



**Mental  
Health  
Europe**

Equal rights.  
Better mental health.  
For all.

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# Guidelines for Co-Creation in Mental Health



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## Disclaimer

These materials are intended to assist any stakeholder – individuals and organisations - as they strive to co-create in mental health. The use of these materials should include a formal acknowledgement to the source. None of these materials may be changed or adapted without the express written authorisation of Mental Health Europe.

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# Background and Purpose of the guidelines

Mental Health Europe's co-creation approach consists of a comprehensive framework to support empowerment of diverse stakeholders - people with lived experience, practitioners, academics, non-governmental organisations, policy and decision-makers - providing insights, practical tools and good practices for effective engagement in mental health co-creation.

Our co-creation approach is embedded in the vision of mental health in the context of a **human rights framework** and the **psychosocial model**. At Mental Health Europe, we align with the World Health Organisation's (WHO) definition of mental health: *"a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community"*<sup>1</sup>. Mental health must be seen in its entirety, as a continuum from good mental health to psychosocial disability.

'Psychosocial disabilities' is an internationally recognised term, enshrined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). It is used to describe the experience of people who experience mental health problems which, in interaction with various societal barriers, can 'disable' them and hinder the realisation of their rights and their full participation in society. This perspective recognizes that any individual can transition along this continuum at any point during their lifetime. According to the human rights approach, it also implies that persons with psychosocial disabilities are "subjects of rights" rather than "objects of care".

The psychosocial model addresses the issues of increased vulnerability to mental health problems deriving from socio-economic determinants like poverty, social isolation, inequality, stigma and discrimination. The evolution of knowledge on these subjects shows how adopting a human rights approach in mental health can help fulfil the fundamental right to health and break down the societal barriers that lead to psychosocial disability.

Co-creating in mental health, when understood and implemented in a consistent way is conducive to undertaking initiatives, services and practices that fulfil human rights related to mental health and psychosocial disabilities and that address socio-

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<sup>1</sup> WHO, <https://www.who.int/data/gho/data/major-themes/health-and-well-being>

economic determinants in addition to personal life experiences. This is because co-creation places the power among participants, valuing diverse expertise equally. This approach transcends mere checkbox exercises; it is a cornerstone for effective mental health policies and practices. Co-creation is not just about outcomes; it is a dynamic journey of growth and discovery, embracing change throughout the process.

These Guidelines on Co-creation in Mental Health complement Mental Health Europe's **Toolkit: Co-creating in Mental Health**, which provides core principles, a training methodology, and planning and evaluation tools. The Toolkit is available [on our website](#). The Guidelines outline how co-creation can benefit various stakeholder groups and individuals; they offer testimonies from actors who engaged in the process of co-creation, as well as examples of good practices of co-creation in mental health in different settings.

The Guidelines were developed by Mental Health Europe's Co-creation Task Force consisting of experts by experience, advocates, health and social care actors, educators and researchers who contributed to all aspects of the Guidelines' development in the true spirit of co-creation. This is a living document that will be reviewed in the future to incorporate new insights, learnings and promising and good practices. Since co-creation is a dynamic approach, likewise guidance on co-creation has to evolve to reflect new evidence and ultimately remain responsive to needs. We therefore encourage feedback from all stakeholders as well as contributions to testimonies and good practices.

## A word about language

These Guidelines make use of terms that reflect Mental health Europe's human-rights based approach as well as our embracing of the psychosocial model of mental health. Furthermore, Mental Health Europe believes that words can guide the change we want to make. The way we talk about mental health and people experiencing mental health problems can hurt, discriminate, and reinforce negative stereotypes and de-stigmatisation in the field of mental health begins with the use of words.

We therefore recommend the reader to refer to Mental health Europe's glossary **['Mental Health: The Power of Language' – A glossary of terms and words](#)**<sup>2</sup> to get

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<sup>2</sup> <https://www.mentalhealtheurope.org/wp-content/uploads/2023/10/MHE-Glossary-of-terms-and-Definitions.pdf>

insights on some of the terms used in these Guidelines, discover the meanings and history behind them and why Mental Health Europe has decided to use these rather than others.

## Who are these guidelines for?

These Guidelines are meant for all stakeholders who play a role in the field of mental health as per Mental Health Europe's approach of addressing mental health according to a human-rights framework and the psychosocial model. Consequently we intend stakeholders in all fields linked to or having an impact on mental health; not only healthcare but also social welfare, economy, education, employment, environment, migration, culture, research to name the main ones.

Each stakeholder is likely to face the same challenges when starting to apply a co-creation approach as this requires questioning and rethinking roles as well as working culture and methods. This change is not an easy one, but the other side of the coin brings benefits and advantages as shown by evidence in the literature and as described in the testimonies and good practices included in these guidelines.

We describe in this section how some of the key stakeholders in mental health can take advantage of co-creation in their own work and to the benefit of the individuals and communities they represent and/or work with. This is not intended to be an exhaustive overview of stakeholders, as any initiative in mental health implemented through a co-creation approach needs to do its own comprehensive and inclusive mapping of the stakeholders to engage. What is certain is that co-creation implies actively engaging a wide range of stakeholders to harness their unique expertise and contributions, which is essential to ensure that mental health undertakings are person-centred, evidence-based, and responsive to the evolving challenges and opportunities in the mental health landscape.

Finally, we recommend that you use these guidelines to embed cocreation as a way of working in your organisation and also extend the cocreation process when engaging in external partnerships, projects, programmes, service developments.

**Policy and decision-makers** Policy making is an inherently political process necessary for the execution of political powers in democratic systems. Decision and policy makers are naturally among the most influential groups in the mental health area as they are responsible for formulating mental health policies, allocating resources, and establishing the regulatory framework that governs the sector. Too often, these decisions are taken without the proper participation of other relevant parties, particularly those who will be directly impacted. At times, even when consultations take place, they may not have an impact on the outcome of the policy

and decision-making processes. This may be due to a tokenistic approach or lack of know-how on how to implement participation effectively.

Co-creation in policy making presumes the generation of sound policies by mobilising human and technical resources to engage communities and ensure political legitimacy of the outcomes (Nabatchi et al. 2017). Co-creation can increase the political capital of policy makers providing significant advantages for public service, communities and the population in general. However, putting together multiple stakeholders is a complex task and asymmetries emerge in access to these initiatives due to different degrees of education, income, knowledge, interest and power (Goulart & Falanga, 2022). Even when co-creation is taken as a guiding principle in policy making, the participation of stakeholders usually falls short of the criteria for successful implementation of co-creation. This is because policy making holds a position of power that belongs to the policy makers and is legitimated by the democratic process of elections. That is why stakeholders in policy making usually have an advisory role, while the decisions are made solely by policy makers.

