How to get co-creation right in mental health research

Summary of messages, discussions, and participant engagement

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In celebration of the European Mental Health Week (2024)
Hosted by:
- ADVANCE (advancementalhealth.ku.dk)

Coordinating team:
- Joyce Anne Quinto (University of Copenhagen)
- Liuska Sanna (Mental Health Europe)
- Raquel Teixeira (University of Porto)
- Cláudia de Freitas (University of Porto)
- Khaoula Mouhand (RDIUP)

Co-organized by:
- SMILE (horizonsmile.eu)
- MentBest (mentbest.com)
- ReConnected (reconnected-project.eu)
- BootStrap (internetandme.eu)
- Improva (improva-project.eu)
- ASP-Belong (augmentedsocialplay.com)

In cooperation with:
- Mental Health Europe (mentalhealtheurope.org)
- European Health and Digital Executive Agency (hadea.ec.europa.eu)

Total registrations: 385
Actual attendees: 203 (peak)

For more information, please contact joyce.quinto@sund.ku.dk

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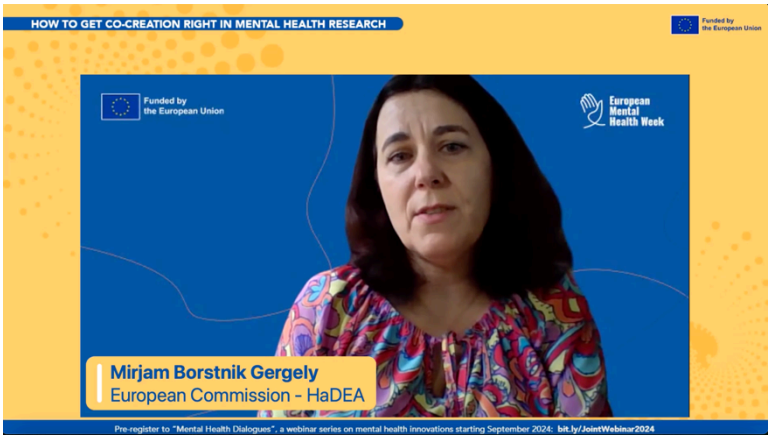
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Opening remarks

Mme. Mirjam Borstnik Gergely, Deputy Head of Health Research Unit, HaDEA- European Commission

Thank you and good morning to everybody. I'm very happy to greet you with some opening remarks in this first, but I believe not the last, of joint webinars between what you have already mentioned: seven EU-funded sister projects coming from the same Horizon Europe call. That collaboration and exchange of ideas among yourselves is exactly the outcome we were hoping for in HaDEA, the European Commission's implementing agency that is managing health research. I would like to acknowledge the joint effort of the seven projects: ADVANCE, ASP-BELONG, BOOTSTRAP, IMPROVA, MENTBEST, RECONNECTED, and SMILE for organizing today's gathering.



Mental health is one of the most pressing challenges in Europe, especially since the COVID pandemic, and particularly for youth. I, myself, have two teenagers, and I've personally witnessed them and their friends going through mental health difficulties that were not so pronounced or not so commonly heard of before 2020. It is estimated that in Europe, 84 million citizens, ranging from all ages and of all socio-economic backgrounds and origins, are suffering various mental health issues in their everyday lives. The staggering figures show that, for instance, the second leading cause of death of young people between 15 and 19 is suicide, coming just after road accidents.

The sheer size of this challenge is now clearly recognized in the EU policies, and, in particular, in the Commission's communication in June 2023 on a Comprehensive Approach to Mental Health. This is also seen in a novel policy approach on the power of the arts and culture for people's well-being and inclusion. It is also reflected in the increased EU budget granted for research and innovation, and the European Commission is looking closely at the results of the ongoing research projects in this domain, including yours, especially now as we are preparing for the next research framework program.

There are other colleagues here from the agency and the Commission among the participants who will follow your discussions with attention and perhaps contribute. So, I wish you a very fruitful and creative morning, and I'm looking forward to hearing about today's conclusions on co-creation and, of course, the continuation of such gatherings. Thank you.

