work under various forms of contract, including occasional collaboration, NGO partnerships, and project-based contracts. Working hours can be around 12 hours/week. Compensation is provided, and funding sources include public services, regional projects, NGOs, and donations.

There are no forms of remuneration for PLEs in all other countries.

There is therefore marked heterogeneity in the ways in which people with lived experience (PLE) are involved in mental health services, particularly with regard to contracts, remuneration and working conditions. This ranges from countries where there are no official forms of contract or any kind of financial compensation, to more structured contexts where PLEs are employed on fixed-term contracts, permanent contracts, occasional collaborations or forms of self-employment. In summary, the analysis of contractual forms highlights a high degree of heterogeneity: while in some countries the role of PLEs is formally recognised, professionalised and adequately

remunerated, in others it remains marginal, lacking institutional recognition and often unpaid. This situation highlights the need to develop policies that value the valuable contribution made by PLEs within mental health services.

PART 8. Evaluation and Monitoring

Survey questionnaire: questions 56 to 61

In conclusion, this section explores the existence of evaluation activities aimed at monitoring the effectiveness of PLE participation in mental health services. The tools used for this purpose are analysed, such as questionnaires, focus groups, systematic data collection and other methodologies. In the area of evaluation and monitoring, the situation across Europe is similarly uneven.

In **Cyprus**, there are no structured evaluation or monitoring systems involving PLEs.

In **Estonia**, no structured evaluation or monitoring systems involving PLEs are reported.

In **Finland**, PLEs are actively involved in all stages of the evaluation process—from design and data collection to analysis and feedback. Evaluations are conducted by national bodies, municipalities, or NGOs and use a variety of tools, including questionnaires, focus groups, interviews, and observational studies. These activities inform policy development, improve services, enhance training, and guide resource allocation. However, evaluations are collaborative and not fully independent. The effectiveness of PLE involvement is assessed by THL, municipalities, and NGOs such as MIELI, as part of the National Mental Health Strategy 2020–2030 and local programs.

In **Germany**, both scientist-led and participatory research models are in place, with varying levels of PLE involvement. Tools include questionnaires, focus groups, and data collection. While findings are discussed, they are not always systematically integrated into service practices.

In **Hungary** there are no monitoring activities as there are no PLEs officially working in the health and/or social system.

In **Iceland**, there are no structured evaluation or monitoring systems involving PLEs.

In **Italy**, evaluation activities do exist, with PLEs involved in the design, interviews, data analysis, and dissemination. Common tools include interviews and surveys. Still, these evaluations are not independent or systematically implemented.

In **Latvia**, there are no structured evaluation or monitoring systems involving PLEs.

In **Romania**, no relevant data is available regarding evaluation or monitoring systems.

In **Spain (Basque Country)**, there are no structured evaluation or monitoring systems involving PLEs. In conclusion, this section highlights that the presence and effectiveness of evaluation activities involving people with lived experience (PLE) in mental health services vary significantly across Europe. Overall, evaluation efforts are often collaborative but rarely completely independent or systematically implemented, reflecting a patchy landscape across the continent.

For further information, please visit these websites:

Country	Websites
Estonia	• https://tai.ee/et/sotsiaaltoo/kogemusteadmised-sotsiaaltoo-korghariduses • https://tai.ee/et/sotsiaaltoo/inimese-tervikkasitlus-taastumise-pohimotted-ja-care-metoodika
Finland	• https://www.julkari.fi/bitstream/handle/10024/137935/Tamminen%20et%20al_mhp%20competencies%20in%20health%20sector.pdf?sequence=1

4. Evaluation of the Workshops

4.1 Introduction

Purpose of this chapter

This chapter aims to provide an overview of the content of the workshops held to promote current good practices in the integration of PLE in Europe. As the workshops were open to participants outside the MENTOR network, they helped to reduce inequalities and achieve greater social inclusion. The discussions during the workshops and the evaluation after the workshops provided us with new insights into the situation in the participating countries and the individual needs of stakeholders with regard to the inclusion of PLE. This document also makes these insights available to those who did not participate in the workshops. Furthermore, the analysis provides implications for the next steps within the MENTOR project to promote PLE participation in Europe.

Summary of the chapter

According to the UN Convention on the Rights of Persons with Disabilities and to the WHO, people with lived experiences should be involved at all levels of healthcare. In this spirit, the grassroots movement of those affected claims „nothing about us without us". However, the degree of participation varies greatly between European countries, regions, and institutions. The workshops aim to valorize good practices and to create a knowledge base for MENTOR partners and beyond with the medium-term goal of implementing PLE at various levels of the mental health system. A total of 47 people participated in the workshops. Their roles were in the areas of mental health work, decision making, family members, and PLE.
The workshops presented the roles of PLE in treatment planning (treatment level), the provision of peer support and peer advocacy (direct contact level), and the evaluation and planning of interventions (co-creation level). The participants reflected on these positions through group discussions and practical examples. Empowerment, recovery and questioning existing power structures were recurring themes. Two approaches of training for peer workers were introduced (EX-IN and Intentional Peer Support). Challenges in implementation include tokenism, peer drift, and role confusion, poor funding, and a lack of trust and structural changes toward recovery oriented practice.

After each workshop, the participants filled out an evaluation form. There was considerable interest in exchange and in comparative learning expressed. Some participants were motivated to enhance PLE participation in their respective environments. The workshops helped the participants to broaden their conceptions on the roles PLE can take within the mental health system, and some participants felt empowered. The workshops helped participants broaden their understanding of the role of PLE within the mental health system, and some participants felt empowered as

a result. There is a need for ongoing support and exchange, for example with regard to the definition of roles, structural adjustments towards a recovery-oriented approach in mental health, and sustainable funding.

4.2 Methodology and approach

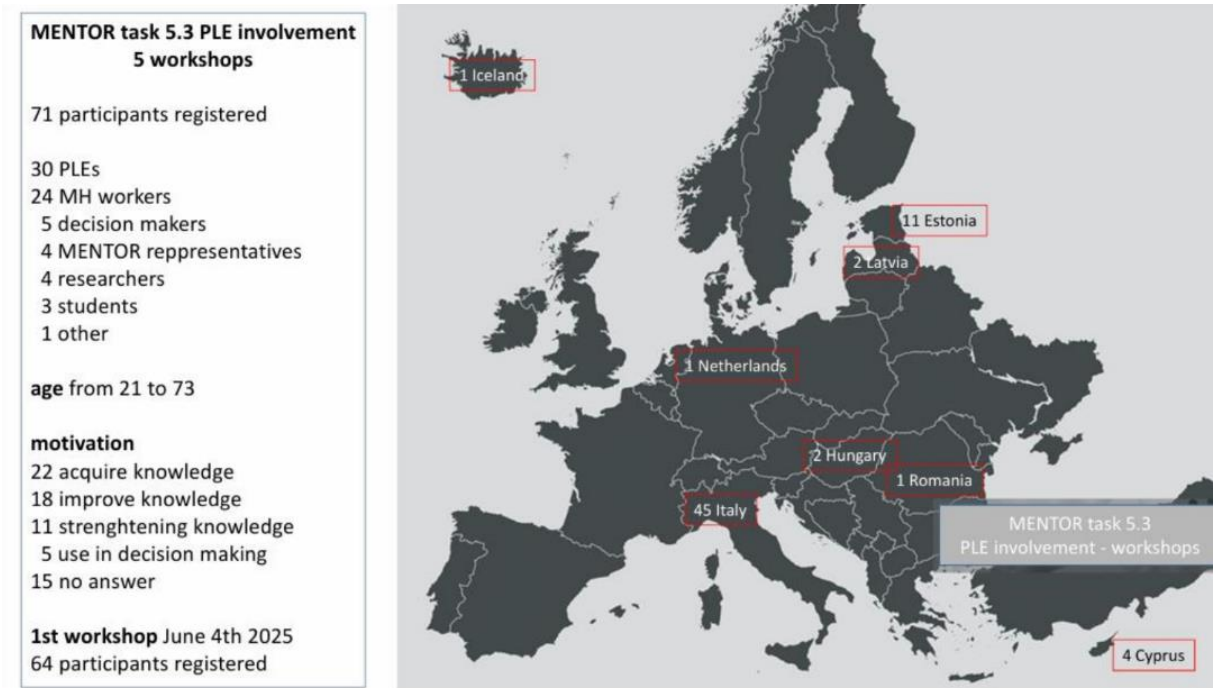
In order to initiate a dialogue on participation in PLE and to impart basic knowledge on this topic, five workshops on various aspects of PLE participation were held. All MENTOR partners were invited to participate. Registration was also open to interested members of the public. Information about the workshops was published on the MENTOR website and disseminated by the project partners using a snowball system.

We invited experts from the respective fields to give presentations at the workshops. We also moderated discussions among workshop participants and collected data on the situation in the respective countries through opinion polls.

Questionnaires were created to evaluate the workshop. The link to the questionnaire was shared at the end of each workshop and sent out by email. The responses to the evaluation questionnaire were evaluated using content analysis. This qualitative method enables the systematic identification of recurring themes and patterns in the participants' responses and provides insights into common perspectives, experiences, and areas of disagreement. In the following sections, we provide an overview of the workshops and the results of the evaluation.

Workshop participants

As shown in the image below, there was a high interest in the workshops, especially in Italy. PLE and mental health workers were represented almost at an equal leval.



However, the actual number of participants was lower: Over all workshops, 49 people participated. The majority of them was not directly linked to the MENTOR project. The initial interest was much higher (71 registrations), and PLE and mental health workers were represented almost equally.

Workshop	Participants	Responses in Evaluation	Percent
#1	29	20	69%
#2	24	7	29%
#3	17	3	18%
#4	23	15	65%
#5	26	11	42%

The majority of participants was extremely or very satisfied with the workshops (78%). On average, the rating was “very satisfied” (m=2.1). In the following sections, the contents of the workshops will be summarized. Also, the participants evaluation of the workshops will be analyzed. This allows to identify current resources and needs of stakeholders involved in Mental Health and peer participation.

4.3 Workshop 1: Forms of Participation of People with lived Experience

Content

The workshop addressed several crucial themes related to the involvement of people with lived experience (PLE) in mental health services. In particular, the discussions focused on peer advocacy, the challenges and success factors in implementing the PLE approach, and the importance of building a network and laying the groundwork for future collaborations. Specifically, the workshop explored the following areas:

Peer Advocacy and Support Tools: Peer advocacy was defined not only as a rights assertion but as a powerful support tool based on shared peer experience. This approach was recognized as effective in reducing stigma and improving power relations within services, facilitating greater user involvement in decisions about their care pathways. Concrete examples were presented, such as in Bremen, Germany, where independent peer advocacy receives funding and is considered a quality assurance measure. Challenges were also highlighted, including the risk of "tokenism" (superficial participation) and the essential need for formal support and recognition of peer advocates themselves.

Implementation of the PLE Approach in Services: The success of integrating PLEs was linked to key factors such as a clear understanding of PLE roles and competencies across the organization, a company culture open to dialogue and change, and the importance of continuous support, training, and supervision for PLEs. Shared experiences emphasized how having multiple experts by experience in a team can make a difference, providing mutual support and distributing expectations. National context specificities were discussed, highlighting that professional and corporate interests can sometimes pose obstacles, making the creation of autonomous PLE groups crucial to maintaining the integrity of their role.

Functions and Roles of PLEs:

At the direct treatment level: Through predefined “treatment contracts” and promoting “shared decision-making,” allowing people to choose their care pathways.

At the structural level: Involving PLEs in planning, evaluation, and policymaking within services, such as in funding allocation for projects or participation in planning committees and conferences. In Bremen, Germany, PLEs hold veto power over funding for specific projects.

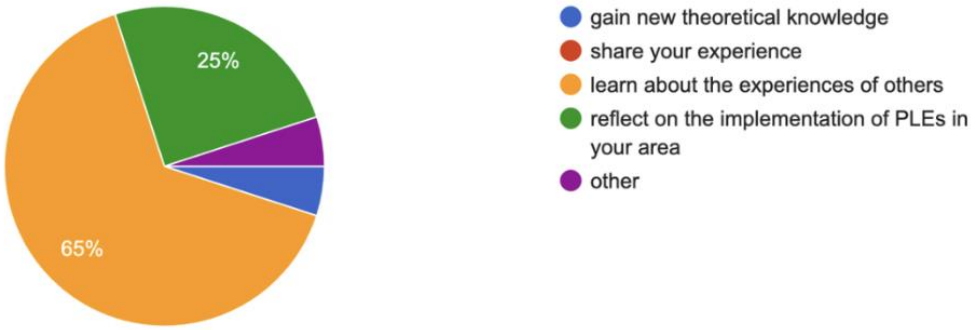
At the level of direct contact and counseling: Roles include recovery companions (models, crisis support, assistance with medical appointments), peer advocates (bridges between users and the system, user voice representation, anti-discrimination efforts, political change promotion), peer counselors (authentic connection, shared understanding, normalization, hope, coping strategies), and support group facilitators.

Evaluation of the Workshop:

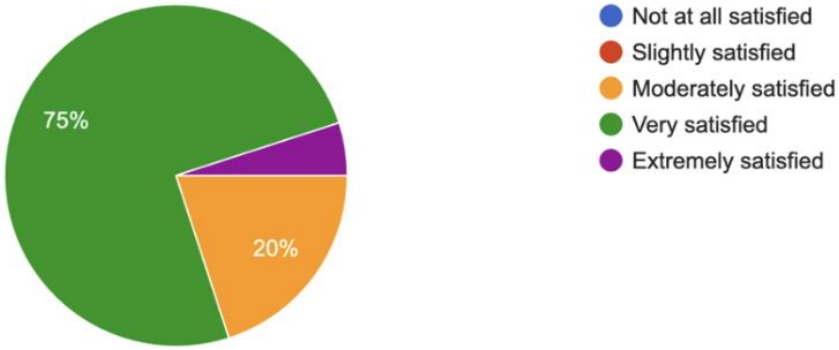
Of the 29 participants in the workshop, 20 (68,97%) completed the questionnaire. Most of the respondents were Italian (12), three were Estonian. Cyprus, Germany, Iceland, Latvia and Spain were represented by one participant each. Seven respondents identified as PLE, four as students or researchers, four as decision/policy makers, three were mental health workers and one was a relative.