For policy making to be successful through co-creation, two premises must be fulfilled. First, stakeholders in policy making must be aware of the limitations of every political process when it comes to participation and that, often because of formal reasons (e.g., in legislative processes) the decision making would rightfully belong to the elected officials. Second, policy makers must be ready to share their political powers with all the stakeholders on the equal basis. This means that not only these stakeholders will participate in guiding how a certain policy shall be developed, but that they will also have the ownership over the policy itself. In this way public policies and decisions can be informed based on real evidence and expressed needs from the communities. This will avoid a biased construction of policy making and, consequently, policy makers ought to consider co-creation not only as a guiding principle, but as a methodological framework in approaching the development of any policy impacting mental health.

**Experts by experience and their supporters** Persons who have lived experience of mental health problems as well as members of their support network can be significantly empowered by co-creation making true the motto "Nothing about us, without us". Due to systemic power imbalances, the voice of those who are ultimately impacted by mental health-related policies and models of care tends to be unheard. Co-creation brings their unique and much needed perspective to the table, where personal narratives and experience matter and can be at the core of improving their and their peers' quality of life, including reducing stigma and discrimination.



*Miloš Šviderský - Person with lived experience, Slovakia*

*Miloš participated to an extensive co-creation process aimed at rethinking and changing the set up and provision of mental health services in the country.*

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*“The opportunity to participate in co-creation was empowering for me, this was giving me the feeling that I belong somewhere and that I am being a part of something bigger and important because this is what helps people who are suffering. I had an opportunity to meet various people, to get inspiration by their personal experiences and mostly to experience the feeling that I am not alone”.*

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Too many experiences of tokenistic involvement have discouraged experts by experience taking their right place in making decisions about policies, services and more. These Guidelines will help them and their supporters highlight the benefits and advantages of their participation – in addition to participation being a fundamental human right - and, used together with our Toolkit on co-creation, pave the way for true meaningful inclusion of all relevant perspectives in mental health.

**Health and social care professionals** This is a very broad group including different profiles from direct service provision to management at different levels of health and social care systems, from a micro to a macro level. In the past decades there have been various forms of involvement of experts by experience in healthcare (co-production, co-design; etc.) with different degrees of success. Health and social care professionals can build on those experiences by embracing co-creation, thus enlarging the range of stakeholders they cooperate with to assess, rethink and reorganise service provision to the benefit of both existing and potential users. The co-creation process enables the development of customised solutions for the healthcare system (Stock, C., Dias, S., Dietrich, T., Frahsa, A., & Keygnaert, I. 2021). No standardised procedures can be used optimally to adapt new care services to the needs and lived experiences of people as well as to the increasing demands of health and social care services in a flexible and effective way. These guidelines can support this group in advocating for cultural, practice and system’s change with their peers, their hierarchy and the competent authorities.

*Safia Akram - Person with lived experience and Project  
Manager for mental health services at NHS, United  
Kingdom*

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*"I think often you get groups of academics and professionals, you know, with academic hat, many qualifications, but yet, on a lower level they're not able to converse with individuals as a human. And I think sometimes that power dynamic comes into play, automatically or not, unfortunately... So, it's that power dynamic where people who were being previously excluded from services and experienced bad experiences of mental health or social welfare or any experiences with statutory involved sector, don't feel confident to speak up to this audience, because they are seen as more powerful, more important...*

*So, there's that power dynamic that comes into play, but in...co-creation everybody is an equal. Or should be equal and I think that's where you get the best results".*

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**Researchers and academia** through their work inform evidence-based prevention and care policies, practices and programmes as well as treatment guidelines and more. Co-creation can help them shift the perspective from studying and teaching about peoples' experience, to teaching, learning and researching with people with said experience. This brings research and its outcomes closer to the needs of people with lived experience as well as the general population with regard to mental health promotion and prevention. It can also help professionals in the education field to teach more inclusively and give them tools to lessen the stigma around mental health and mental health issues.

**Civil society** includes very diverse organisations that play a vital role in raising awareness, reducing stigma, advocating for mental health policy reforms and often providing services: community-based associations, advocacy organisations, youth and sport centres, support groups, just to name a few. Collaboration with these entities ensures that co-creation efforts benefit from the expertise and insights of

those deeply involved in the community. These organisations are usually proactive and vocal in making their perspective known even in complex circumstances. They can definitely make good use of the opportunities co-creation gives to strengthen their role and will benefit from using these Guidelines and the Toolkit both internally to develop/increase their own capacity as well as externally in promoting a co-creation approach to other stakeholders.

*Andrej Vršanský – CEO, Mental health League, Slovakia*

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*“The essence of our co-creation project was to create a safe, accepting space in public meetings where people with lived experience, relatives, professionals, local government representatives or people interested in the mental health care system and services could meet and discuss what they need, what they don't need, what their issues are, what they suggest, and therefore what their ideas are about how the mental health care system should work and to map these experiences, suggestions and needs. We were able to achieve these goals”.*

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# Why you should co-create in mental health

Let's acknowledge it, co-creating is not easy and arguments and reasons for not engaging in co-creation are known. Being inclusive and involving all parties that have a stake on equal terms requires time and investment of resources. For many it is simpler to keep the status quo, continue business as usual, without questioning the need to change the way of doing things.

People with mental health problems and psychosocial disabilities could refrain from engaging due to self-stigma, fear of being discriminated or be involved in a tokenistic way, lack of time and/or capacity to engage if on a voluntary basis, accessibility issues, and their health status.

Another challenge is the lack of understanding of what can be done in a co-creation approach and how to do it. People and organisations may have no previous experience and find it difficult to navigate the existing frameworks and tools and to use them in practice within their sector or work environment.

Finally, there may be insufficient evidence of positive outcomes of co-creation in different areas as the application of co-creation in the mental health field has been limited outside of the service provision area.

Whatever the issue, any challenge can be overcome with the commitment of all parties engaged and co-creation should be seen as bringing a good "return on investment". Stakeholders should move from the status quo of top-down "one size fits all" interventions and strategies to interventions based on bottom-up co-creation with a diversity of views.