Summary of Questions and Discussions



Moderator: **Liuska** Sanna, Head of Operations, Mental Health Europe

Panelists:

- ADVANCE: Dr. **Cláudia** de Freitas, Institute of Public Health, University of Porto
- SMILE: Dr. **Mel** McKendrick, Heriot-Watt University
- Mentbest: Dr. **Arlinda** Cerga Pashoja, St Marys University
- Reconnected: Dr. **Karthrin** Schopf, Ruhr University Bochum
- ASP-Belong: Dr. **Kate** Woodcock, University of Birmingham
- BootStRaP: Dr. **Célia** Sales, University of Porto
- Improva: Dr. **Rodrigo** Antunes Lima, Sant Joan de Déu

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1. Along the co-creation pathway, how can we actively prevent tokenism and ensure that individuals with lived experiences of mental health problems are not merely seen as a diversity checkbox, but as equal collaborators in developing solutions?

Arlinda: *I think it is important for everyone to consider it from the beginning when planning a research proposal. The key is involvement in planning, but also in engaging throughout the stages of development. This involvement is transformative rather than merely informative. Co-creation is conducted with participants, not on participants, so the insights that emerge from co-creation processes are the product of collaborative work.*

I want to share a brief analogy that I find fascinating and that we've tried to implement in our projects. A few years ago in Moscow, there were new buildings with large parks being developed. When the park was finished, it was all green with no pathways, just grass and flowers. The sponsor asked, "Where are the pathways?" The architect replied, "You will have the pathways in three months."

What they did was wait for all the residents to walk and create their own pathways in the grass. Those pathways, formed by the residents' natural movements, were where the permanent paths were eventually laid. This approach ensures that the design truly meets the needs and behaviors of the people using the space.

Key points:

- Importance of involvement from the beginning of the project.
- Co-creation should be transformative, not just informative.
- Insights from co-creation are products of collaborative work.
- Analogy: Residents creating pathways in a park illustrates meeting user needs.

Claudia*: I must start by sharing that, in my view, co-creation in research is first and foremost a relational process. It involves setting the goal of co-constructing knowledge and delivering innovation together with all parties that this knowledge will likely impact. To advance knowledge development, we need stakeholders to have a common understanding of what co-creation means, what roles are expected from them, and which resources are available. Additionally, we must anticipate and address the challenges of implementation, as they will inevitably arise.*

These challenges can include anything from stakeholders having incompatible agendas to unequal bargaining skills, not sharing a common language, or having conflicts of interest. This complexity is further compounded by research teams often facing very pressing schedules and output production pressures. Enabling meaningful collaboration and avoiding tokenistic involvement, especially for people with lived experiences of mental health issues, depends greatly on our ability to manage these challenges and conflicts.

I believe, and I think my fellow panelists agree, that there is no simple recipe for this. Instead, we must continuously monitor, self-reflect, and create safe spaces where we feel free to express our doubts and concerns. We should share potential solutions to arising problems and work together through any tensions that may emerge. One approach we have found helpful is to adhere to principles of equity and solidarity when making decisions. In practice, this means allocating resources first to those stakeholders who need them the most and lowering the thresholds of participation by prioritizing the needs of stakeholders who may be at a greater disadvantage.

This might involve holding meetings in person instead of online, which would be more convenient for many stakeholders but not for all, and conducting them in the language most participants are comfortable speaking. However, one caveat I must make is that, in adopting this approach, we should not assume that people with lived experiences of mental health issues are inherently the least equipped to engage in co-creation. It may turn out that practitioners or researchers who are less familiar with co-creation also require support in accommodating different forms of knowledge.

To prevent tokenism, we must encourage and support all stakeholders without exception, ensuring they can indeed be equal partners and collaborate for mutual benefit.