As shown in the first graph below, most participants found the workshop useful primarily for two reasons: the opportunity to learn from experiences in other countries and the chance to reflect collectively on how to implement the ESP role while taking into account the specificities of each national context. These findings are consistent with the objectives of the workshops themselves, which were designed to foster operational exchange and provide concrete guidance for introducing the role into mental health services. The overall rating of satisfaction with the workshop was “very satisfied” (see graph below).

Did the workshop allow you to:



Overall, were you satisfied with the workshop?



For what reasons would you recommend this workshop?

International Exchange and Comparative Learning: Participants valued the opportunity to engage with diverse perspectives from different countries. The workshop allowed for the comparison of national approaches to peer involvement and fostered mutual learning across systems.

Inspiration and Critical Reflection The workshop was described as intellectually stimulating and reflective. It offered a space to challenge assumptions, explore new ideas, and critically assess participants' own practices and contexts.

Advocacy and System Transformation Many responses highlighted the workshop's potential to support user-led advocacy and systemic change in mental health services. It was seen as a platform for promoting more inclusive, horizontal, and co-produced models of care.

What does "participation" of people with lived experience in mental health services mean to you today?

Voice and Visibility: Participation is viewed as a way to make lived experiences visible, validate marginalized voices, and ensure they are seen, heard, and acknowledged within the mental health system.

Influence on Service Design and Policy: Many respondents highlighted the importance of involving people with lived experience (PLE) in shaping, organizing, and improving services—from needs assessment to service delivery and evaluation. Participation is associated with guiding systemic change and contributing to mental health reform.

Transforming Professional Practice and Culture: Participation is seen as a means of changing traditional power dynamics in mental health. This includes promoting horizontality, mutual respect between professionals and PLEs, and redefining what counts as valid knowledge within services.

Empowerment and Agency: Participation is linked to restoring agency and power to individuals with lived experience. It involves decision-making roles, leadership in service provision, and the co-creation of care pathways.

Inclusion in Teams and Structures: Being part of service provider teams and institutional decision-making bodies is considered crucial. Respondents stressed the importance of integrating PLEs meaningfully at all levels of the mental health system.

Innovation and Systemic Change: Some respondents connected participation to broader innovation in mental health, advocating for a shift from clinical to person-centered approaches, and the development of alternative care models.

Challenges and Ongoing Struggles: Participation is also seen as a continuous, complex challenge. It involves negotiating space for multiple perspectives, questioning existing hierarchies, and ensuring that inclusion is meaningful and not tokenistic.

What thoughts did you develop regarding the different forms of PLE participation presented?

Recognition of the Complexity and Diversity of PLE Participation: Participants acknowledged that PLE participation takes many forms, depending on national and local contexts. They noted how the roles, terminology, and implementation vary significantly, even within countries. This complexity was seen as both a challenge and a source of richness.

Need for Greater Conceptual Clarity: Several respondents expressed a desire to better understand the different roles and terms used (e.g., PLE, peer supporter, expert by experience). There was a call for sessions dedicated to clarifying these concepts across contexts to enable meaningful comparisons and exchange of practices.

Importance of Cultural and Structural Foundations: Some participants emphasized that sustainable PLE participation requires a supportive "peer culture" and institutional frameworks. Without these, efforts may remain fragmented or symbolic.

Value of Comparative Learning: The opportunity to learn from how other countries implement PLE roles was appreciated. The exchange sparked inspiration and interest in adapting successful practices to local systems.

Affirmation of PLE Legitimacy and Relevance: The workshop reinforced for many the necessity and value of PLE involvement at all levels of mental health services. Participants highlighted the importance of integrating lived experience into service design, delivery, and evaluation.

Challenges to Implementation: Despite the positive attitudes, challenges were acknowledged—such as the lack of champions, insufficient role clarity, and disparities in perception and support for PLEs. Participants also noted the early stage of development in many contexts.

What ideas or concepts helped you see PLE participation in a new or different way?

Broader Ethical, Legal, and Economic Dimensions: Several participants noted a shift in their understanding by considering the legal, ethical, and especially economic dimensions of PLE involvement. Concepts such as remuneration, resource allocation, and negotiation with service providers and insurers emerged as critical but previously underappreciated aspects.

Professionalisation vs. Human Experience: The discussion prompted reflection on the balance between recognising peer support as a professional role (including training and supervision) and maintaining the personal and experiential essence of lived experience. Over-professionalisation was seen as a risk that could shift the focus away from the individual's humanity and authenticity.

Value of Practical and International Examples: Concrete examples—such as PLEs in Germany or Estonia engaged in service assessment or public education—helped participants imagine new possibilities. Seeing these models in action, especially from outside their own contexts, challenged assumptions and offered inspiration.

Empowerment and Recovery Reconsidered: Concepts like empowerment and recovery were revisited and deepened. Participants recognised the need to approach these not only as outcomes, but also as processes shaped by peer involvement, relational dynamics, and systemic transformation.

PLEs as Agents of System Change: PLEs were seen not only as service users or supporters, but as active contributors to research, policy, and education. This re-framing positioned them as change agents capable of identifying systemic issues and innovating from within.

Recognition of PLE Fallibility: An important insight emerged around the acceptance that PLEs, like any professional or contributor, may face failure or challenges—but that

this does not diminish their value. Rather, it reinforces the need for supportive systems and a culture of learning.

Real-Life Presence and Visibility: The participation of many PLEs in the workshop itself was seen as powerful and legitimising. Their presence reinforced the practical reality and significance of peer work, especially for participants in policymaking or institutional roles.

Do you think the topics covered could have a concrete impact on your workplace or the reality you come from? In what way?

Challenges in Implementing Social Models and Concepts: Several participants noted that in their contexts, especially where the social model of disability is not widely understood, introducing PLE roles represents a significant cultural shift. This shift challenges stigma and traditional views, signaling a breakthrough even if progress is slow.

Practical Utility for Advocacy and Policy Development: The workshop was seen as providing valuable evidence, peer-reviewed references, and practical insights useful for advocating PLE rights, establishing vocational standards, and influencing policy-making. Participants expressed intentions to apply these learnings in their professional roles.

Interest and Intention to Implement PLE Participation: Many respondents showed interest in actively involving PLE in ongoing or future projects, including educational settings like universities. There is a recognized potential for expanding understanding and appreciation of PLE roles within organizations.

Promotion of PLE Roles to Enhance Service Delivery: Respondents highlighted that clarifying and legitimizing the roles of peers in services can contribute to improved respect and recognition for PLE, which may ultimately enhance the quality and humanity of mental health services.

Hope for Systemic Change Through PLE Participation: There was expressed hope that PLE engagement can lead to fundamental improvements in mental health care systems, including bottom-up approaches, participatory research, and modifications to institutional protocols.

What main challenges do you see in achieving meaningful PLE participation in your context?

Resistance from Existing Power Structures: A significant challenge lies in the resistance from established psychiatric and healthcare power hierarchies.

Professionals, especially clinicians and psychiatrists, may be reluctant to relinquish control or share decision-making authority, which creates barriers to genuine inclusion of people with lived experience (PLE).

Cultural and Mindset Barriers: Deep-rooted cultural norms within health services, including hierarchical attitudes and a prevailing biomedical model, hinder the acceptance of PLE participation. There is a need for a cultural shift towards empowerment, shared decision-making, and viewing service users as equal partners.

Systemic and Structural Issues: Structural challenges include lack of resources, insufficient funding, absence of formal employment opportunities, and limited organizational infrastructure to support PLE roles. Middle management's concerns, legal and bureaucratic barriers, and inconsistent policies also impede progress.

Need for Clear Role Definition and Training: Variation in understanding and defining the roles and competencies of PLEs, alongside inconsistent training quality, calls for standardized curricula and clearer frameworks to facilitate their integration within healthcare teams.

Political and Bureaucratic Barriers: Political resistance, regulatory constraints, and bureaucratic hurdles complicate the implementation of PLE participation, requiring advocacy and systemic reform to address these obstacles.

Sustainability and Recognition: Ensuring fair remuneration, manageable workloads, and formal recognition of PLE roles is critical for sustainable participation. Without concrete employment opportunities and respect for their professional status, PLE involvement risks remaining superficial.

4.4 Workshop 2: From Attendance to Participation to Co-Production

Content:

This workshop focused on two central concepts: the different levels of participation and the concept of co-production, with a specific application to mental health services. During the session, several key points emerged and were explored in greater depth:

The "levels of participation": A framework was presented to describe varying degrees of involvement:

Information: The lowest, one-way level where individuals receive data but have no influence.

Consultation: Individuals are asked for their opinions, but have no control over outcomes or interpretation.

Collaboration: A more active role with dialogue, though still with limited decision-making authority.

Co-determination and shared decision-making: Suggest greater influence, but final decisions often remain with institutions or professionals.

Decision-making authority: Represents an equal partnership where people with lived experience (PLE) hold substantial decision-making power, ideally with equitable representation.

Self-organised initiatives: The highest level, where services or activities are entirely led and managed by PLEs, without external compromise, although collaboration for funding may still be needed.

The concept of tokenism: Tokenism was defined as the superficial inclusion of underrepresented individuals or groups to create the appearance of inclusion, without addressing underlying inequalities. It was noted that tokenism can occur unintentionally due to lack of staff training or poor communication, but may also be used strategically to improve the public image of a service. The discussion highlighted that tokenism is part of a broader cultural issue, visible beyond mental health—for example, in the involvement of young people or parents. Participants reflected on the challenge of recognizing tokenism and transforming it into a starting point for genuine change.

Co-production as an evolution of participation: Co-production was presented as the next step beyond participation, requiring a genuine shift in power and equal collaboration between professionals and PLEs. It is not just about listening, but about actively enabling people to become leaders in driving change. Co-production is a continuous process, not a one-off event, and involves rebalancing values—giving equal importance to hope, meaning, and social context alongside diagnosis and measurable outcomes.

Examples and implementation of co-production:

Participatory research: Involving PLEs at all stages—from defining questions to evaluating and disseminating results.

Joint decision-making on funding: Mixed groups of PLEs, family members, health insurers, and professionals deciding together how to allocate mental health project funds.

Services: PLEs and professionals working together as a “tandem”, though full implementation requires time and the overcoming of biases and obstacles.

Service evaluation: Hospital review boards that include PLEs and family members with equal decision-making power.

Challenges and solutions in implementation: Discussions emphasized the need for professionals to “unlearn” traditional approaches in order to embrace co-production. It was stressed that PLE involvement improves service quality and can even lead to cost savings. Training for both PLEs (such as Germany’s one-year program for becoming a "recovery worker", EX-IN) and professionals was identified as essential. Cultural differences between countries affect implementation, and adaptable strategies are needed rather than universal models. The importance of linking co-production to the broader implementation of recovery-oriented services was also highlighted.

Areas for future exploration: Participants suggested further work on topics such as recovery-oriented service implementation, the development of “knowledge hubs” with examples of both successes and failures, training models for PLEs (like the German program), and the importance of appropriate language in mental health communication, including in media.

The workshop highlighted that while many forms of PLE involvement already exist, full implementation of co-production is an ongoing and complex process requiring sustained commitment and cultural adaptation. The ultimate goal is to enhance the quality and effectiveness of services through genuine, equal partnerships.

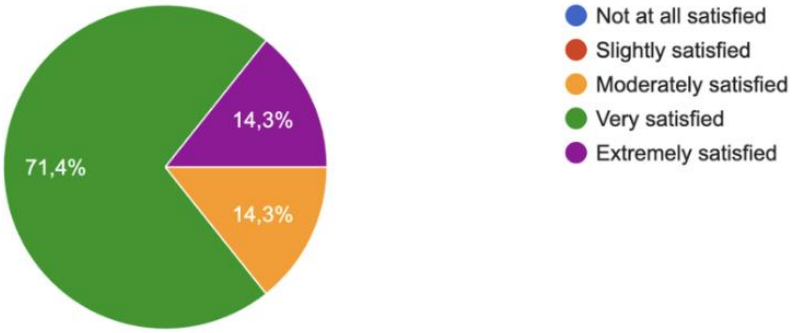
Evaluation:

Of the 24 participants in the workshop, 7 (29,17%) completed the questionnaire. Three respondents were Italian, and there was one respondent from each of the following countries: Iceland, Germany, Cyprus, Estonia. Four respondents identified as PLE, two were policy/decision makers and two were mental health workers (multiple entries were possible). 71,4 % of the respondents had a professional role in the mental health field.

Overall, most respondents found Workshop 2 useful, primarily for learning about the experiences of PLEs in other countries and, secondly, for gaining new information. Those who selected “other” clarified that they were in fact referring to the same aspects: the opportunity to learn from international experiences and the additional insights gained during the workshop. The overall rating of the workshop was “very satisfied” (see graph below).

Did the workshop allow you to:

Overall, were you satisfied with the workshop?



For what reasons would you recommend this workshop?

Personal Growth and Reflection: Several participants described the workshop as a mind-opening and reflective experience. It was seen as a valuable space for self-exploration and critical thinking.