There are two fundamental reasons that make co-creation an important approach in the area of mental health: the first one is linked to human rights and the second to the benefits it brings in terms of results, impact and ownership of those.

## The human rights perspective

The right to participation is the basic and fundamental right of people to have a say in how decisions that affect their lives are made. Political and public participation is a cornerstone of every democratic system. There are also participation frameworks and instruments for other contexts and for specific groups, e.g. several provisions in

the Convention on the Rights of the Child are about children’s participation. Article 4 of the 1978 Declaration of Alma-Ata on Primary Health Care states that “people have the right and duty to participate individually and collectively in the planning and implementation of their health care.”

When it comes to mental health and participation, it is primarily about the right to participation of people with mental health problems and psychosocial disabilities that we naturally focus on without forgetting their supporters.

The full and effective participation and social inclusion of people with mental health problems and psychosocial disabilities is primarily reflected in the general principles of the United Nations Convention on Rights of Persons with Disabilities (UNCRPD). This principle is intrinsically connected with other human rights in the applicable international law; of particular interest for these Guidelines are those of equality and non-discrimination and participating in political and public life. The UNCRPD Committee recognizes that the active and meaningful involvement of persons with disabilities resulted in achieving a ground-breaking human rights treaty and established the human rights model of disability. Consequently, international human rights law now recognizes unequivocally persons with disabilities as “subjects” of all human rights and fundamental freedoms and demands their meaningful participation in all the processes concerning them. The notion “Nothing about us, without us” is now a cornerstone of international human rights law.

*Enrico L. - Member of Clubhouse Club Itaca Milan (Italy)*

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*“Working in co-creation is definitely useful and enriching because we, as Clubhouse members, can participate in every step of the project design process. Without listening to us, staff wouldn't know whether the beneficiaries would be interested in a certain project. Working together allows us to understand which direction to take”.*

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*Gina Delaney - Development Officer, Mental Health  
Ireland and family lived experience, Ireland*

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*"I think that co-creation is important because it gives people who have lived experience the chance to influence best practise because we know best what works and what doesn't work, and then people who are making decisions can use that information to make better decisions".*

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Co-creation holds the participation and empowerment of people with lived experience as its pillar. It does however go further affirming the principle that also other actors playing a role in mental health need to participate and be empowered to work not only with experts by experience, but also with each other.

## Benefits of co-creation

Co-creation provides a range of benefits to all concerned. These benefits come from a macro or organisational level and/or a micro or personal level as illustrated by literature and the testimonies collected from persons from different stakeholder groups who participated to activities done via a co-creation approach.

**Creating shared value** - The co-creation approach, by enabling all concerned parties to contribute helps creating shared value, usability of results and sustainability.

*Elena Meta Adejevaite - Clinical psychologist at public hospital Saint Rokas, Vilnius, Lithuania*

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*“There are not many workshops like that. This kind of method with different groups presenting their ideas is very important for both the working environment and the results. Our views were taken on board”.*

*Elena definitely recommends the co-creation approach.*

*She acknowledges working in co-creation can be challenging for some people, particularly for professionals if they are not used to this approach and also if they come from very different fields. The main benefit Elena sees in co-creation is “to feel that I am not alone facing certain issues and having ideas about what could be changed and be able to talk about it and share.*

*The possibility to hear about others’ experience and discuss my own and search for solutions together is the main benefit, but not only that. The second aspect is knowing that these discussions will be taken on board by those who led this activity, and they will translate it into some concrete action. Knowing this adds value to the experience”.*

*Elena thinks that the co-creation approach is important because, no matter the field you work in or your profession, you are bringing your perspective, and each one brings in something different. This diversity of opinions is important to see the same issue from different angles. It is also about equality and there is still a lot to do to address inequalities with certain professions. It is how people see others; “I see the person and interact with the person independently of what their profession is”.*

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Stimulating innovation - Co-creation challenges the old ways of “doing things”, thus facilitating innovation. With each party contributing a different perspective to a posed question or issue co-creation leads us to think differently and approach issues from different angles.

*David Dwyer - Involvement Centres Coordinator,  
Community Health Care South-East, HSE and lived  
experience of mental health and addiction recovery,  
Ireland*

*David's experience in co-creation relates to recovery  
education and some research.*

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*“...the benefits I see of co-creation... it's that shared  
understanding and the shared learning and... creating  
new forms of knowledge tapping into people's  
experiences. You know, I've seen it in action. You know  
the knowledge that gives rise to, and it makes it  
easier...to influence change within services when more  
voices are heard...”*

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Achieving effective and meaningful outcomes – Bringing all the perspectives to the table helps understanding not only the needs of the ultimate beneficiaries, but also of those that play a role in achieving impact. By better understanding needs co-creation is conducive to envisaging solutions that bring real changes.

For instance advantages of co-creation in mental health services not only include improved health outcomes and increased mental health literacy for people with mental health problems (Piper & Emmanuel n.d.). Such literacy also relates to staff who through co-creation can learn how to successfully communicate with service users (Jones *et al.* 2020) ultimately improving service provision. This not only empowers and provides confidence to service users, but it also supports individuals to rewrite and successfully navigate their own recovery journey (Spencer *et al.* 2013; Ewert and Evers 2014; Thorneycroft and Dobel-Ober 2015; Fisher *et al.* 2018; Norton 2021).

Other advantages of co-creation from an organisation perspective are observed through hospital admission statistics. Spencer *et al.* (2013) identified a 30% reduction



in emergency presentations and a 50% decrease in hospital admissions as a direct result of co-creative activity. In this way, co-creation has been noted to improve service delivery which inadvertently improves service outcomes (OECD 2011). This is possible as co-creation transforms the therapeutic relationship so that it is more user inclusive thus providing ownership of one's recovery journey (Pestoff 2013). Interestingly, co-creation also has economic and recovery benefits (Department of Health 2006).

*Isabella G. - Counsellor, Clubhouse Club Itaca Milan staff  
worker*

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*"...working in co-creation also helps to improve the recovery journey of Clubhouse members. From a perspective of personal recovery, Clubhouse daily activities help members to develop self-esteem, personal empowerment, new skills and the ability to carry out projects. Therefore, it certainly helped our organisation, but it also helped individual people. These two aspects are inextricably linked. It is a virtuous process".*

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Building longer term partnerships – The kind of joint interaction and links that co-creation creates can nurture partnerships going beyond the specific activity or project and inspire future cooperation.