Key points:

- Co-creation is a relational process aimed at co-constructing knowledge and innovation.
- Need for stakeholders to have a common understanding and resources.
- Addressing challenges like incompatible agendas, language barriers, and conflicts of interest.
- Continuous monitoring, self-reflection, and creating safe spaces are essential.
- Adherence to equity and solidarity principles in decision-making.
- Flexibility in meeting formats and language to accommodate all participants.
- Support all stakeholders, not assuming those with lived experiences are less equipped.

Celia: *The greatest challenge when involving citizens who are not professional researchers in a research project is to create a cohesive team. Both citizens and researchers must be brought onto the same page, which is something that must be built gradually throughout the project. In academia and research projects, we are not accustomed to working with a citizen science approach. Typically, researchers with extensive experience are used to working without citizen involvement. These researchers must recognize the benefits of adopting a new way of working.*

On the other hand, we have citizens, including adolescents, patients, and users who are not professional researchers. They do not know the language, rules, or methods of research. Consequently, they might not understand why some of their proposals are not accepted or why certain processes are followed. Creating a team where everyone is on the same page, collaborating, and open to each other's views is key.

Some of the previously mentioned proposals and recommendations apply here, and I would like to add two more. First, it is important to surprise researchers by creating project activities and tasks where they have direct contact with citizens and their inputs. This interaction allows researchers to realize they are conducting better research projects because of these citizen contributions. Creating opportunities where citizens teach something to researchers fosters openness to teamwork.

Second, honesty is crucial. We must be transparent with citizens about what we are doing with their inputs, knowledge, and efforts. In long-term projects, it is essential to provide ongoing feedback and self-evaluation of citizen involvement. This includes communicating what has been proposed by citizens, how it has been included or not included in the project, and the reasons why. This dialogue between researchers and citizens should be clear. When people understand their roles and feel that all ideas are respected and considered, it fosters a true team of co-researchers where everyone contributes equally to the project's success.

Key points:

- Challenge: Creating a cohesive team of citizens and researchers.
- Importance of mutual understanding and gradual team building.
- Direct contact between researchers and citizens enhances project quality.
- Transparency about the use of citizen inputs.
- Ongoing feedback and self-evaluation of citizen involvement.

Mel: *We are actively trying to prevent tokenism by involving young people and other stakeholders actively within the game design process. We engage them at different stages, starting from understanding the issues that are important to them and the real-world challenges that might cause them distress. We gather perspectives from young people themselves and from their support structures, such as parents, teachers, and clinicians, who may also have an understanding of their needs.*

We make it a point not to make assumptions. This is especially important in mental health, as not everyone has a diagnosis, and mental health can fluctuate over time. We recruit broadly, involving people in various projects to understand the issues affecting them and how these issues impact them at different stages of their development and day-to-day lives.

At different stages of game design, we hold workshops where young people can input and prioritize what is important to them. Our partners create priority maps addressing issues and features of the game, including design, biomarkers, AI implications, and ethical considerations. Young people have a real voice in all of this.

We believe that diverse recruitment is crucial. Ensuring diversity by allowing it to naturally emerge, rather than targeting predefined groups, is vital. Additionally, involving young people in the dissemination stage allows them to see their voices reflected in the project's outputs.

Key points:

- Active involvement of young people and stakeholders in game design.
- Gathering perspectives from young people and their support structures.
- Broad recruitment to understand diverse issues affecting participants.
- Workshops at different stages for input and prioritization.
- Ensuring diversity through natural emergence and involvement in dissemination stages.

Kate: *I think one of the key points mentioned earlier is the importance of designing co-creation from the very beginning of the project. For us, this is crucial because it integrates with all aspects of our design. That's one reason why I'm here today; we couldn't have just one person represent co-design because it's integral to everything we're doing. I'd like to give three examples that illustrate some of our work so far.*

Our project aims to develop new psychotherapeutic experiences for young people to strengthen their sense of belonging and, through that, boost their mental health. These experiences are led by a smartphone, bringing a technological aspect that adds a magical element to the experiences. These are group-based, collaborative experiences involving fictional stories, allowing us to address potentially sensitive issues within a fictional context. Collaborating with young people is essential because we need their input to understand what is magical to them.