Networking and Motivation: The workshop was valued as a space for connection and exchange. Respondents highlighted the opportunity to build networks, gain motivation through others' stories.

European Perspectives and Knowledge Sharing: One participant emphasized the workshop's role in broadening awareness of the roles PLE play across Europe.

Destigmatisation and Social Impact: Although mentioned only once, the reference to destigmatisation points to the perceived potential of the workshop to challenge existing stereotypes and support social change.

"What does 'participation' of people with lived experience in mental health services mean to you today?"

Meaningful Inclusion and Voice: Participants emphasized the importance of genuinely listening to people with lived experience and ensuring that their perspectives actively shape service development.

Empowerment and Co-Leadership: The responses reflect a growing understanding of co-creation as involving autonomy, leadership, and trust. Lived experience is not merely consulted but seen as central to decision-making and the design of services.

Peer-Based and Experiential Practices: There is a strong emphasis on concrete practices such as peer support groups, experiential training, and empowerment-based activities. These are understood as effective ways to foster meaningful involvement and transformation.

A Field in Transition: Some participants recognised that the concept of participation is still evolving. It is described as a "developing field," suggesting that while progress has been made, there is ongoing work to fully centre the experiences and knowledge of service users.

"What thoughts did you develop regarding the different forms of PLE participation presented?"

Value of Contextual Flexibility: Participants appreciated the diversity of participation models, recognising that adaptability to local contexts enhances relevance and effectiveness. Flexibility is seen as a strength that supports broader implementation and greater success.

Awareness of Gaps and Emerging Perspectives: Some participants expressed a sense of how much remains unknown or underexplored. At the same time, the presentation of new perspectives was seen as enlightening and as opening doors to expanded roles for people with lived experience (PLEs).

Call for Global Recognition and Legitimacy: A recurring theme was the perceived need for greater international recognition of PLE participation.

"What ideas or concepts helped you see PLE participation in a new or different way?"

Evidence-Based Justification for Inclusion: Participants valued the idea that an evidence base can be used to advocate for the inclusion of people with lived experience (PLEs) in co-production.

Unlearning as a Transformative Process: The concept of "necessary unlearning" emerged as a thought-provoking idea. It highlights the importance of challenging established assumptions, and opens up questions about how progress in this area can be meaningfully assessed.

Inspirational International Models: Participants were inspired by examples from countries like Iceland and Estonia, particularly in relation to university-linked models of co-production.

"Do you think the topics covered could have a concrete impact on your workplace or the reality you come from? In what way?"

Potential for Cultural Change: Some participants indicated that the workshop supported ongoing efforts to shift organisational culture—particularly by introducing and legitimising the idea of meaningful contributions from people with lived experience (PLEs).

Intentions to Apply and Share Insights: A few participants expressed a direct intention to implement what they learned or to share these insights with stakeholders in their own settings, suggesting potential downstream impact beyond the individual level.

Uncertainty and Mixed Responses: Not all participants were certain about the applicability of the workshop content in their own contexts, reflecting either systemic limitations or a need for more time to assess relevance and feasibility.

"What main challenges do you see in achieving meaningful PLE participation in your context?"

Stigma and Professional Resistance: A recurring theme was the persistence of stigma toward people with lived experience (PLEs), particularly among mental health professionals. This is often accompanied by resistance to change and scepticism about the legitimacy of PLE contributions.

Institutional and Political Barriers: Several participants highlighted obstacles at the policy or governmental level, including outdated governance models and fear among decision-makers about the complexity and risks of participatory approaches.

Structural and Resource Constraints: Challenges such as limited budgets, lack of training, and the difficulty of embedding participatory models in project-based or outcome-driven systems were seen as barriers to meaningful inclusion.

Power Imbalances and Unequal Dynamics: Concerns were raised about entrenched hierarchies—such as dominant roles held by managers or professionals—which may inhibit equal collaboration and prevent PLEs from having real influence in service design or delivery.

4.5 Workshop 3: Peer Advocacy

Content:

The final workshop in the series proved to be a valuable opportunity to explore in depth two key themes related to the involvement of people with lived experience (PLE) in mental health services: peer advocacy and the challenges of implementing the PLE approach.

Peer Advocacy: A Voice of Equality

The workshop began by defining peer advocacy as the act of asserting one's own rights and needs, distinguishing it from self-advocacy (speaking for oneself) and professional advocacy (speaking on behalf of others, such as lawyers or doctors). What sets peer advocacy apart is the shared experience between the advocate and the person seeking help, placing them on an equal footing. This approach is particularly effective for marginalized and hard-to-reach groups, as it is client-centred, supportive, and non-judgemental. Self-disclosure by the advocate can help build rapport, provide a role model, and instil hope.

The benefits of this approach include improved management of power dynamics between users and professionals, reduced shame and stigma, greater user involvement in treatment decisions, and better access to the mental health system, leading to improved outcomes.

A concrete example was presented from Bremen, Germany, where the goal is a person-centred, recovery-oriented system. Local mental health networks there include PLEs as integral actors of change. Independent peer advocacy is recognised as a quality assurance measure and is publicly funded by the ministry. Around two individuals in each of Bremen's five regions perform this role, supporting people in finding their voice in the system and offering confidential, non-bureaucratic advice, focused on recovery and empowerment.

However, implementing peer advocacy comes with challenges and critical issues:

Gap between theory and practice: Despite ideals of collaboration, institutions often fail to understand or support the peer approach, sometimes seeing advocates' interventions as disruptive. Bureaucratic constraints, financial pressures, and staffing shortages hinder openness to new approaches.

Tokenism: Tokenism was highlighted as a significant risk – the superficial inclusion of PLEs to create an illusion of involvement without granting real influence. It was suggested that peer advocacy should be given more power to prevent tokenism, for instance by allowing it to influence organisational evaluations.

Lack of support for advocates: The experience in Cyprus showed that without appropriate support (e.g. psychologists) for peer advocates, projects may fail due to high risk of burnout and the responsibilities of dealing with sensitive issues, such as suicidal ideation or manic states. It became clear that peer supporters also require support themselves.

Formal recognition of roles: In Italy, a key issue is the lack of formal recognition of PLE roles, which can lead to confusion and role distortion. Without clear roles and rules, burnout becomes more likely. One proposed solution was the creation of independent and separate PLE groups to address service contradictions free from external pressures, countering professional and corporatist interests that may distort the concept of advocacy. [1]

[1] In Italy, where there is still some ambiguity between direct PLE and family involvement processes, several key issues have emerged that must be considered in engagement processes specifically aimed at families and caregivers. These issues can support PLE involvement processes without distorting the difference between roles: the conceptualization of the family in psychotherapeutic perspectives; different perspectives, from psychoanalytic to systemic approaches about families; the "death of the family" in critical theories; research on attachment models and integrated perspectives; the scientific literature on family members, burden, stigma, and caregiving; the history of family associations in mental health and disability in Italy and internationally; the history, practice, and theory of self-help; conflicts between user organizations and family organizations internationally: controversies over the link between associations and the pharmaceutical industry; issues of conflict between family associations and user associations at the European level (coercive practices, invalidation, corrective interventions); the case of autism and the clash about corrective therapies; the family in sociological readings: "amoral familism" in Italy, the relationship between family and welfare, and the results of scientific research on new forms of family today; the political, cultural, and legislative debate on the family: the ideology of the "natural family" and its political function, transfeminist and queer perspectives on family critique, definitions of "caregiver," and the role of the family in relationships with social and health services; when the family faces stigma and when the family is a source of retraumatization: the case of “rainbow” families, and the struggles of families of trans and queer people.

Cultural differences and integration: Different national contexts present varying challenges. In Estonia, advocacy is often integrated into peer support, while in Germany, psychologists reportedly lack awareness of PLEs. This underscores the need for ongoing efforts to raise awareness.

Nature of the work: Advocacy work is often emotionally draining, and drawing on personal experience may lead to projection. People approach advocates to complain rather than praise the system. Complex situations can arise, such as interactions with individuals in psychotic states or “targeted individuals”.

Implementing the PLE Approach: Success Factors and Challenges

The second part of the workshop focused on key success factors for the effective implementation of PLEs or recovery companions in mental health services. The discussion was primarily based on German experiences but included reflections relevant to broader contexts. Key success factors include:

Knowledge and training: It is crucial that the entire organisation understands the competencies and potential roles of PLEs. Staff training and workshops can help overcome scepticism and highlight opportunities.

Multiple levels of PLE involvement: Organisations should recognize that PLEs can contribute on various levels:

- Direct contact with clients/patients.
- As team members and colleagues, influencing internal culture (e.g. promoting respectful, resource-focused language) and showing that recovery is possible.
- Structurally, by influencing policies, processes, and management decisions.

Clear role descriptions: The lack of well-defined tasks and job roles is a leading cause of unsuccessful PLE integration. Without clarity, confusion and frustration among staff can arise, along with burnout among PLEs.

Organisational culture: Organisations must foster a culture of open dialogue and be receptive to change in order to welcome PLEs. Leadership must view PLEs as an asset; without this, implementation is likely to fail.

Support and supervision: Ongoing training, supervision, and mentorship are essential for both PLEs and non-peer staff. Mentors at multiple levels (staff and management) are highly beneficial.

Acknowledging change: Organisations must be aware that including PLEs will bring cultural, structural, and procedural changes.

More than one PLE: Having at least two PLEs per team is important to share the workload, offer mutual support, and distribute staff expectations across multiple individuals.

Willingness to engage in dialogue: The organisation must be genuinely open to dialogue and transformation.

The Italian context presents specific challenges for implementation. Professional groups and corporatist interests may seek to define – or manipulate – the concept of advocacy to fit their own agendas, sometimes attempting to co-opt PLE groups to promote compliant forms of advocacy. Approaches often vary and even conflict across Italian regions. The proposed solution is the formation of autonomous, independent PLE groups to navigate service contradictions without external influence.

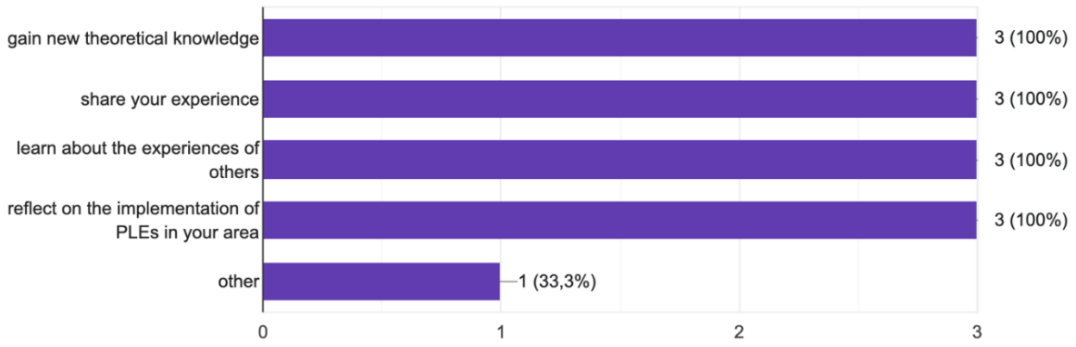
The Icelandic model was shared as an example of good practice: it includes an “ideological guide” with lived experience (such as Nina) who holds management-level power to safeguard the unique contribution of lived experience experts and prevent both “peer drift” (the erosion of peer identity) and tokenism.

Evaluation:

Of the 17 participants in the workshop, 3 completed the questionnaire (17,65%). The respondents were from Iceland, Poland and Estonia. All were PLE, one was also a mental health worker.

The graph below shows that all participants found the workshop useful for acquiring new theoretical knowledge, sharing experiences, learning from others' experiences and reflecting on the implementation of PLEs in their own area. Only one participant indicated another reason. The satisfaction with the workshop ranged from „moderately” to „extremely” satisfied and thus was on avarage „very satisfied”.

Did the workshop allow you to:



For what reasons would you recommend this workshop?

Diversity and Comprehensive Coverage: The workshop is valued for its variety of perspectives and thorough coverage of topics, providing a broad and inclusive understanding.

Cross-Level Learning: It proves beneficial not only for newcomers to the topic of PLEs but also for experienced workers and peer support staff, offering new insights and deeper understanding.

Stigma Reduction and Paradigm Shift: The workshop promotes cultural change by recognising lived experience as a crucial resource for improving services and communities, benefiting politicians and professionals as well.

Awareness of Best Practices and Pitfalls: It provides information on existing solutions as well as challenges, helping those involved in developing peer support systems avoid repeating mistakes and enhance effectiveness.

What does "participation" of people with lived experience in mental health services mean to you today?

Listening and Power Sharing: Participation involves genuinely listening to people with lived experience (PLE) and creating space for them to hold real influence and power within mental health services.

Paradigm Shift and Equal Positioning: There is a recognised need for a fundamental change in the approach to mental health and social services, moving beyond token inclusion towards empowering PLE with an equal and meaningful role at decision-making tables. Expectations for participation have risen, emphasising empowerment as a core element.

Multi-Level Involvement: Participation is seen at multiple levels: from direct support of individual patients to active involvement in service development. PLE bring crucial insights about the barriers and challenges faced by patients, enabling improvements in service navigation and delivery.

What thoughts did you develop regarding the different forms of PLE participation presented?

Concerns About Overrepresentation of Non-PLEs: One participant highlighted that the main issue is not PLE participation itself but the overparticipation of individuals without lived experience, suggesting a need to prioritise authentic voices.

Recognition of Diversity and Flexibility in Participation: There is a broadening understanding that PLE participation can take many forms and operate at various levels.

Awareness of Challenges Faced by Peer Support Workers: The workshops brought attention to the difficulties and potential pitfalls experienced by peer support workers, highlighting that participation is not without its challenges.