*Belinda Coyle - Family Peer Support Worker, Community Health Care South-East, HSE and family lived experience,  
Ireland*

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*"...You're learning shared learning but also you're building trust and cooperation and... the most important thing is you build a lot of friendships..."*

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Personal and professional growth – Co-creation has many advantages for the individual (Bovaird and Loeffler 2013). The mutual learning taking place in a co-creation process is enriching at both personal and professional level supporting for

example the improvement of self-awareness, soft skills, technical knowledge and professional networks.

In the case of people experiencing mental health problems, it could even help reach career goals despite the presence of those problems (Boyle et al. 2006; Salisbury 2020). For example, co-creation of lectures on mental health can open opportunities to be part of a teaching team; or co-creating recovery workshops can prepare individuals for employment as peer educators and other recovery educational roles.

*Dario L. - Member of Clubhouse Club Itaca Milan, Italy*  
*Isabella G. - Counsellor, Clubhouse Club Itaca Milan staff*  
*worker*

*Dario is a graphic designer who, after his complicated last job experience decided to take some time to take care of his mental health. He has been involved in the co-creation experience of Club Itaca Milan's magazine called "Odissea del Mese". Clubhouse staff and members participate and equally contribute to the co-creation and co-planning of each magazine issue.*

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***Dario:** "Working in co-creation for our magazine helped me personally and our organisation as well. It helped me refine my social and graphic skills in multiple ways: I had the chance to interface myself in new and challenging work relationships, acquire new technical and digital skills, learn new tools. Working in co-creations helped me improve my soft skills and establish new effective and productive relationships with other Clubhouse members and staff. This co-creation process helped our organisation and magazine as well. It also allows every Clubhouse member to communicate openly and often, to express themselves and build positive relationships. This experience is a great example of co-creation and teamwork. Moreover, working together on our magazine sparked an interest in writing in many Clubhouse members and helped them engage in this activity".*

*Isabella: “Working in co-creations certainly benefited me personally because the Clubhouse psychosocial rehabilitation model is based on both staff and members’ competence, participation and motivation; therefore, there is a real exchange of ideas, skills and information in everyday life within our Clubhouse. So I personally think it's a very enriching job for all parties involved”.*

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*Dario strongly supports the co-creation approach:*

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*“In my opinion, working in co-creation is essential to achieve goals and the intended results. It teaches you how to properly work in a team. A shared leadership has been essential to achieve our intended results. We managed to achieve many goals because everyone had the possibility to express himself and felt listened to. Working in co-creations means that every proposal, idea or feedback has an equal value, and that every opinion is respected and listened to”.*

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Reviewing biases – Within relationships, co-creation allows everyone to remove the labels attached to them so that all are welcome at the table (Ewert and Evers 2014; NHS England 2015). The opportunity of getting insights on other parties’ perspectives favours reconsidering prior opinions and perceptions on their role and work. In the case of people with lived experience of mental health problems or psychosocial disabilities this may get as beneficial as to decreasing stigma and discrimination – real or perceived – towards them as individuals and towards the role of the constituency they represent.

*Melina Waelle - Expert by experience and health  
professional, Switzerland*

*Since 2018 Melina uses practice situations to teach students about her lived experience with mental health problems and recovery. She has been involved in the co-creation process to create the course "Person-Centered Mental Health" in a Competence Centre for Mental Health. She participates to lectures together with University teachers.*

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*"It is always noticeable that my experiential knowledge is placed on an equal footing with the expertise of the professionals. I received support in the area of didactics since I have no training in this area. I am very grateful for the opportunity to pass on my experience to the students at the highest level."*

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*Melina's view on the importance of co-creation:*

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*"It is important to consider every perspective. The studies/research and subject teaching materials are important for good education to professionals. However, the lived experience is equally important because it critically reflects the subject perspective." And thinking of outcomes: "Through co-creation, a CAS course has now been created where the professional perspective and the lived experience perspective are teaching on equal footing. Working together on this is the right way for the best possible support for people with mental health problems."*

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# Mental Health Europe Co-creation

## Approach

### What do we mean by co-creation?

Co-creation is relatively a new term compared to the more known and used 'coproduction'. Coproduction concepts and related definitions started appearing in the literature as far as 1977 in relation to goods and services in general as well as more specifically with regard to public services and also healthcare. With time the concept has been enriched with principles, values and other criteria to define different types or levels. According to the literature co-creation is a component of the broader concept of coproduction.

Due to this diversity of definitions and frameworks and to the lack of one capturing our vision of co-creation, Mental Health Europe has endeavoured to develop its own definition and framework. Most importantly, this work falls within our overall approach of promoting positive and empowering language and communication on mental health.

#### **Mental Health Europe's working definition of co-creation:**

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*A collaborative approach involving all actors in mental health working together on an equal basis to develop and implement policies, services, programmes and communication that foster positive mental health according to a psychosocial model and human rights-based approach.*

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## Principles of co-creation

Mental Health Europe's definition of co-creation is underpinned by seven principles.

- 1 Inclusivity** Co-creation is representative of all groups having a stake and ensures diversity
- 2 Equality** Everyone's perspective is acknowledged as essential and valued, and each participant brings their own experience, expertise, skills and insights
- 3 Respect** Due regard is paid to working together and communicating in a respectful and constructive manner
- 4 Reciprocity** Reciprocity is a genuine sharing of thoughts, feelings, and experiences between a group where mutual learning occurs, and shared meanings develop
- 5 Power-sharing** Sharing of power recognises different areas of expertise resulting in democratic shared ownership of decisions
- 6 Accessibility** Everyone involved has equal opportunities to participate and contribute to the process
- 7 Transparency** The whole process is jointly and clearly outlined and understood

## Translating principles into practice

In this section you will find suggestions and tips on how to put the principles outlined above into practice and create an environment that is conducive to co-creation.