We approached the project design by ensuring we avoid tokenism and, more importantly, capacitate young people so their contributions are genuinely valuable for both them and us. We have a group of adolescent co-researchers, two young people from each of our participating countries. They have been involved since the start of the project, meeting every two weeks remotely. We designed the process to ensure young people are part of all aspects of the project, overseeing everything we do. We provide them with training in various scientific and creative

methods, as well as the experience of collaborating with peers from different countries and languages. This ensures their involvement is valuable and they remain with us throughout the project, becoming the most valuable scientific contributors they can be.

Another group of young people, recruited by the Unicorn Theatre, our UK partner and the largest children's theatre in the UK, are our creative associates. They work with us weekly on the co-creation of a specific experience. To ensure they were well-informed before committing, the theatre ran sessions in local schools similar to the creative sessions they would participate in. This gave them a taste of what to expect, and those interested applied and were selected. We meet with this group weekly from January to August this year, building relationships and ensuring they know exactly which elements of the experience they are contributing to, such as tech magic, story, and character. This helps them feel comfortable and enjoy their involvement.

The third example involves cultural exchanges with groups of young people from three of our countries, where we will evaluate our first intervention. These exchanges give young people the opportunity to travel and work with peers from different countries. From a research perspective, we ensure our experience is sensitive to different cultures. For the young people, the outcome is a deep understanding of different cultures and the experience of acting across cultures. For many, it will be their first time doing something significant in a different country, beyond a holiday. This cultural exchange broadens their perspective on the world.

Those are the three examples I wanted to share.

Key points:

- Designing co-creation from the start is crucial for integration.
- Development of psychotherapeutic experiences for young people through collaboration.
- Adolescent co-researchers are involved in all project aspects and receive training.
- Weekly meetings with creative associates to build relationships and clarify contributions.
- Cultural exchanges to evaluate interventions and broaden perspectives.

Rodrigo: *At Improva, we are developing a health platform to promote universal mental health and well-being in adolescents. Because of this, we are including not only adolescents as our primary group in the co-creation process but also teachers, parents, and policymakers. We aim for our platform to be integrated into the educational system by the end of the project, so we need the perspectives of various stakeholders.*

To prevent occasional setbacks in our co-creation procedures, it is crucial to include these stakeholders from the conceptual phase of the project. Some of our colleagues have already highlighted the importance of involving stakeholders in the project design and program development and partnering with them as early as possible. This can be extremely challenging because different stakeholders have different interests and urgencies, and the scientific timing from project grant to implementation phases can be very tight. We strive to engage stakeholders as early as possible and dedicate time and resources to the co-creation process, which is of utmost importance.

We have implemented various strategies to accommodate the different phases of the project. A key point I want to emphasize is the importance of involving stakeholders throughout the entire

duration of the project. One effective strategy we used is creating a commission comprising stakeholders who participate in and support the development of the program from the very beginning to the end of the project. This continuous involvement ensures that the perspectives and contributions of all stakeholders are integrated into the project's development and implementation.

Key points:
- Inclusion of adolescents, teachers, parents, and policymakers in co-creation.
- Early involvement of stakeholders to address diverse interests and urgencies.
- Continuous involvement of stakeholders throughout the project.
- Creation of a commission of stakeholders to support program development.

Kathrin: *Many good points have already been mentioned, and I would like to add two more, which are crucial at the very beginning of the co-creation process.*

First, it is about attitude. As researchers, we need to be more humble. We should not think that we are the only ones who know what a good intervention looks like. While we may be experts in science, scientific design, and conducting research, an intervention is only good if it fits the needs and lives of the users. We need feedback from our users to create effective interventions that will actually be used. We must acknowledge that we are not experts in everything.