What ideas or concepts helped you see PLE participation in a new or different way?

Learning from International Policy Approaches: Participants valued insights into policies and practices from other countries, recognising that different contexts offer useful lessons and broaden perspectives.

Do you think the topics covered could have a concrete impact on your workplace or the reality you come from? In what way?

Policy Influence and Advocacy: Participants see potential for increased pressure to integrate PLE participation more firmly into policies, indicating an impact on systemic and organisational levels beyond direct service provision.

Clarity of Roles and Boundaries: There is recognition of the importance of clearly defining roles, responsibilities, and boundaries from the outset to prevent burnout and confusion—highlighting a practical takeaway for improving workplace structures.

Personal Empowerment and Valuing Expertise: One respondent noted a personal shift in self-perception, feeling more valued and equal as a PLE among professionals.

Need for Structured Implementation and Training: Effective impact requires structured integration of topics covered, combined with awareness training for medical

and administrative staff, ensuring that PLE participation fits cohesively within existing systems.

What main challenges do you see in achieving meaningful PLE participation in your context?

Low Reputation and Recognition of Peer Support Workers: General societal and professional scepticism toward PLE roles remains a significant barrier. Personal relationships and demonstrated values can help overcome this challenge on an individual level, but wider acceptance is still limited.

Process and Patience for Change: Meaningful participation is viewed as a gradual process requiring time to build trust among professionals, policymakers, and institutions.

Funding and Employment Issues: Lack of paid positions for trained PLEs leads many to volunteer roles or unemployment despite workforce shortages in mental health. Absence of sustainable funding and systemic structures to integrate PLEs nationally is a major obstacle.

Structural and Cultural Barriers in Healthcare Systems: Existing healthcare systems, such as Poland's, remain clinical, hierarchical, and centralized, necessitating a broader cultural shift to truly recognise and respect PLE contributions.

4.6 Workshop 4: Empowerment Colleges

Content

The Empowerment College is defined as a place where people with diverse perspectives and backgrounds meet to acquire knowledge about mental health topics and exchange ideas in courses with a manageable time commitment. Participants are students who independently choose their courses and goals. It is important to note that the Empowerment College is an educational offering, not a treatment center or therapy. This approach emphasizes participation and being part of society again, moving away from isolation.

The concept of Recovery Colleges first emerged around 2000 in the USA (Arizona, Boston) from the Recovery Movement. It came to Europe in 2009 via Great Britain (NHL South London), leading to over 80 Recovery Colleges in England within a decade. The idea spread to other European countries, including Germany. Bremen was the coordinator of an European project (Erasmus+) in 2017-2018, led by FOKUS and involving partners from Italy, Bulgaria, Poland, Netherlands, Great Britain, and Germany. The Bremen college developed independent ideas while learning from the

English model, leading to its name "Empowerment College", which references the empowerment concept and recovery approach. This choice also reflects differences in funding systems, as German health insurance is private compared to the state-run system in the UK. The name "Empowerment" was chosen to emphasize political ideas, empowering individuals, and fostering solidarity.

Target Group: The college is open to everyone interested in mental health topics. Specifically, the target group includes: People with lived experience of mental health issues (often referred to as PLE). Approximately 70% of participants are individuals with lived experience, their relatives and closest friends (approx. 20% of participants), people working in the mental health sector (approx. 20% of participants) and participants do not have to disclose their background (e.g., if they are ill, mental health workers, or relatives).

The Empowerment College operates on six core principles:

Co-productive at all levels: This means people with lived experience of mental health issues (often with EX-IN recovery support training) work alongside people with professional expertise on an equal level. This collaboration happens within the Empowerment College team, as trainer tandems in course development and implementation, and participants have various opportunities to contribute to the design. EX-IN refers to "experience involvement" or peer support work, involving a significant training program (around 400 hours in Germany).

Experience-based learning: While input, teaching, and learning methods are used, the core of the college is the exchange of previous experiences coupled with new experiences during the courses. Experiences with mental health issues and coping strategies are considered valuable resources, and sharing this knowledge is crucial.

Inclusive – low-threshold access to education for all: Courses are open to people with very different symptom experiences and varying degrees of severity. The college provides a very personal initiation/registration process and asks participants about their individual needs and wishes for successful participation before courses begin. They maintain personal contact and provide support to enable participation and prevent dropouts, creating a very appreciative and accepting learning atmosphere.

Empowerment-oriented: Participants are seen as students who learn and contribute from their wealth of experience. Students experience themselves as self-determined in choosing course topics and learning goals. Certain course topics encourage people with experience of psychiatry to have more influence in society and be recognized as experts. The college also encourages the formation of social networks. The fundamental approach is to empower individuals to "take your life into your own hands".

Recovery-oriented: Students can discover new ways to promote their health and well-being and learn how to influence symptoms and life situations. The college imparts knowledge that can be used independently, and the acceptance of all participants and a resource-oriented focus convey hope, enabling the discovery of new paths and the transformation of crises and illness experiences into recovery expertise.

With quality assurance instruments: This includes co-productive workshops for developing courses, clear and measurable learning objectives, participants formulating their own goals, feedback forms, evaluation of learning objectives, trainer training, trainer questionnaires and reflection meetings, and external evaluation. A continuous cycle of needs assessment, planning, implementation, evaluation, assessment, and improvement is followed.

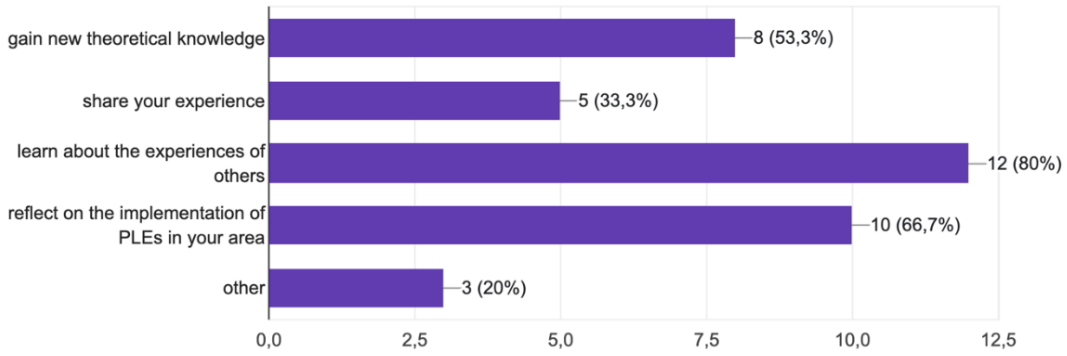
Areas of Operation and Benefits: The Empowerment College operates on themes such as: Self-efficacy, Aftercare, Dialogue, Prevention, Self-help, (Self-)Acceptance, Social contacts, Social skills, Psychoeducation (low-threshold, practice-oriented, open-ended), Stabilization, Daily structure, Meaning, hope, personal growth (leading to recovery/empowerment).

Evaluation

Of the 23 participants in the workshop, 15 (65, 2%) completed the questionnaire. 7 of them identified as PLE, 3 as mental health workers. One third of the participants has a professional role in the mental health field. The rest of the participants were composed of one researcher, one student, one EX-IN trainer, one decision maker, a relative, and one activist. Most participants were from Italy (10). Estonia and Germany were represented by two participants. There was one person from Iceland and one from Cyprus. The overall rating of satisfaction with the workshop was “very satisfied” (M = 2,13, SD = 0,64).

The graph shows that most respondents said they were able to learn from the experiences of others (80%) and reflect on the implementation of PLEs in their own area (66.7%). 53.3% acquired new theoretical knowledge, while 33.3% had the opportunity to share their own experience.

Did the workshop allow you to:



"What does participation of people with lived experience in mental health mean to you today?",

Empowerment and Inclusion: Many respondents emphasized the importance of empowerment and inclusion of people with lived experience (PLE) in mental health processes. One participant stated, "Participation for me is empowerment: the people who participate is part of a society... in a way that promotes freedom and wellbeing." This highlights the belief that involvement in mental health services not only benefits individuals but also fosters a sense of belonging and agency within the community.

Recognition and Professional Integration: The recognition of PLE as valuable contributors to mental health services was a recurring theme. One response noted, "The professional recognition of this role and the reflection on the contents of the training are really important." This suggests that acknowledging the expertise of PLE can enhance the quality of care and training for professionals in the field.

Systemic Change and Stigma Reduction: Several participants pointed out the need for systemic change and the role of PLE in combating stigma. One individual mentioned, "change system; deeper understanding; fight stigma; liberation," indicating that the involvement of PLEs can lead to broader societal shifts and a more profound understanding of mental health issues.

Quality Improvement and Best Practices: The contributions of PLE were also linked to improving service quality, training of professionals and best practices. A respondent remarked, "it gives depth and motivation to improve best practices," suggesting that their insights can lead to more effective and compassionate care strategies.

What thoughts did you develop regarding the different forms of PLE participation presented?

Economic Disparities in PLE Participation: A participant notes the economic differences between countries, stating, "Germany is much more richer" and that "in Germany PLE are paid and in Italy no." This highlights the disparity in support and recognition for people with lived experience, which can affect their participation and empowerment in mental health initiatives.

Hopes and Challenges concerning Co-Production: One participant indicates “PLE can take various roles in MH, as long as the system allows them”. Another response points out that "often we intend to reach the co-production but stop at lower levels." This reflects a common challenge in fully integrating PLE into decision-making processes, suggesting that while there is an intention to include them, practical implementation often falls short. One participant asserts that "PLE can have an important role in the reality of colleges presented today," indicating a recognition of the valuable contributions that people with lived experience can make to mental health systems and the need for their voices to be heard.

Shifting Perspectives on Expertise: One respondent reflects on their own experiences, stating, "I think we could welcome a movement from professionals know it all to accepting patients/PLEs/People as experts on themselves." This indicates a desire for a cultural shift in mental health care, moving away from stigma and towards empowerment and recognition of lived experience as a form of expertise. The importance of autonomy is highlighted in the response that discusses "the relevance of the ability of people to make their own decisions." This underscores the belief that individuals should have the freedom to choose how to address their challenges, which is a fundamental aspect of empowerment.

What ideas or concepts helped you see PLE participation in a new or different way?

Empowerment and Recovery: A significant number of responses highlight the concepts of empowerment and recovery as pivotal in reshaping perceptions of PLE participation. One participant noted, "The concept of empowerment, when it comes before the concept of recovery: what do I need to recover when I’m free and empowered?" This suggests that empowerment is viewed as a foundational element that precedes recovery, emphasizing the importance of autonomy in the healing process. Additionally, the mention of "the possibility of working in an empowerment college" indicates a desire for PLEs to engage in meaningful work that not only supports their recovery but also impacts others positively.

Collaboration and Co-production: Collaboration among professionals and PLEs is another recurring theme. One respondent stated, "Strong collaboration between Profis and PLE's but a bit preoccupation for the independence of PLE," indicating a

recognition of the need for teamwork while also expressing concerns about maintaining PLE autonomy. The concept of co-production is particularly emphasized, with one participant asserting, "For me, co-production was the key to improving my idea of PLE." This highlights the importance of shared decision-making and the integration of lived experiences in educational practices.

Professional Identity: The responses also reflect a growing awareness of the professional identity of PLEs. One participant expressed the desire "to be seen as professional workers," which underscores the need for recognition and respect within the broader professional landscape. The idea of contributing to public debates on ethical issues further reinforces this theme, as it positions PLEs as knowledgeable and valuable contributors to discussions that affect their field.

Do you think the topics covered could have a concrete impact on your workplace or the reality you come from? In what way?

Engagement and Empowerment: A number of respondents expressed a belief in the transformative potential of the topics discussed, particularly in relation to empowerment and engagement. One respondent noted, "If properly designed, an organization based on principles of empowerment and recovery can become transformative for people." This highlights the importance of creating an environment that fosters empowerment. Another participant mentioned, "Todays workshop gave me inspiration to contact 2 of my fellow-countrymen," indicating a proactive approach to applying the concepts learned.

Regional Development and Implementation: Several responses pointed to the specific context of the respondents' regions and the potential for developing new initiatives. For instance, one individual stated, "Yes, because in my region in Italy there aren't recovery colleges, so this could be a reality that can be created and improved in my area." This reflects a desire to adapt the discussed concepts to local needs. Another respondent mentioned, "I could bring some ideas on the table but always based on my country's culture and capabilities," indicating an awareness of the necessity to tailor approaches to fit regional contexts. This theme underscores the importance of localizing initiatives to ensure their relevance and effectiveness.

What main challenges do you see in achieving meaningful PLE participation in your context?

Funding and Resources: A significant number of responses highlight the critical issue of funding as a barrier to meaningful participation. Many participants express the need for financial support to sustain activities and compensate individuals involved in Peer-Led Engagement (PLE). One respondent states, "Money of course. There is a lot of

enthusiasm, but it will not last if there is no funding." This sentiment is echoed in multiple responses, emphasizing that without adequate financial resources, the enthusiasm for PLE initiatives may wane. Additionally, the challenge of securing funding is compounded by the "critical situation of services, cuts, cultural politic situation," which further limits available resources.

Cultural and Societal Challenges: Cultural stigma surrounding mental health is another prominent theme. Several participants mention the "stigma about mental health" as a significant barrier to developing participatory approaches. One response notes, "Cultural challenges: stigma about mental health is still relevant in my country and it slows down the development of participatory approaches." This stigma not only affects public perception but also impacts the acceptance of peer support roles within professional settings. The need for a shift in societal values regarding participation and involvement is also highlighted, with one participant stating, "The question of values in society and culture of involvement as well as participation are important for the practices to develop."