1. Inclusive mapping of stakeholders - Stakeholders' mapping is a common practice in many contexts, however the way the mapping is approached could influence the process in very different ways. Consider:
  - Think out of the box - there may be stakeholders you have not considered to involve for many reasons: e.g. you may believe they have no role to play in what you plan to do, or you do not know where to find them, or you

need to broaden your perspective on the project / service beyond the mental health area. It is important to be mindful there are different perspectives; you could: ask several people to contribute to the mapping, get inspiration from similar initiatives, put out a call for expression of interest (you may get surprised by the return!);

- Keep diversity in mind - whatever you do in co-creation you have to bear in mind that the results will have to meet the needs of your targeted beneficiaries, and that these will include people with diverse needs and coming from diverse backgrounds. Think of different types of lived experience of mental health problems, their family and supporters, service providers, community members, age, gender, socio-economic background, religion, etc. and the interconnection between these and the project / service. Make sure that your co-creation approach is as inclusive as possible from the start.
2. When liaising with stakeholder to engage them in the co-creation activity check what they need to be enabled to fully participate.
  3. Make sure you have the necessary resources to co-create properly based on the needs you assessed: time, human resources, finances, venues, etc. Factor in that some flexibility will be needed because co-creation can be a bit messy and time consuming, but the result will be worth it! Be transparent about the resource's allocation, particularly if funding is involved.
  4. Identify what expertise, experience, skills and knowledge every participant brings and where they can contribute most effectively.

*Enrico L. - Member of Clubhouse Club Itaca Milan (Italy)*

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*“Within the Clubhouse we are valued as we do what we can do best according to our abilities, skills and experience. The Clubhouse allows us to use our expertise, empower our abilities and help other members. Moreover, the Clubhouse staff encourages us to learn new things and make new experiences”.*

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5. Inform participants about what co-creation is and how it works.

6. Jointly identify and agree on the focus and expected outcome of the piece of work to be done in co-creation. Where a piece of work is somehow already defined (e.g. a strategy) agree on how co-creation can be applied within the existing framework.

*Safia Akram - Person with lived experience and Project  
Manager for mental health services at NHS, United  
Kingdom*

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*“You know, the more recent project that I am working on is around mental health, around shared experiences and that’s a group of people who have lived experience of using mental health services, whether that’s at crisis point or even primary care level, or actually not even being known by health professionals as somebody who has problems...”*

*So, it’s really important to have all of those voices with different experiences supporting what we do and actually holding me accountable to how I’m delivering the work, what my future plans are for the project, so, I put out to the group “this is what I’m thinking”, let’s get together and talk it through, brainstorm ideas – what works, what doesn’t work, what is needed and how can I help facilitate that. So, although the job title is project manager, I see myself more as a facilitator”.*

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7. Establish a group agreement on how you will be working together, this should include:
  - Agreement on elements that create a safe environment for everyone;
  - A plan for managing the communication between participants and strategies for addressing challenges to participate that some people may face;
  - A process for managing conflict;
  - Agreement about how decisions will be reached.



You will need to check/review the group agreement regularly and adapt as needed. It could for instance be done at the beginning of every meeting as a group or people could send written suggestions individually (this may be a more comfortable option for some).

8. Outline an action plan describing the steps of your co-created activity so that everybody is clear about the process, but keep it simple and, obviously do it in co-creation too. Acknowledge that in reality not everybody may be able to contribute to each single step and that this is accepted by all as long as outcomes are shared with everybody. If funding is involved in the project, be transparent about the budget allocation.

Having an action plan should not lead however to a too rigid and formal process. After all co-creation is about “creating” together, so leave space for creativity, out-of-the box ideas and informality.

9. Co-create the evaluation plan and tools to be used for checking whether your way of working is in line with the co-creation approach.
10. Provide information and documents related to the activity/project in a friendly format for everyone involved. If the language used is too technical for instance or only in one language not everyone will have the same opportunity to contribute.
11. Be mindful of participants with diverse needs; e.g. need for signs interpretation.
12. Plan tasks and activities according to everyone’s professional and personal circumstances, e.g. should some meetings be planned during the weekend to enable participation of those who are involved on a voluntary basis and cannot take time off their week job?
13. Pay attention to practical aspects - if a meeting is online does everyone can and know how to join and participate? If it is face-to-face, is the venue easy to access via different transport means?
14. Find ways to value and acknowledge both formally and informally the contribution that everyone involved has made.

## Promising & Good practices

In this section we have sought to provide examples of different type of activities, sectors and countries in support of the argument that co-creation is an approach that can be applied by any stakeholder in any kind of work endeavour. These good practices were self-assessed by the organisations leading them using the assessment tool designed to this purpose by Mental Health Europe's Co-creation Task Force, as explained in the last section of these Guidelines.

Some of the practices included come from members of Mental Health Europe that applied our co-creation approach as described in the Toolkit. Hence, in their description these practices reflect more closely the indicators of the assessment tool since they were shaped from the start according to Mental Health Europe's co-creation approach.

### Examples of good practices

**YouCoMent Project: Young person's Co-creation approach to promote Mental health during their training in health and care professions.**

***By the Competence Centre for Mental Health (OST - Eastern Switzerland University of Applied Sciences).***

This example from a research project in Switzerland describes a means and process how co-creation can be applied in the field of research. The purpose was to develop an intervention aiming to support and promote the mental health of young students.

The first step was to set up a diverse group consisting of trainees of the vocational and further education centre St. Gallen representing all years, educators, researchers, mental health professionals, technology development professionals, methodological design and monitoring professionals, a health insurance representative and a legislation representation. They were identified through a stakeholder mapping and were encouraged to participate in the project through information events and open calls using the intranet of the centre and visiting all classes providing information of the project.

The second step in the YouCoMent Project was to organise a series of design thinking activities and workshops that allowed participants to be on the same page and define their needs and requirements before they could start defining their

challenges in context of their mental health and developing ideas co-creatively. The intervention development started by presenting the results from previous empirical work (quantitative and qualitative studies) to the participants and discussing these with them. Among the potentially numerous ideas, the recurring core elements were agreed upon in a participatory manner. These core elements guided the intervention development.

In the YouCoMent project shaping the co-creation process through collaboration with stakeholders from different fields and experience was essential to ensure that the project's ultimate beneficiaries – young students in the health and care sectors – would receive adequate mental health support, which is relevant to both their personal and future professional life. Through this approach the intervention provided is relevant and responding to their needs, and the acceptance level is increased.

As an additional positive effect, working in co-creation established a stronger bond and growing mutual respect between the actors involved, because they were not simply presented with pre-conceived ideas, but were actively involved throughout the process. In fact stakeholders who were relevant to the topic were involved before the project was launched and, moreover all phases were open for others to get involved. Also, this research was conducted entirely on-site in the centre rather than in the university building to facilitate accessibility.