4.7 Workshop 5: Training of Recovery Companions

Content

The workshop introduced two prominent peer support training models: EX-IN (Experienced Involvement) which was developed in Europe and is widely used in Germany, and Intentional Peer Support (IPS), which is used in Iceland and originated in the US. Both models aim to integrate individuals with lived experience of mental health challenges into the healthcare system to foster recovery and promote a paradigm shift in psychiatry.

Common Themes and Key Concepts in the Training Approaches

Role of Lived Experience: Both models centralize the lived experience of mental health challenges as a unique form of expertise. They emphasize the importance of individuals developing their own explanatory models for their crisis, rather than solely relying on medical explanations.

Recovery-Oriented Approach: Both EX-IN and IPS firmly believe in recovery and challenge the concept of chronicity, emphasizing hope as essential.

Importance of Relationships: While IPS explicitly makes relationships and attachment its core focus, EX-IN also emphasizes the importance of sharing experiences and building understanding within groups.

Peer Drift: A significant challenge highlighted is "peer drift," where peers inadvertently morph into traditional staff roles by performing non-peer tasks (e.g., making coffee, cleaning). Clear role definition is crucial to prevent this and ensure the unique value of peer work.

Implementation Facilitators and Barriers: Successful implementation often depends on leadership readiness and engagement, organizational culture openness to change, clear job descriptions, training for both peers and non-peers, integration of peer voices, and ongoing supervision. The presence of "champions" (authority figures who advocate for peers) is a key facilitator, but their departure can hinder progress. Conversely, a hierarchical culture and economic concerns can act as significant barriers.

Good Practices for Implementation: Recommended practices include bottom-up inclusion of people with lived experience, structural organizational change, shared power and resources, continuous communication, building trust, restorative justice, psychological safety, and establishing independent peer teams. Fair employment, appropriate payment (including hazard pay), allowing peers to define their work, and client-involved, confidential documentation are also crucial.

EX-IN (Experienced Involvement)

The EX-IN program, developed from a European project in 2005-2007, focuses on the "Involvement of experts through experience". An "expert of experience in healthcare" is defined as someone who has active experience with illness, disability, and/or mental health problems and has acquired specific skills to live with and cope with them. Becoming an expert requires reflection on one's own experiences and sharing them with others who have had similar experiences, comparing them across diverse situations. EX-IN literally means "Experienced Involvement". Some peer support workers also interpret it as having been "ex" (out) and now "in" again in a new way.

A core goal of EX-IN is to facilitate a "paradigm shift in psychiatry," moving "from the limitations of the patient role to a self-determined, meaningful life," as expressed by Pat Deegan. This involves encountering the world of lived experience, seeking meaning in emotional distress, using coping models, and actively involving experts through experience in developing and delivering services.

The training aims to qualify individuals as experts through experience for collaboration in the healthcare system, contributing their knowledge as an "innovative contribution to psychiatric and social services" (as recovery companions), and participating in training, continuing education, and user-led research.

The training is for individuals with psychiatric experience or who have experienced deep psychological trauma/mental health issues, with stability required at the start of the course. Most participants have diagnoses or psychiatric hospital stays, though it's not absolutely necessary. A willingness to share experiences in the group is crucial, and experience in self-help or trialogue groups is desired. Participant Selection Process in Germany: Germany employs a four-stage selection process for EX-IN participants: an information event, a written application, a group assessment, and an individual interview. This process helps identify candidates who can reflect on their crisis experiences, give others space, and are interested in diverse recovery paths.

The EX-IN training comprises 12 modules, each three days long, totaling approximately 270 hours. The first half focuses on personal growth and understanding concepts like: Health and Well-being, Empowerment, Experience and Participation (including exclusion and return), Recovery, Trialogue, Self-exploration (including a "tenant minute" speech where participants share their background), Peer advocacy/complaint management, Inventory and target planning (assessment), Advise and accompany, Crisis intervention, Teaching and Learning. Participants also complete two internships and write a portfolio documenting their personal professional profile.

"From I-knowledge to We-knowledge": The training helps participants move from individual "I-knowledge" to a collective "we-knowledge" by structuring and reflecting on personal experiences, sharing them, and understanding commonalities and differences across various recovery journeys. This fosters tolerance for diverse recovery ways, moving beyond a single, prescriptive approach.

EX-IN trained peers can be deployed in a wide range of settings including clinics, outpatient psychiatric care, dormitories, assisted living, day care centers, social psychiatric services, integrated care, workshops, work rehabilitation facilities, offices, health insurance companies, training institutions, and companies. They can perform roles such as recovery support, (peer) counseling, intercession, crisis intervention, quality management, public relations, training, research, and project work.

Challenges in Implementation can include reluctant implementation of peer work, with low trust and commitment from management and resistance from operational staff. Peer support can be seen seen as temporary relief, and there was a risk of "peer drift" into assistant roles, where compliance with the status quo was rewarded. Economic concerns frequently serve as an "ultimate argument for human rights violations". Despite progress, peers are often paid the minimum possible amount in public service.

Distribution: EX-IN courses are currently available at 30 locations in Germany, with an umbrella organization (EX-IN Deutschland e.V.) and international distribution in Austria, Switzerland, Italy, and Poland.

Legitimacy and Payment: EX-IN is not a registered profession in Germany, meaning there are no national regulations on payment levels. Wages depend on the employing organization**.**

Intentional Peer Support (IPS)

IPS is a distinct peer support training model delivered over 40 hours or five days. IPS trainings are structured to ensure diversity and include underprivileged voices by offering significantly discounted or free seats alongside full-paying members, making the job of a peer supporter accessible to everyone.

Core Principles: IPS is built on three principles and four tasks.

From helping to learning together: Peers do not give advice but learn alongside the individual, going beyond a traditional helper role.

From individual to relationship: Focus is on the connection between people rather than solely on individual diagnoses or patient notes (peers do not read patient notes).

From fear to hope & possibility: Emphasizes looking towards the future and what can be created, rather than dwelling on past crises or negative aspects.

Tasks: These principles are enacted through the tasks of connection, worldview, mutuality (both parties responsible for the relationship), and moving towards (having a shared goal).

Philosophical Focus: IPS deeply explores the philosophy of what it means to be a patient versus a person, focusing on identity, trauma-informed views, relationships, and attachment. It reframes all behavior, even harmful ones, as "survival instincts" that kept people alive at some point, fostering respect for these reactions.

Role Definition: In Iceland, IPS-trained peers are not clinical staff and have no clinical responsibilities. They are not part of treatment plans, do not write notes of content, and do not administer medications or perform clinical tasks. Their only aim is to build a relationship with the person.

Implementation in Iceland: Nina Eck's experience in Iceland demonstrates a systematic approach to IPS implementation:

Trust and Support from Leadership: Gained initial support from bosses and decision-makers.

Peers Define the Service: Nina, as a peer, researched and selected the IPS training, which was chosen for its fit and cost-effectiveness.

Introduction to New Wards: Nina conducts presentations for new wards, explaining peer support, managing expectations, and instructing staff on how to make peers feel welcome. Staff are encouraged to "pull the peer" into their group to foster integration.

Experienced Peer Support: An experienced peer (Nina) offers support in a new ward to understand its rhythm and key situations (e.g., need for keys). This also helps control staff expectations by clarifying the peer role (e.g., not administering medication).

Hiring Inexperienced Peers: Following the experienced peer's acclimation period, inexperienced peers are hired, with consideration for fitting the ward's population.

Ongoing Support and Empowerment: Regular (bi-weekly) supervision meetings for peers, led by experienced peers (like Nina), provide a space to discuss work challenges, ask questions, and learn together.

Informal Results in Iceland:

Patients reported "more natural conversation" and felt empowered. Staff reported more pride in their work, less contact-seeking behavior from patients, and a sense of calm during staff shortages, knowing peers were addressing social needs. The Institution-Community Contact improved, fostering anti-stigma work. Peers reported increased recovery, personal growth, and ambition, with their voices being valued. Nina observed a peer doubling work hours and taking on new projects after IPS training.

Peer Work Contributions: Peer work in Iceland is divided into three parts: direct support for the person, work for the institution (e.g., policy review, change management), and work towards the community (lessening stigma, connecting activities).

Payment in Iceland: The hospital, funded by the government, pays for peer roles. Peers are currently employed as "untrained staff", paid as consultants or counselors, as there isn't yet a specific pay grade for them.

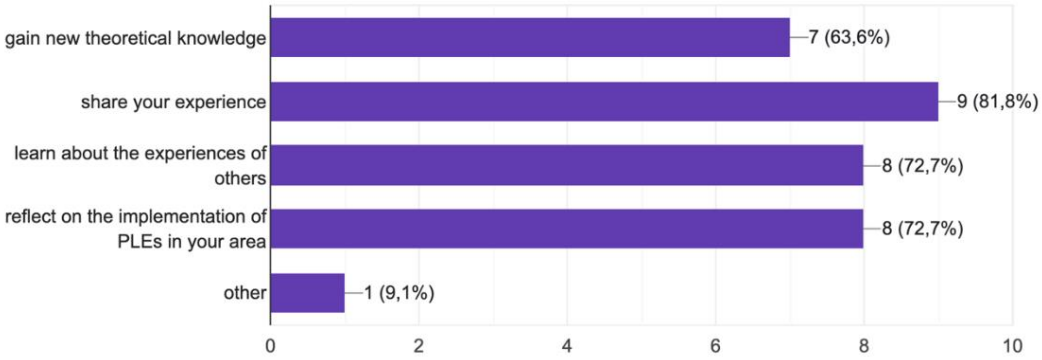
Evaluation of the workshop

Of the 26 participants in the workshop, 11 (42.3%) completed the questionnaire. Four of the respondents identified as PLE, three as mental health workers. There was one sociologist, one EX-IN trainer, one advocate, one decision maker and one person that

didn’t specify their role. The majority of the participants (64 %) has a professional role in the mental health field. Most participants were Italian (6), three from Estonia, one from Iceland and one from Germany. The overall rating of satisfaction with the workshop was “very satisfied” (M = 2,22, SD = 1,3).

The graph below shows the benefits perceived by 11 workshop participants. The majority highlighted the opportunity to share their experience (81.8%), followed by the opportunity to learn from others' experiences and reflect on the implementation of PLEs in their own context (both 72.7%). 63.6% acquired new theoretical knowledge.

Did the workshop allow you to:



What does “participation” of people with lived experience in mental health services mean to you today?

Empowerment and Inclusion: A significant theme in the responses is the empowerment of people with lived experience (PLE) and their inclusion in mental health services. Respondents emphasize the importance of recognizing PLEs as active contributors rather than mere recipients of care. One participant states, "It means that people with lived experience are not only recipients of care, but active contributors in designing, delivering, and evaluating services." This highlights the need for PLEs to have a voice in all phases of service development, from design to evaluation. Another respondent mentions, "to give PLE a role with appropriate payment, to hand over power to PLE," indicating that financial recognition is also a crucial aspect of empowerment.

Collaboration and Co-creation: The theme of collaboration is prevalent, with many responses advocating for a partnership approach between PLEs and mental health services. One participant notes, “Listening, making space and trusting," which underscores the importance of mutual respect and open communication. Additionally, the idea of co-creating therapeutic plans is highlighted: "To have the possibility and

right to negotiate the therapeutic plan; co-projecting the services." This suggests that PLEs should have a say in their treatment and the overall direction of mental health services, fostering a sense of ownership and responsibility.

Challenges and Confusion: Despite the positive aspects of participation, several responses point to challenges and confusion within the current system. One participant reflects on their experience in a work group, stating, "I had not much power or say in the decisions, but at least I was one PLE at the table." This indicates that while there may be opportunities for involvement, the actual influence of PLEs can be limited. Furthermore, concerns about the qualifications of peer support workers are raised: "there are some cases of people claiming they are peer supporters as they have experience (without any training)." This confusion can undermine the effectiveness of peer support and highlights the need for clear guidelines and training.

What thoughts did you develop regarding the different forms of PLE participation presented?

Importance of International Collaboration: Several responses highlight the significance of learning from international experiences and practices. One participant noted, "it is important to learn about different experiences to open our mind to new ways of working." The emphasis on international networks indicates a collective desire to enhance PLE practices through shared knowledge and experiences.

Validation and Evolution of Diverse Roles within PLE: A recurring theme in the responses is the need to recognize and validate various roles within PLE participation. One participant expressed concern about the validation of roles, stating, "I just wonder how much this role has been validated by consensus." This highlights the importance of establishing a clear mandate and providing training for different positions within the sector. Another participant reflected on their own understanding of PLE, stating, "I did not think of advocacy, training, policy level, educational materials as real peer supporter work." This realization underscores the need for broader recognition of diverse contributions to PLE, beyond traditional one-on-one or group support. The responses also indicate a reflective consideration of the boundaries and limits of participation of PLE. One participant mentioned, "Reflected previous thoughts on participation boundaries and limits," suggesting a critical examination of what constitutes valid participation. This theme aligns with the idea that the understanding of PLE roles is evolving, as another participant noted, "I'm glad to know it is perfectly valid for PLE work," indicating a shift in perspective regarding what activities are considered legitimate within the PLE framework.

What ideas or concepts helped you see PLE participation in a new or different way?

Collaboration and Co-Creation: A significant number of responses highlight the importance of collaboration and co-creation in the context of PLE participation. The idea of "co-creating" is emphasized.

Diverse Perspectives and Context: Another prominent theme is the value of hearing from different countries and contexts. One participant remarked, "Learning about the concrete experiences of countries such as Germany and Iceland has made me realise that the participation of PLEs is already a viable reality." The phrase "hearing from different countries and contexts" suggests that diverse perspectives can challenge preconceived notions and inspire new approaches to participation.

Flexibility and Power Dynamics: The responses also touch on the themes of flexibility in participation and the complexities of power dynamics. One individual mentioned, "Participation form flexibility - got me thinking on procedures how to move between different roles and targets (possible bureaucracy)." This indicates a recognition of the need for adaptable structures that allow for fluid participation. Furthermore, the reference to "power relations problems" suggests an awareness of the challenges that can arise in hierarchical systems, prompting an evaluation of how power dynamics influence participation.

Do you think the topics covered could have a concrete impact on your workplace or the reality you come from? In what way?

Awareness and Advocacy: Several respondents highlighted the importance of enhancing political awareness and advocacy within their respective contexts. One respondent emphasized the role of workshops in shaping their views, noting, "these workshops have in a very positive way shaped my own view of PLEs and peer support workers." This suggests that the discussions not only informed participants but also empowered them to advocate for change within their organizations.

Ideas and Challenges for Implementation: The theme of implementation and the integration of new research into practice was prevalent in the responses. One individual mentioned, "I have some new research to read and to add to my work on implementation," reflecting a commitment to applying new knowledge in their setting. Another participant stated "Yes, workshop provided arguments that help to implement (convince, validate, role-model) positive changes." This indicates a desire to translate insights gained from the workshops into actionable strategies that can enhance their work environments.

What main challenges do you see in achieving meaningful PLE participation in your context?

Cultural and Structural Challenges: Several respondents highlighted the cultural barriers that impede the integration of PLEs into mental health services. One individual noted, "cultural challenges are probably the main ones", another respondent referred to "non recovery oriented services". The resistance to change within established professional groups is also a significant hurdle, as indicated by the need to "limit corporative power of professional groups." Furthermore, the lack of structural support that facilitate PLE involvement is a recurring theme.

Recognition and Trust Issues: The recognition of PLE as a legitimate and valuable part of the mental health landscape is another critical challenge. One respondent articulated that "the figure of the Person with Lived Experience (PLE) is still very vague and not yet recognized in an official or structured way."

Service Quality and Clarity: The quality of services and the clarity of PLE participation are also significant concerns. One respondent noted that "the variety of PLE participation also could translate to lack of clarity in messaging and participation/service quality." This suggests that without clear guidelines and structured opportunities for involvement, the effectiveness of PLE contributions may be compromised.

Partners roles and responsibilities

SB and ASL of Turin organized the contents of the workshops and recruited speakers. UniPd realized the technical and organizational aspects of the workshops and the evaluation of the workshops. Joint efforts were used to analyze the workshops and to create the deliverable. The participants of task 5.3 revised the document and some of the provided input during the workshops.

4.8 Conclusion of the workshop evaluation

The involvement of peers at different levels of the mental health system can have a positive impact on the quality of care, as peers have specific knowledge and skills based on their lived experiences that goes beyond professional knowledge and the experience of family members. Good practices for PLE involvement exist, e.g. as peer support workers, as peer advocates, as researchers and as lecturers/trainers in recovery colleges.

The high level of participation by PLE in the workshops and workshop evaluation, as well as the predominant theme of empowerment, demonstrate the desire for genuine participation. Promoting factors include trust and support from institutions, clear role descriptions and sustainable projects. However, if institutions are not adequately

prepared, there is a risk of tokenism and peer drift, so that peers cannot adequately fulfill their roles and the goal to reach true participation fails.

In order to reach true participation, every call for co-design must be open to all local associations, including those of users and family members. Otherwise, traditional MH services might implicitly select the most favorable forms of participation and critical voices might be ignored and thus the participatory process would be manipulated despite an apparent inclusion of PLE. Indeed, if engagement processes were initiated by the service in contexts where associations critical of the service already exist, these processes might insist on the distinction between "demanding" and "collaborative" subjects: a way of distinguishing "good" from "bad" forms of participation. In fact, we know that the distinction between "demanding" and "collaborative" is a mystification used by power structures to delegitimize criticism and prevent conflict. If those in power are willing to question themselves and create a genuine environment for debate, open to the clash of different positions, this distinction becomes superfluous: it is the profound nature of discussion and the willingness to criticize that allows constructive possibilities to emerge—even from approaches that seem more "demanding." Opening a service to the presence of PLEs implies that the service is ready to address criticism and develop a dialogue with it, without manipulative intent. To verify that this availability exists, the service must open the co-design of engagement processes to existing associations and groups.

Moreover, structural challenges include establishing recovery-oriented institutions that work in line with the idea of peer support and that are open to the organizational changes that might emerge from the employment of PLE. The foundation for this is the recognition of peer support and to build trust in PLEs contribution in the mental health field. For this, it is necessary to establish clear roles for peer workers. It is crucial that this is reflected in appropriate and sustainable remuneration for peer employees.

The implementation across countries, regions, and institutions varies greatly and a standard for forms of participation and the corresponding knowledge and skill sets still needs to be established across stakeholders. For this, the international exchange and comparative learning was experienced as helpful. However, uncertainties still exist – that reflects a need for further (international) exchange and development in that field. The next paper will introduce established strategies to foster PLE involvement.

6. Conclusion

The level and status of PLE involvement varies greatly across participating countries. In some countries, there has been a tradition of several decades of inclusion in addiction and mental health (MH) services (e.g., Iceland, Italy, Germany); in other countries, the field is hardly explored. In two of the partner countries (Estonia, Finland),

the work profile is officially recognized. The estimated overall number of working peers in all participating countries is low compared to other medical and social staff. Thus, the field of peer work in MH services and MH strategies is still evolving and needs further improvement.

Five online workshops were conducted to valorize good practices. There was a high level of interest, especially in Italy. As the workshops were open to professionals, PLEs, policymakers, and relatives, individuals with varying degrees of experience and expertise came together. The topics peer support work, training of peer workers, peer advocacy, and reasons to involve PLEs were discussed. The participants were very satisfied with the workshops. The evaluation revealed a desire for meaningful participation of PLEs, but also highlighted structural barriers.

The conditions and possibilities of each of the partner organizations are very diverse. Thus, the promotion of PLE involvement must be fostered in a very individual way, taking into account the local conditions and the scope of action of the partner organizations.

Literature and further reading

Adams, W. E. (2020). Unintended consequences of institutionalizing peer support work in mental healthcare. *Social Science & Medicine*, *262*, 113249.

Åkerblom, K. B., & Ness, O. (2023). Peer workers in co-production and co-creation in mental health and substance use services: a scoping review. *Administration and Policy in Mental Health and Mental Health Services Research*, *50*(2), 296-316.

Alberta, A. J., & Ploski, R. R. (2014). Cooptation of peer support staff: Quantitative evidence. *Rehabilitation Process and Outcome*, *3*, RPO-S12343.

Anthony, W. A. (1993). Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. *Psychosocial rehabilitation journal*, *16*(4), 11.

Barlott, T., Aplin, T., Catchpole, E., Kranz, R., Le Goullon, D., Toivanen, A., & Hutchens, S. (2020). Connectedness and ICT: Opening the door to possibilities for people with intellectual disabilities. *Journal of Intellectual Disabilities*, *24*(4), 503-521.

Bock, T., & Priebe, S. (2005). Psychosis seminars: an unconventional approach. *Psychiatric Services*, *56*(11), 1441-1443.

Charles, A., Nixdorf, R., Ibrahim, N., Meir, L. G., Mpango, R. S., Ngakongwa, F., ... & Mahlke, C. (2021). Initial training for mental health peer support workers: Systematized review and international Delphi consultation. *JMIR mental health*, *8*(5), e25528.

Cronise, R., Teixeira, C., Rogers, E. S., & Harrington, S. (2016). The peer support workforce: Results of a national survey. *Psychiatric rehabilitation journal*, *39*(3), 211.

Cymru, Participation. (2011). *National Principles for Public Engagement in Wales*. National Office of Mental Health Engagement and Recovery (MHER). *Mental Health Engagement Framework 2024–2028.* https://www.hse.ie/eng/services/list/4/mental-health-services/mental-health-engagement-and-recovery/guidance-and-support-documents/ [2025-09-15].

Davidson, L., & Guy, K. (2012). Peer support among persons with severe mental illnesses: a review of evidence and experience. *World psychiatry*, *11*(2), 123-128.

Department of Health (Northern Ireland). (2018). *Co-production Guide: Connecting and Realising Value Through People*. Department of Health (Northern Ireland). Link: https://www.hse.ie/eng/services/list/4/mental-health-services/mental-health-engagement-and-recovery/mental-health-engagement-framework-2024-2028.pdf

Dixon, L., Krauss, N., & Lehman, A. (1994). Consumers as service providers: The promise and challenge. *Community mental health journal*, *30*(6), 615-625.

Faccio, E., Rocelli, M., Bitetti, L., Salamina, G., Brunelli, S., Mangione, F., & Aquili, L. (2025). One or Many Recoveries? Recoveries in the Plural for a Better Understanding of One's Healing Journey. *Health Expectations*, *28*(2), e70209.

Frieh, E. C. (2024). Resistance to the biomedicalization of mental illness through peer support: The case of peer specialists and mental health. *Social Science & Medicine*, *341*, 116521.

Gillard, S., & Holley, J. (2014). Peer workers in mental health services: literature overview. *Advances in psychiatric treatment*, *20*(4), 286-292.

Hegedüs, A., Burr, C., Pfluger, V., Sieg, D., Nienaber, A., & Schulz, M. (2021). Peer support worker training: Results of the evaluation of the Experienced Involvement training programme in Switzerland and Germany. *International journal of mental health nursing*, *30*(2), 451-460.

Ibrahim, N., Thompson, D., Nixdorf, R., Kalha, J., Mpango, R., Moran, G., ... & Slade, M. (2020). A systematic review of influences on implementation of peer support work for adults with mental health problems. *Social psychiatry and psychiatric epidemiology*, *55*(3), 285-293.

Jacobson, N., & Farah, D. (2012). Recovery through the lens of cultural diversity. *Psychiatric rehabilitation journal*, *35*(4), 333.

Kane, L., Leighton, C., Limbrick, H., Kilinc, S., Ling, J., & Eberhardt, J. (2023). You clapped, you cheered, but did anybody hear? A mixed-methods systematic review of dementia homecare workers' training and psychosocial needs. *Home Health Care Services Quarterly*, *42*(4), 282-310.

Llewellyn-Beardsley, J., Rennick-Egglestone, S., Callard, F., Crawford, P., Farkas, M., Hui, A., ... & Slade, M. (2019). Characteristics of mental health recovery narratives: systematic review and narrative synthesis. *PloS one*, *14*(3), e0214678.

McWade, B. (2016). Recovery-as-policy as a form of neoliberal state making. *Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice*, *5*(3), 62-81.

Meehan, T., Bergen, H., & Stedman, T. (2002). Monitoring consumer satisfaction with inpatient service delivery: the Inpatient Evaluation of Service Questionnaire. *Australian & New Zealand Journal of Psychiatry*, *36*(6), 807-811.

Moran, G. S., Russinova, Z., Gidugu, V., & Gagne, C. (2013). Challenges experienced by paid peer providers in mental health recovery: A qualitative study. *Community mental health journal*, *49*(3), 281-291.

National Office of Mental Health Engagement and Recovery (MHER) (no year). Mental Health Engagement Methods. Link: https://www.hse.ie/eng/services/list/4/mental-health-services/mental-health-engagement-and-recovery/guidance-and-support-documents/mental-health-engagement-methods.pdf [2025-10-30].

Otte, I., Werning, A., Nossek, A., Vollmann, J., Juckel, G., & Gather, J. (2020). Challenges faced by peer support workers during the integration into hospital-based mental health-care teams: results from a qualitative interview study. *International Journal of Social Psychiatry*, *66*(3), 263-269.

Piat, M., & Lal, S. (2012). Service providers' experiences and perspectives on recovery-oriented mental health system reform. *Psychiatric rehabilitation journal*, *35*(4), 289.

Pitt, V., Lowe, D., Hill, S., Prictor, M., Hetrick, S. E., Ryan, R., & Berends, L. (2013). Consumer-providers of care for adult clients of statutory mental health services. *Cochrane Database of Systematic Reviews*, (3).

Rebeiro Gruhl, K. L., LaCarte, S., & Calixte, S. (2016). Authentic peer support work: challenges and opportunities for an evolving occupation. *Journal of mental health*, *25*(1), 78-86.

Rennick-Egglestone, S., Ramsay, A., McGranahan, R., Llewellyn-Beardsley, J., Hui, A., Pollock, K., ... & Slade, M. (2019). The impact of mental health recovery narratives on recipients experiencing mental health problems: qualitative analysis and change model. *PloS one*, *14*(12), e0226201.

Rose, D. (2014). The mainstreaming of recovery. *Journal of Mental Health*, *23*(5), 217-218.

Salzer, M. W., Hughes, M. K., Bunn, A. G., & Kipfmueller, K. F. (2009). Recent unprecedented tree-ring growth in bristlecone pine at the highest elevations and possible causes. *Proceedings of the National Academy of Sciences*, *106*(48), 20348-20353.

Schleswig-Holsteinischer Landtag: *Psychiatriebericht 2016* (2016). https://www.landtag.ltsh.de/infothek/wahl18/drucks/4900/drucksache-18-4921.pdf, p. 249 (retrieved on October 18, 2025).

Simpson, A., Quigley, J., Henry, S. J., & Hall, C. (2014). Evaluating the selection, training, and support of peer support workers in the United Kingdom. *Journal of psychosocial nursing and mental health services*, *52*(1), 31-40.

Sinclair, A., Gillieatt, S., Fernandes, C., & Mahboub, L. (2023). Inclusion as assimilation, integration, or co-optation? A post-structural analysis of inclusion as produced through mental health research on peer support. *Qualitative Health Research*, *33*(6), 543-555.