This project served as a starting point to understand and identify important priorities that must be considered when designing the program. Nevertheless, there must be an openness and understanding to discuss and, if necessary, discard these identified priorities with the people involved. This ensures that all the stakeholders have the same right and opportunity to contribute their views and make decisions at every stage of the process.

While this co-creation project was evaluated as proficient, there are refinement opportunities. For instance, in regard to indicator 4 we had some difficulties to provide the same grounding and highlight that all experience are equally important. This situation was especially true for the involved adolescents at the beginning; even more as some of their educators were participants as well. We also could improve indicator 5 and 6 as several backgrounds, knowledge and experience were involved. Also, some professionals were asking for more guidance, and prompt decisions to be taken through the co creation process, even if some other members were asking for more time for development and discussion to be conducted. Again, some work concerning indicator 11 on how the evaluation looks into how the co-creation

approach can be sustained and applied in future activities should be improved. As not all stakeholders are part of the sustainability and implementation of the program, this indicator was perceived with different relevance from participants.

### **Co-creation Workshop “Violence against women with disability prevention”.**

#### ***By Mental Health Perspectives Lithuania***

In Lithuania, women with disabilities, including psychosocial disabilities experience 2-5 times more risks of violence, coercion and exploitation than the general population. Mental Health Perspectives saw a gap in how policies and services were addressing their specific situation and undertook to bring together stakeholders and look into actions that could be taken.

To this purpose they held a full day co-creation session to develop guidelines for governmental organisations for the prevention, intervention and postvention of violence against women with disabilities. Participants were social workers, psychologists, psychiatrists, teachers, lawyers, state workers, supporters in decision making, a non-governmental organization representing people with disabilities.

Participants were divided into four groups, making sure that in each group there were differing actors to share their unique perspectives. There were brainstorm sessions on what mechanisms should be applied in mental health and social care institutions to prevent violence, intervene and follow up. At the end of each brainstorm session participants presented their ideas and after all ideas were presented, voting of every member took place to mark which solutions were most relevant in their perspective.

At the end of the co-creation session, a summary of the ideas was presented to make sure all participants were on the same page. After the co-creation session, the proposed solutions were formulated into guidelines to present to the Health Ministry of Lithuania, but before that, the guidelines were sent to all participants for feedback.

While the concept of co-creation was new to participants and they were of quite diverse backgrounds, using a co-creation approach helped each of them understand and appreciate what others were bringing to the table; a genuine exchange of experiences and perspectives took place. This interaction was undoubtedly supported by the fact that an action plan of the steps of the co-creation activity was prepared and agreed upon; so everyone was clear about how they would be working.

While this co-creation session was evaluated as co-creation proficient, there are some lessons learned on aspects to improve. For example, in regard to participants there were not enough experts with lived experience, in this case women with disabilities who have experienced violence. This was due partly to the fact that the topic is very sensitive, and those women may feel uncomfortable to share their experience in this kind of setting. Therefore additional efforts need to be made to understand how to engage people in vulnerable situations in a safe and comfortable way through the co-creation approach.

Another aspect where co-creation could have been applied better was the communication between participants when sending them the draft guidelines: the document was quite long and not well structured enough and might have been hard to read for some of them. Maybe proposing those same ideas in a more pleasant, friendlier way (such as with illustrations, slides) could have improved participants' possibility to provide comments and also the quality of the feedback received.

## **“Responding to Mental Health Distress in the Community” Workshop for An Garda Síochána Senior Managers**

***By Mental Health Ireland***

This workshop was co-created with managers of An Garda Síochána, the national police and security service of Ireland. The purpose was to provide their teams with an increased knowledge and understanding of how to support people in mental health distress and, ultimately to enhance the experience of people experiencing mental health distress during their interactions with An Garda Síochána in times of crises.

Using a co-creation approach throughout the process facilitated tailoring the messages for the managers and creating specific resources to support the aims and objectives of the workshop. It also enabled gathering lessons learned that would inform future steps and improvements.

The co-creation effort started with a literature review to make sure the result would be evidence based and up to date. There was a first co-creation meeting to identify the aims and objectives of the workshop and then Mental Health Ireland Development & Training team (the working subgroup for the project) produced a draft workshop outline, that was subsequently reviewed by the wider co-creation team of Garda Management and personnel, people with lived experience,

supporters, Mental Health Ireland team members. The working subgroup prepared a revised workshop outline, and after approval from the coproduction group, they developed a series of custom tools and resources, including a resources pack with relevant literature. The pilot workshop was delivered in person to 12 participants from Garda senior staff. The workshop was facilitated using a blend of presentations, interactive discussions, group work and evaluations processes. A full evaluation was conducted including individual evaluation forms, a reflective discussion with participants, and a focus group with specific feedback questions. Facilitators' feedback was also collected.

A key asset was the input from facilitators with lived experience of being in mental health distress necessitating An Garda Síochána interventions. Feedback from participants highlighted the impact having someone with lived experience of mental health distress cofacilitating had on them. It increased their understanding and provided opportunities to see things from 'the other side' of the intervention. The impact was so great that many participants suggested including a presentation from a person with lived experience of mental health distress as part of the core training for the police and security forces.

The evaluation also clearly outlined the importance of exploring an understanding the difference between mental health and mental illness and how the latter can impact on a person's behaviour when in distress. However, the workshop could benefit with more of a focus on familiarizing participants with having conversations about mental health.

Participants found it beneficial to share their learning and to have the opportunity to discuss frontline experiences with colleagues. It clearly emerged that there are difficulties in relation to workplace health and safety for An Garda Síochána and that they must balance their own safety and that of the person to whom they provide an intervention. It was also noted that An Garda Síochána require more structured support and guidance from the Mental Health Services in the Health Service Executive.

The workshop was positively received and, based on the feedback Mental Health Ireland made a number of adjustments to the workshop, further developed signposting materials, engaged with 5 An Garda Síochána to provide follow up learning materials for the internal Portal, and reconsider the number of workshop objectives relative to the time allotted. Other lessons learned were that, as this was an interactive workshop the room set up (boardroom style) wasn't suitable, that wall space for flip chart sheets used in group work was needed and that having two facilitators would be optimal in the delivery of this workshop. Mental Health Ireland

completed a report on this co-creation experience and on piloting of the workshop including further recommendations.