Straßburger/Rieger (Hg.) Partizipation kompakt - Für Studium, Lehre und Praxis sozialer Berufe 2014: S.232f

Straßburger, G. & Rieger, J (2014). *Die Partiziaptionspsyramide*. http://www.partizipationspyramide.de/ (retrieved on October 20, 2025).

Tate, M. C., Roy, A., Pinchinat, M., Lund, E., Fox, J. B., Cottrill, S., ... & Stein, L. A. R. (2022). Impact of being a peer recovery specialist on work and personal life: Implications for training and supervision. *Community Mental Health Journal*, *58*(1), 193-204.

Toikko, T. (2016). Becoming an expert by experience: An analysis of service users' learning process. *Social Work in Mental Health*, *14*(3), 292-312.

Toolkit: Co-creating in Mental Health. Mental Health Europe (2022): https://www.mentalhealtheurope.org/wp-content/uploads/2023/05/MHE-Co-Creation-Toolkit-FINAL.pdf

Tse, S., Yuen, W. W., Murray, G., Davidson, L., Lai, Q., & Kan, A. (2019). Combining technical and expert-by-experience knowledge in the quest for personal recovery from bipolar disorder: a qualitative study. *BMC psychiatry*, *19*(1), 368.

Van Erp, N. H., Hendriksen-Favier, A. I., & Boer, M. (2010). Training and employment of consumer provider employees in Dutch mental health care. *Psychiatric Rehabilitation Journal*, *34*(1), 65.

Vandewalle, J., Debyser, B., Beeckman, D., Vandecasteele, T., Van Hecke, A., & Verhaeghe, S. (2016). Peer workers' perceptions and experiences of barriers to implementation of peer worker roles in mental health services: A literature review. *International Journal of Nursing Studies*, *60*, 234-250.

Walker, G., & Bryant, W. (2013). Peer support in adult mental health services: a metasynthesis of qualitative findings. *Psychiatric rehabilitation journal*, *36*(1), 28.

White, W., Boyle, M., & Loveland, D. (2005). Recovery From Addiction and From Mental Illness: Shared and Contrasting Lessons.

World Health Organization. (2025). Roadmap for Integrating Lived and Living Experience Practitioners Into Policy, Services and Community.

World Health Organization (2025). *With 17% of people in the Region living with a mental health condition, 31 countries commit to integrating mental health into all policies*. https://www.who.int/europe/news/item/16-06-2025-with-17--of-people-in-the-region-living-with-a-

mental-health-condition--31-countries-commit-to-integrating-mental-health-into-all-policies (retrieved on October 8, 2025)

World Health Organization (2025). *WHO launches roadmap for mental health services, steered by life experience*. https://ebs.publicnow.com/view/697E3D89FD7D850C3E88284E43D12E4E3A827B3D (retrieved on October 25, 2025).

Attachment

- READER (online)
- Job description
- Literature
- References to other resources/best practices

Partners roles and responsibilities

Annex - Survey questionnaire

Dear Colleagues,

Within the framework of the "MENTOR" project, we present a questionnaire aimed at gathering detailed information about the involvement of Persons with Lived Experience (PLE) in mental health services or in other sectors for each partner country involved in Task 5.3. The information may represent the entire country or be limited to specific regions or local districts within the country. The questionnaire is divided into several sections, each section addressing specific topics. We recommend you to ask for the collaboration of anyone you think could help in collecting the information required and with multiple expertise and knowledge may ensure a more comprehensive perspective.

The questionnaire has been developed by an Italian team and reviewed by colleagues from different European countries. Despite efforts to make the questionnaire as much as possible adherent to the national contexts of the countries participating in Task 5.3, we are aware that certain elements may be missing or not fully adapted to local situations. Therefore, we invite you to enrich the information you will provide with references, comments, and descriptions of experiences that might not have been considered or included in the questionnaire that will help in understanding the situation in your country. In particular, we encourage you to use the "other" option to provide additional information that you deem relevant and that is not covered by the options proposed.

For the purpose of the questionnaire, we use the acronym "PLE" throughout the questionnaire, though we know that different countries use different definitions and acronym. We apologize in advance if anyone feels unrepresented or excluded by this choice. Indeed, the collection of this information can be an opportunity to describe what definition and acronym is generated in relation to different contexts, profiles of activities and culture and together to reflect about the most appropriate terminology and about what seems more representative.

This questionnaire is part of the project's activities planned in the first-year. A complete and careful information is essential for a meaningful mapping of the existing experiences among participating countries, in order to produce an adequate plan for next project steps, consisting mainly in training proposals and pilot activities. We kindly ask you to dedicate your attention to it. Take the necessary time to collect the information. Do not hesitate to ask for our support or any clarification.

For any question or further clarification, please send a mail to michele.rocelli@unipd.it.

Thank you very much for your contribution and collaboration.

Summary of questionnaire

Section 1: Introduction

1. What is the term and the acronym used in your country to indicate a person with a direct personal experience of psychological suffering, who use his/her own experience to offer help, support, advice in mental health services or in other context? Please indicate all the acronyms and definitions existing in your language, for example in Italian we have the following three:

acronym	definition	English translation
ESP	esperto in supporto tra pari	Peer support expert
--	esperto per esperienza	Expert by experience
UFE	Utente e famigliare esperto	Expert as service user or family member

2. Is there a formally recognized profile/qualification in your country?

yes ☐ no ☐ don't know ☐

3. If yes, what is the name of this professional qualification? _____

4. The experience of PLEs can be offered in different roles, in clinical or psychosocial work, in trainings and education, in research…) Since how many years one or more of these roles have been present in your country?

In the field of addiction in the field of mental health

|__|__| |__|__|

We would like to invite you to offer your estimation about the number of PLEs acting in your country in the field of mental health or in the one of addiction; if you do not have an overall estimation for the country, you can also provide an estimate related to a specific territory (region, province, district, town…). If the estimate has been published somewhere, we kindly ask you to provide with the information source, in all the other cases, the estimate you will provide will remain confidential and will not be cited in future publications or documents. We need your estimation just for having an idea of the presence of PLEs in your country.

5. Approximately how many PLEs are involved in clinical or psychosocial work in your country?

in mental health |__|__|__|__|__| in addiction |__|__|__|__|__|

estimate is for _____ estimate is for _____

(country or the name of the region, province, district, town) (country or the name of the region, province, district, town)

don't know |__| don't know |__|

6. Approximately how many PLEs are involved in trainings and educational work in your country?

in mental health |__|__|__|__|__| in addiction |__|__|__|__|__|

estimate is for _____ estimate is for _____

(country or the name of the region, province, district, town) (country or the name of the region, province, district, town)

don't know |__| don't know |__|

7. Approximately how many PLEs are involved in research work in your country?

In the field of addiction in the field of mental health

in mental health |__|__|__|__|__| in addiction |__|__|__|__|__|

estimate is for _____ estimate is for _____

(country or the name of the region, province, district, town) (country or the name of the region, province, district, town)

don't know |__| don't know |__|

Section 2: Mental Health System: few descriptive elements

This section has not the ambition of describing in detail how the mental health system is organized in your country, how services are delivered, etc. The objective is rather to try to understand where, within your mental health organization, PLEs may play a role or are already included.

8. In your country, HOSPITAL care for mental health-related conditions is delivered in (multiple choices allowed):

□ Stand alone psychiatric hospitals

□ Psychiatric wards in general hospitals

□ Private psychiatric clinics

□ You do not have psychiatric hospitals, but exclusively psychiatric wards which are integrated into general hospitals

9. Has your country any formal limit in the maximum number of days of hospitalization? (“formal” meaning by national law, or according to regional/local recommendations, others..) yes ☐ no ☐

10. If you have limits, these apply for:

☐ Voluntary hospitalization, please indicate the maximum duration |__|__|__|

days, months, years

☐ Forced hospitalization, please indicate the maximum duration |__|__|__|

days, months, years

11. Do you know what is in your country the average number of mental health-related hospitalizations days? |__|__|__|__|__|

12. Are there in your country one or more of the following mental health services?

☐ Outpatient clinics

☐ Crisis resolution teams (CRT) i.e. a multidisciplinary mental health teams providing short-term, intensive home treatment as an alternative to acute hospital admission.

☐ Assertive community treatment (ACT) i.e. programs offering treatment, rehabilitation and support services, using a person-centered, recovery-based approach

☐ Community based team (CBT)

☐ other service, please describe: _____

_____

_____

13. What type of rehabilitation activities are provided in your country's mental health services? (Describe the main rehabilitation activities offered).

1) _____

2) _____

3) _____

4) _____

5) _____

6) etc. _____

14. Are there RESIDENTIAL rehabilitation services in your country, i.e. places where people live together in a community?

☐ None

☐ Yes, public

☐ Yes, private

☐ Yes, both

15. Does your country's mental health service collaborate with other public/private entities? (Which of the following entities are involved? Please provide examples for each one selected)

☐Municipalities; describe:_____

_____

☐Social sector; describe:_____

_____

☐Schools; describe:_____

_____

☐Associations/NGOs; describe:_____

_____

☐Families; describe:_____

_____

☐ Other describe:_____

_____

16. Access to mental health services:

☐ is direct/open access

☐ requires a referral procedure; If so, describe the referral and intake procedures, i.e. a GP or specialist prescription, payments, etc….

_____

_____

_____

17. Which service in your country is responsible for delivering treatment/ help/ support to people with alcohol related problems?

Name of the Service _____

18. Is this Service integrated with the Mental Health Service?

☐ yes, it is part of the mental health service

☐ no, it is a separate Service

☐ sometimes, please describe _____

19. Are there PLE of alcohol dependence in your country, working in peer support with persons with alcohol-related problems? yes ☐ no ☐ do not know ☐

20. Are you planning or interested in developing peer support in alcohol dependence with PLE with this type of lived experience? yes ☐ no ☐

21. Which service in your country is responsible in delivering treatment/ help/ support to people with illicit drugs related conditions?

Name of the Service _____

22. Is this Service integrated with the Mental Health Service?

☐ yes, it is part of the mental health service

☐ no, it is a separate Service

☐ sometimes, please describe _____

23. Are there PLE of substance use problems in your country, working in peer support with persons with illicit drugs related disorders? yes ☐ no ☐ do not know ☐

24. Are you planning or interested in developing peer support in substance use with PLE with this type of lived experience? yes ☐ no ☐

25. Which service in your country is responsible in delivering treatment/ help/ support to people with behavioral addictions (e.g., gambling, eating problems, internet addiction…) related problems?

Name of the Service _____

26. Is this Service integrated with the Mental Health Service?

☐ yes, it is part of the mental health service

☐ no, it is a separate Service

☐ sometimes, please describe _____

27. Are there PLE of behavioral addiction in your country, working in peer support with persons with this type of problems? yes ☐ no ☐ do not know ☐

28. Are you planning or interested in developing peer support in behavioral addiction with PLE with this type of lived experience? yes ☐ no ☐

29. Which service in your country is responsible in delivering mental health treatment/ help/ support in young people aged less than 18 years of age

Name of the Service _____

30. Is this Service integrated with the Mental Health Service?

☐ yes, it is part of the mental health service

☐ no, it is a separate Service

☐ sometimes, please describe _____

31. Are there experience of peer support in your country among young people aged less than 18?
yes ☐ no ☐ do not know ☐

32. Are you planning or interested in developing peer support among young people aged less than 18? yes ☐ no ☐

33. Are there users associations and self-advocacy groups in your country (at the national and local level)? If yes, please provide the name and website link: (add more rows, if needed)

Name Website

34. Are there family associations in your country (at the national and local level)? If yes, please provide the name and website link:

Name Website

35. Are there associations of both users and families together in your country (at the national and local level)? If yes, please provide the name and website link:

Name Website

36. Are there self-help groups in your country (at the national and local level)? If yes, please provide the name and website link:

Name Website

Section 3: Mental Health User/Survivor Research, Collaborative and Participatory Research

This section will explore the prevalence and institutional conditions of mental health user/ survivor research, collaborative and participatory research in the participating countries of the MENTOR project.

In the context of the project, we define these forms of research as research, in which people who receive(d) psychiatric treatments are either involved or which are undertaken by them.

In user-led/ survivor research, all researchers receive(d) psychiatric treatments, some of them have scientific qualifications, others do not. These researchers mostly are active in self-help, peer-support or advocacy, and thus bring individual and collective experiential knowledge to a research project. Synonyms used in this research field: patient research, positioned/ situated research, Mad Studies.

In collaborative research, psychiatric service users, mostly with academic training, work as part of research teams in academic institutions that mostly are led by research professionals without experiences as psychiatric patients. Synonyms for this research is: co-productive research, co-design etc.

Participatory research starts from conventional researchers (who have not received psychiatric treatments) that involve people with lived experience to collaborate. The latter, thus, usually do not have any academic degree nor prior research experience, the decision-making usually remaining in the hands of the conventional researchers. Common terms for this kind of research is: engagement, involvement, patient and public involvement etc.

Given these definitions, is there any kind of this research that is practiced in your country? If so, could you provide with the name(s) of the (non-)academic institutions/ initiatives/ persons by which this research is implemented:

User-led/ survivor research: _____

_____

Collaborative research: _____

_____

Participatory research: _____

_____

Section 4: Regulatory Framework and Socio-Cultural Context, enabling participation, and involvement of PLE

37. Indicate which of the following activities at your knowledge involve PLE in your country

(Davidson et al. 2018; Cooper et al., 2024)

(please rate from 0 to 4; 0=no activity; 1=rare; 2=frequent; 3=very frequent)

☐ Formal support groups: PLEs included in structured groups providing peer support under professional supervision.