### **The Shared Experiences & Local Mental Health Systems project in Watford, United Kingdom**

This project, inspired by a similar project in Italy started in 2018 in Watford. It involves service users, service professionals, informal carers, the third sector, representatives of the Town Council and people with diverse mental health needs and backgrounds.

The aim of the project is to counter any kind of institutionalization and overcome the current over clinicalization of mental health issues by transitioning service delivery from institutions to a community environment. This is implemented through the co-creation of neutral spaces in the community where different people outside their different social roles can exchange their personal experiences far from a diagnostic/therapeutic settings. Such exchanges are deemed to be beneficial for all participants showing how it is possible in a significant number of cases to better understand people and their needs outside the mainstream illness-focused approaches of most services characterized by the “us and them” distance.

The project approach consists of three main steps involving the same group of people/actors where both the personal and collective aspects are both considered:

- the sharing experiences meeting (called “Common Sense Group”) held every second Monday for one and a half hours. The group gathers a maximum of 15 people representing different actors interested in mental health issues and interacts through verbal and extra verbal communication;
- the online reflective group on the other Mondays (for one hour) for those who attended the previous meeting;
- the monthly steering group meeting held online or in person according to circumstances. This group, composed by the same participants of the above-mentioned two groups, has policy and administrative tasks and liaises with mental services, local governments and other organizations of the local community.

Currently the project has some funding and some members of the group are paid whereas others do voluntary work. A few people can be accompanied at meetings depending on their health status. Members are asked to use as much as possible a daily language and not a clinical or technical one, particularly healthcare professionals. Being in a space of the local community and not using clinical

language and setting, appears to be a good incentive to foster ownership, cooperation and power sharing.

All participants are aware of the basic assumptions and goals of the project and contribute to further develop it. The meetings venues, as well as the time and the agenda of the meetings are chosen by the whole group; leaflets about the project are regularly updated.

Theoretically the project has not an end. The aim is to establish a permanent interlocutory space between the mental health services and the community. This can develop both better services and better communities where people can choose their own way to understand their problems, to recover and feel part of an evolving process both at individual and collective level.

## **Toolkit on young people mental health and wellbeing for Youth Offices**

### ***By Psychosocial Innovation Network (PIN), Serbia***

The project is a small-scale one, with a duration of three months. The project's goal was the creation of a toolkit for coordinators and employees of Youth Offices in Serbia with the topic of youth's wellbeing, habits, and mental health. The toolkit was planned as a resource for the education of Youth Office staff so they could transfer that knowledge to youth through various activities and practices. Thus, the final beneficiaries were to be young people in the local municipalities. PIN planned to include all relevant stakeholders, primarily young people since they are most often excluded from the creation process of any material aimed at them. The plan consisted of three co-creation sessions with youth from different backgrounds, youth workers, psychologists, and project team members, with follow-up sessions, and piloting with a different group of young people.

The objective to involve all relevant stakeholders in the co-creation process was partially fulfilled. There appeared to be frictions between some relevant actors, a situation PIN did not have a prior understanding of, even after a thorough mapping of relevant stakeholders and their relationships. This made the process complicated because different priorities had to be balanced, those of PIN's donors, as well as those of state institutions to whom the donors are accountable. Because of this, it was not possible to include all planned stakeholders, and PIN made a conscious decision to only include youth and a wider spectrum of participants from its member organisations, who had similar perspectives to the stakeholders that had to be let go



of. Practically speaking, they mapped a structure most similar to the original ideal group structure, but with the reality check of who could objectively be involved and took into account the final beneficiaries of the project as the most important stakeholders, that is, the youth.

Participants were of truly very diverse and different backgrounds, spanning different cultures, ages (17 to 33), places of residence (the goal was to include youth originally not from the capital), sexual orientation, experience with mental health services, working experience, education, and family background. The one negative note was that only one participant was male because two male participants cancelled at the last moment and could not join in later. The group had to accept this and move forward with the process. However, to prevent further dispersal of the group and to preserve diversity, PIN made sure to always have a group agreement on the best possible date and time for the sessions and to always hold them only when the participants could all fully participate. By accommodating their needs, time, obligations, and availability, the group remained complete throughout the whole process.

A lot of time and attention was paid to the first, preparatory phases and steps of the process. All participants were informed about all aspects of the project: goals, stakeholders involved, project constraints, their role, and the final product as well as the project activities they were not part of. Before the first session, all participants were briefed about the project via calls and text messages (so, verbally and in writing). During the first session, a group agreement was made which included a clear description of who participants were, what expertise each would bring, and what their role in the group was. It also outlined clear expectations on the whole process and on each session, an agreement on how the group was to build a safe place for everyone during the process, and all of the limitations and existing power unbalances that had to be taken into account. For instance the young people were informed the project team was paid for the project, and that crucial decisions would be made by the project team with full consideration of their input, but because of the accountability towards their donors. Furthermore, the group agreed on how to deal with conflict if any should arise, the steps in all the activities from the first session to the finalization of the toolkit and on how everyone's contribution would be valued. All of the agreements were written down on a flipchart used during all sessions, and everyone could at any time go back to it. At the beginning of each session, the group took the time to go through it and remind what was agreed, and if needed, add or change something in it. This group agreement was truly the most important step that allowed overcoming some limitations and challenges faced along the way.

With regard to taking care of the resources needed for everyone's full engagement and practical aspects influencing their capacity to contribute, this was fulfilled to the highest possible degree, despite limitations which were overcome through total transparency and the group agreement aforementioned. PIN made sure to be transparent about the project team being compensated for their work and ensured that the participants who were not paid would not work outside of the planned sessions and that they were compensated in other ways collectively agreed upon, e.g. they would all be mentioned in the toolkit by name, with a clear description of how they contributed to the toolkit and the project. As for the logistical resources, sessions were organised accommodating their availability so that everyone could have equal opportunity to participate, e.g. taking care no one had to leave early or to have to miss classes, or to have to travel far. Decisions on the time and duration of each session were made by the group itself.

All participants were also briefed about the evaluation of this project verbally and in text. Each participant partook in the evaluation process by going back to the expectations expressed at the beginning of the process and assessing if they had been met. The outcome was positive.