☐ Informal self-help groups: PLE participating in or facilitating self-organized groups without direct involvement of professional staff.

☐ Mental health day centers: PLE involved in supporting and co-managing user services at day centers.

☐ Co-design services: PLE actively participates in the design and review of new mental health services or programs.

☐ Recovery projects: PLE engaged in recovery-oriented programs, providing support to users at various stages of their recovery journey.

☐ Participatory research: PLE as co-researcher in academic or institutional research projects on mental health services.

☐ School or community interventions: PLE is involved in raising awareness and educating about mental health in schools, communities, or organizations.

☐ Hospital collaboration: PLE working within hospital facilities to provide support to patients and mediate with healthcare staff.

☐ Information or listening services: PLE working at listening desks for users, families, and caregivers.

☐ Supervision of other PLE: PLE with more experience providing supervision and mentoring to less experienced PLE.

☐ Crisis intervention: PLE included in crisis management teams to provide immediate support to people in distress.

☐ Prevention and low-threshold programs: PLE involved in prevention, awareness, and risk reduction activities (e.g., addictions, suicide).

☐ Collaboration with housing services: PLE integrated into housing support projects for people with mental health issues.

☐ Participation in advisory boards or committees: PLE contributing to advisory boards or committees overseeing mental health services.

☐ Other: (specify)

_____

_____

38. How PLE have been integrated into active mental health services in your country? (Foglesong et al., 2022)

(Select all the options that apply to the reality of your country)

☐ Peer supporter: PLE provides direct support to service users based on their lived experience.

☐ Advocacy and representation: PLE acting as user representatives, defending their rights and promoting changes in mental health services.

☐ Proximity work and accompaniment: PLE offers direct support, accompanying users in their care pathways and community integration.

☐ Interaction with other services: PLE facilitates connections between users and available services, promoting better interaction among various mental health and social services.

☐ Working within the team: PLE participates as members of the clinical team, actively collaborating with professionals to provide experiential insights into decision-making processes.

☐ Facilitation of support groups: PLE leading and facilitating support groups for users, promoting mutual help and experience sharing.

☐ Testimonial activities: PLE sharing their personal experiences with other users, families, or professionals as part of educational or awareness activities.

☐ Health promotion and anti-stigma: PLE conducting activities promoting mental health and participating in initiatives to reduce the stigma associated with mental disorders.

☐ Co-design of services: PLE collaborates with professionals in designing or reviewing services, contributing based on personal experience.

☐ Participatory research: PLE participate as researchers or collaborators in studies on mental health services.

☐ Assistance in case management: PLE supports the clinical team in case management, offering experiential perspectives in user interactions.

☐ Mentoring: PLE provides individual support to new users or people in transition phases of their mental health journey.

☐ Treatment planning: PLE collaborates with clinicians and users in defining personalized treatment goals and plans.

☐ Mental health education: PLE conducts educational programs for users, families, and communities on mental health topics.

☐ Support during service transition: PLE helps users during discharge and transition out of mental health services, providing guidance and continuous support.

☐ Mediation: PLE acting as mediators between users and mental health professionals, helping to resolve conflicts or misunderstandings.

☐ Reception activities: at mental health services and activities of front office, orienting users upon first entry, informing, facilitating relationships with professionals.

☐ Other: (specify)

_____

_____

39. Are there official documents, such as recommendations, standards, or laws, that support the inclusion of PLE and facilitate the introduction of these roles in mental health services in your country or other sectors?

If yes, attach or describe some of the main legislative and regulatory documents related to this area.

_____

_____

_____

_____

40. What socio-cultural, economic, or political factors have most influenced the implementation or transformation of peer support services in your country?

(Rate from 1 to 5, with one being a low relevant and five high relevant influential factor) (Davidson et al., 2018; Lyons et al., 2021)

|__| Legislative changes: New laws or regulations that support or hinder the integration of peer support into mental health services.

|__| Availability of funding: Increase or decrease in public or private funds allocated to peer support programs.

|__| Social stigma: The social perception of people with mental health problems or addictions, which can affect the acceptance of services.

|__| Cultural evolution: Changes in beliefs or cultural values regarding mental health and peer support.

|__| Activism and social movements: The role of advocacy groups or social movements in promoting the rights and inclusion of people with lived experience.

|__| Initiative run by single individuals: (PLEs and/or professionals) or small groups who have played a driving role in promoting the inclusion of PLEs

|__| Technological innovations: The use of technology (e.g., online platforms) to facilitate remote or digital peer support.

|__| Pandemic or health emergencies: Global health crises, such as the COVID-19 pandemic, have changed access to peer support services.

|__| Changes in welfare policies: Social assistance policies that influence access to and quality of peer support services.

|__| Inter-institutional collaboration: Partnerships between public entities, NGOs, and private sectors for implementing peer support services.

|__| Economic pressures: Economic crises or austerity policies that reduce the resources available for mental health services.

|__| Inclusion policies: Governmental or social initiatives to promote diversity and inclusion in mental health services.

|__| Education and training: Availability and accessibility of training programs for peer support workers.

|__| Local or community initiatives: Peer support projects developed at the local or community level, reflecting the specific needs of a given population.

|__| Demographic changes: Population changes, such as aging or immigration, require new approaches to peer support.

|__| Pressure from the stakeholders: Actions by political parties or groups of interest that influence mental health policies.

|__| Influence of international experiences: Influence of models or practices from other countries in designing and implementing peer support services.

|__| Other: (specify)

_____

_____

_____

_____

41. In your opinion, what are the barriers to implementing services or strategies involving PLE in your country?

(Rate from 1 to 5, with 1 as low relevant and 5 as high relevant barrier)

|__| Cultural barriers: Resistance related to stereotypes, stigma, or prejudice towards people with lived experience in mental health contexts.

|__| Organizational barriers: Internal structures of services that do not support or facilitate PLE integration, such as lack of resources or operational protocols.

|__| Legal barriers: Constraints related to regulations or norms that make it difficult to employ or collaborate with PLE formally.

|__| Lack of training: Absence of training programs for PLE or staff on the roles and methods of collaboration between professionals and PLE.

|__| Staff resistance: Opposition from healthcare workers or professionals to working with PLE due to trust or respect for roles.

|__| Inadequate funding: Lack of funds to support programs that structurally and sustainably include PLE participation.

|__| Communication barriers: Difficulty in communication or mutual understanding between PLE and healthcare professionals.

|__| Lack of role clarity: Ambiguity or overlap in the roles of PLE and professionals can create conflicts or inefficiencies.

|__| Issues related to legal responsibility: Concerns regarding risk management or responsibilities related to involving PLE, like for example confidentiality, accident during work…

|__| Technological barriers: Difficulty integrating PLE into services using technological or digital tools, such as online support platforms.

|__| Lack of political support: Absence of government policies or guidelines promoting or encouraging PLE participation in services.

|__| Economic barriers: PLE may not be sufficiently compensated or economically supported, limiting participation.

|__| Social inclusion issues: Difficulty involving PLE from disadvantaged or marginalized groups due to cultural, linguistic, or socio-economic differences.

|__| Other: (specify)

_____

_____

_____

_____

42. To your knowledge, are there areas or activities within mental health services where Persons with Lived Experience (PLE) cannot be involved due to explicit legal or service policy restrictions?

If yes, which areas or activities are involved? and what are the reasons for these restrictions?

_____

_____

_____

_____

Section 5: Best Practices

43. Are there significant activities (best practices) in your country regarding the involvement of PLE in mental health services that you would like to report?

(Describe them briefly and provide links or publications, documents, grey literature on the experience, if available.) (Cooper et al., 2024; Foglesong et al., 2022)

_____

_____

_____

_____

_____

_____

_____

_____

44. Has your country developed guidelines for peer support in communities or mental health services? If yes, could you provide a copy/document available? (Awadalla, 2023)

Section 6: Training

45. Are there specific training programs in your country for PLE? or are there trainings on the inclusion of PLE addressed to MH or other Service professionals? or to other stakeholders?

(World Health Organization, 2021; Brinkely & Volpe, 2024)

(Indicate if training experiences are available and to whom they are addressed)

☐ PLE with experience in mental health

☐ PLE with experience in addiction

☐ PLE with other type of experience, please specify _____

☐ family members of PLE

☐ Mental health professionals

☐ Professionals from other sectors, such as _____

☐ Trainings for trainers in this field

☐ Other _____

46. Could you provide details?

Training name;

Location:

Target audience (PLE, MH professionals, other professionals, please specify):

Organizing Institution:

Selection criteria:

Training organisation (hours of training; duration months: stage/apprenticeship, etc.)

In presence/ online/ residential/ mixed

Nb of participants

Cost

Main content

Theoretical approach

Type of certification at the end of the training

PLE involved as trainers

link

Training name;

Location:

Target audience (PLE, MH professionals, other professionals, please specify):

Organizing Institution:

Selection criteria:

Training organisation (hours of training; duration months: stage/apprenticeship, etc.)

In presence/ online/ residential/ mixed

Nb of participants

Cost

Main content

Theoretical approach

Type of certification at the end of the training

PLE involved as trainers

link

add more boxes, if needed

Section 7: Contracts

47. What Do PLEs receive any form of payment for the activities performed? If so, in what form? (Select all applicable options) (World Health Organization, 2021)

☐ 1 Permanent contract

☐ 2 Fixed-term contract

☐ 3 Occasional collaboration

☐ 4 Paid internship

☐ 5 Project collaboration contract

☐ 6 Partnership with associations or NGOs

☐ 7 Freelance or self-employment contract

☐ 8 Other: (specify) _____

☐ 9 Volunteering with reimbursement of expenses

☐ 10 Volunteering without reimbursement of expenses

48. Which of the above is the most common type of payment or reward for PLEs in your country? (indicate the corresponding number, not more than two) |__| |__|

49. What is the average hourly payment in euros received by PLE working in mental health services in your country?

|__|__|__|,|__|__|€

50. What is the average number of hours per week worked by PLE in those contracts?
|__|__|

51. What is/are the professional qualification/s used?_____

don't know ☐

52. Are there funding sources for training costs? yes ☐ no ☐ do not know ☐

53. What funding sources are used for training costs

☐ Public funds (e.g., regular resources of the National Health Service)

☐ Donations (private subjects, foundations, etc.)

☐ Internal budgets for Services

☐ Dedicated project funds (e.g., European calls, national calls)

☐ Other, describe: _____

54. Are there funding sources for PLE Contract Payments yes ☐ no ☐ do not know ☐

55. What funding sources are used for PLE Contract Payments

☐ Public funds (e.g., regular resources of the National Health Service)

☐ Donations (private subjects, foundations, etc.)

☐ Internal budgets for Services

☐ Dedicated project funds (e.g., European calls, national calls)

□ Other, describe: _____

Section 8: Evaluation and Monitoring

56. Is there in your country any form of evaluation activity to monitor the effectiveness of PLE participation? yes □ no □ do not know □

57. If yes, what is the level of involvement of PLEs in the evaluation process? (please describe, for example PLEs participate in designing the evaluation project, conduct interviews, collect data, participate in the analysis, etc..))

_____

_____

_____

_____

58. What evaluation tools (e.g., questionnaires, focus groups, data collection, etc.) are used to monitor the effectiveness of PLE participation in mental health services? (Watson & Meddings, 2019)

_____

_____

_____

_____

59. Do you know if there are in your country experiences of evaluation activity entirely and independently implemented by PLEs?

yes, there are □ no, there are not □ do not know □

60. If yes, please provide references (link, documents, reports…)

_____

_____

61. How are evaluation results used to improve PLE participation or adapt mental health services? (Watson & Meddings, 2019)

Section 9: Publications and Research

62. Are there publications or research (at the local, regional, or national level) that document the impact of PLE involvement in mental health services in your area? If yes, please provide references (link, documents, reports…).

_____

_____

Bibliography

Davidson, L., Bellamy, C., Chinman, M., Farkas, M., Ostrow, L., Cook, J. A., ... & Salzer, M. (2018). Revisiting the Rationale and Evidence for Peer Support. Psychiatric Times, 35(6).

Awadalla, D. (2023). National Model Standards for Peer Support Certification.

Brinkely, A., & Volpe, J. (2024). Peer Support Services Across the Crisis Continuum.

Lapidos, A., Jester, J., Ortquist, M., Werner, P., Ruffolo, M. C., & Smith, M. (2018). Survey of peer support specialists: Professional activities, self-rated skills, job satisfaction, and financial well-being. Psychiatric Services, 69(12), 1264-1267.

World Health Organization. (2021). Peer support mental health services: promoting person-centred and rights-based approaches. World Health Organization.

Foglesong, D., Knowles, K., Cronise, R., Wolf, J., & Edwards, J. P. (2022). National practice guidelines for peer support specialists and supervisors. Psychiatric Services, 73(2), 215-218.

Cooper, R. E., Saunders, K. R., Greenburgh, A., Shah, P., Appleton, R., Machin, K., ... & Johnson, S. (2024). The effectiveness, implementation, and experiences of peer support approaches for mental health: a systematic umbrella review. BMC medicine, 22(1), 72.

Lyons, N., Cooper, C., & Lloyd-Evans, B. (2021). A systematic review and meta-analysis of group peer support interventions for people experiencing mental health conditions. BMC psychiatry, 21(1), 315.

Watson, E., & Meddings, S. (Eds.). (2019). Peer support in mental health. Bloomsbury Publishing.

National Ethical Guidelines and Practice Standards National Practice Guidelines for Peer Supporters Recovery is a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential. SAMHSA Working Definition of Recovery (2011).


MENTOR
Building Mental Health
and Well-being Together