Based on this activity and others (a research project and a strategic planning) where PIN has been applying the co-creation approach promoted by Mental Health Europe, PIN is committed to sustain a structured co-creation approach. A key step in achieving that was to get on board the whole team who is now well familiar with the co-creation approach and agreed that co-creation is something PIN, as an organisation, wants to include in their model of work. PIN made sure to inform the team on how co-creation works and in their weekly team meetings they also discuss the co-creation aspects of their projects - process, challenges, next steps - which fosters learning on co-creation implementation.

## **The Clubhouse model**

### ***By Progetto Itaca (member of Clubhouse Europe)***

The Clubhouse model is quite a peculiar example of co-creation as it relates to the whole structure, governance and operations of the model itself. Clubhouses are local, community-based locations that offer people living with mental health problems opportunities for friendship, employment, housing, wellness and access to

health services in a single caring and safe environment, thus fostering their social and economic inclusion.

This model reflects the principles of co-creation defined by Mental Health Europe. For instance, one of its core elements is the principle of inclusivity. As per Clubhouse International Standard 4, *“All members have equal access to every Clubhouse opportunity with no differentiation based on diagnosis or level of functioning.”* This model builds itself on the strength and capacity of its members; everyone contributes to the daily running of the Clubhouse within the limits of what they are willing and able to do. The Clubhouse method can be seen as an example of a structure striving to use co-creation in a very practical way for its daily functioning.

The principle of accessibility is covered by the standard 26 that ensures that all Clubhouses are located in an area where access to local transportation can be assured.

Another key success factor of this approach is the equality between the staff and the Clubhouse members and power sharing. All the important choices regarding the day-to-day running, governance, policy making, and the future direction and development of the Clubhouse, are taken through consensus of both staff and members. This includes interviews for new staff, evaluation of the staff, intake of new members, choosing new projects and activities to undertake. All Clubhouse meetings are open to both members and staff. There are no formal “member only” meetings or formal “staff only”. This approach takes time but ensures that members are heard, and that the Club succeeds in providing the restorative environment it means to support their recovery journey.

Relationships in the Clubhouse should always be respectful and focused on members taking responsibility, to gain self-confidence and self-esteem. When the Clubhouse provides an in-house education program, it significantly utilises the teaching and tutoring skills of members. To ensure an effective active role of the members, staff are sufficient to engage the membership, yet few enough to make carrying out their responsibilities impossible without members’ involvement. The mutual support is necessary for the actual functioning of the structure, this ensures that members feel needed and expected at the Club each day. The most common example of this is the kitchen unit: one staff will be in charge of supervising the cooking, if there are no members available to work in the kitchen or do the shopping, the staff will not substitute itself to the members; that day everyone will eat plain rice!

The co-creation approach is not only internal to the Clubhouse. It also involves the community, the local health authorities as well as national authorities as they should also contribute their perspectives and be part of the project group.

## Tool for assessing co-creation practices

Based on the more extensive indicators' set available in section 6.2 Evaluation of our Toolkit, we developed an online tool ([link here](#)) for assessing promising and good practice examples of co-creation work in mental health. The tool can be used to self-assess any type of project and activity from developing a brochure to running a policy consultation and so forth. It consists of 11 indicators esteemed to be key during the different phases of co-creation: preparation, implementation and evaluation.

| Indicator   | Description  |
|---|--|
| <b>1. All relevant stakeholders are involved in the co-creation process</b>   | Co-creation should be representative of all groups having a stake. This indicator will tell you to what extent you have succeeded in being inclusive and engaging the relevant stakeholders.   |
| <b>2. Participants represent diverse profiles within their stakeholder group</b>                                      | Whatever you do in co-creation you should bear in mind that your targeted beneficiaries include people with diverse needs and backgrounds. Ensuring diversity will bring better results.   |
| <b>3. All resources needed for everyone's full engagement are secured and they are allocated in a transparent way</b> | When engaging stakeholders in your co-creation work you will have checked what they need to be enabled to fully participate. You will also have catered for the necessary resources (e.g. time, human resources, finances, venues, transport). |
| <b>4. Participants are aware of the expertise each brings</b>   | Making sure the group understands what each participant brings in terms of experience, expertise, skills and insights will foster ownership and cooperation that is respectful and built on equal power sharing.                               |

|  |  |
|--|--|
| <p><b>5. Participants understand what co-creation is and how it works</b></p>  | <p>This will ensure everybody is in on the same page. Co-creation is easy to understand in principle, but in practice doubts and questions will arise.</p>   |
| <p><b>6. The focus and expected outcome of the piece of work to be done in co-creation has been jointly discussed and agreed</b></p> | <p>Often you won't be starting from a blank page. Where aspects of the work are somehow already defined (e.g. topic, deadline), agree on how co-creation can be applied within the existing framework.</p> |
| <p><b>7. A group agreement is in place</b></p>   | <p>It is important to agree on how you will work together, create a safe environment, manage communication and reach decisions.</p>  |
| <p><b>8. An action plan describing the steps of your co-created activity is in place</b></p>   | <p>Clarity will foster a smoother process and help keeping everyone on board.</p>  |
| <p><b>9. Practical aspects take into account everybody's circumstances influencing their capacity to contribute</b></p>              | <p>Meetings' timing, language used, the way info is provided, etc. – there are many practical aspects that should not be neglected since they may hinder your work in co-creation.</p>                     |
| <p><b>10. All actors who were involved in co-creation are able to contribute their perspective to the evaluation</b></p>             | <p>When you co-create, be consistent and do it till through the end.</p>   |
| <p><b>11. The evaluation looks into how the co-creation approach can be sustained and applied in future activities</b></p>           | <p>Commitment to co-creation implies embedding it as a work approach within organisations and promoting it.</p>  |

Each indicator is evaluated by means of five rating possibilities and this numerical assessment leads to a certain positioning defined by the following levels: Novice, Beginner, Competent, Proficient, and Expert.

These levels represent distinct levels of achievement in applying Mental Health Europe's co-creation approach and serve as a valuable framework for individuals/teams/organisations to understand and assess how they have been doing in working in co-creation in their activity or project and what aspects need to be improved in order to reach the next stage.





**Mental Health Europe** is the largest independent network organisation representing people with mental health problems, their supporters, care professionals, service providers and human rights experts in the field of mental health across Europe. Its vision is to strive for a Europe where everyone's mental health and wellbeing flourishes across their life course. Together with members and partners, Mental Health Europe leads in advancing a human right, community-based, recovery-oriented, and psychosocial approach to mental health and wellbeing for all.

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