The second point relates to knowledge and knowledge transfer. In psychotherapy, for example, we aim for our clients to become their own experts, able to manage their own problems. We transfer our knowledge to our clients to empower them to become true experts. This is also important in co-creation. As researchers, we should share our knowledge with our co-creators so that they can eventually become experts themselves. This enables them to make well-informed decisions and design the best possible and most suitable interventions, ultimately making our research better.

Key points:
- Importance of humility and recognizing researchers are not experts in everything.
- Need for user feedback to create effective interventions.
- Knowledge transfer to empower co-creators to make informed decisions.

Audience inputs (via Slido):

- **Fahmida Akter**: As a person with lived experience of Mental Health challenges as well as an early career public health researcher, I'd go for creating more opportunities for people with lived experience for capacity building in their interested areas of life. Once they feel safe and included, they'll initiate their active participation. The key here is creating or establishing a safe, transparent process in research or any other setting. Additionally, a consolidated framework needs to be developed to protect the safety, and rights of the people with the lived experience to prevent tokenism.
- **Anonymous**: Empowerment and shared leadership: Empower individuals with lived experiences to take on meaningful roles within the co-creation process, such as leadership positions, facilitation roles, or spokesperson roles.
- **Anonymous**: Ensure that there is genuine value for the participants to get involved in the process - what will they get out of it?

- **Anonymous**: As researchers we should involve organizations who have skills and experiences in working with people with lived experiences of mental health issues. Such a cooperation partner builds a bridge between us and people we want to work with and all three parties learn from each other and create the co-creation process.
- **Anonymous**: In the absence of co-creation we operate on assumptions. We must not assume our interpretation is that of the groups we study. Their interpretations are essential for the best solutions.
- **Anonymous**: This is a cultural challenge. Getting people used to sharing their experience can help prevent stigma, judgment and prejudice. Training on active listening and enhancing emotional intelligence can be good strategies
- **Anonymous**: Developing rapport with the co-creation group and giving them enough confidence that their contribution is immensely helpful. Might also use a third-party evaluator who can ensure that information gathered in co-creation meetings are being used in the program and are reflected back and shared with the group.
- **Anonymous**: Actively support the genuine co creation process giving access for individuals with lived experience to share their insights and can make their voice heard.
- **Anonymous**: Value those we co create with as equals. Respect there knowledge and experience of the subject (problem, treatment, barrier etc)
- **Anonymous**: The term "citizens" excludes certain groups of people that may be especially suffering from mental health problems.
- **Anonymous**: When we try to recruit we try to mention that it's for mental health research however this could lead to exclusivity. Or marginalized people participating in research. So maybe need a better wording. Like distress and anxiety or wellbeing.
- **Anonymous**: It is important to map the stakeholders at the beginning of the project, and then to actively engage the different stakeholders in the different stages of the project.
- **Anonymous**: allocate sufficient time to the co-creation process
- **Anonymous**: In the project I'm working on we organise regular meetings where individuals with lived experience can explain what is really relevant to them and suggest features to include in the solutions under development. In this way they do not only provide a feedback on an already existing design but drive the actual design process
- **Anonymous**: This depends on how inclusive the research team are in both their language and collaboration style, but also how open they are for other forms of debates
- **Anonymous**: Ensure their active involvement in all stages of the process.
- **Lonneke Fuhler (Youth GEMs):** Integrate it into the plan and planning of a project from the start and at important (and less important) moments in the project. For example, at Youth GEMs we have Science Cafes where young advisors think with and give feedback to researchers about all parts of the project. They also regularly join the meetings of the work packages to be informed and also give their perspective and feedback. We experience this as very valuable for all the people involved. Researchers are glad to hear the questions and contributions, the young advisors feel seen and heard and are taken seriously.
- **Sophie Bertocchi**: I'm Sophie Bertocchi and I'm working on the project YouthGems and I feel I can give my contribution because I, myself, suffer from a mental health disorder. So I'm very thankful because including us in the team, I think is the best way to approach the challenge

- **Anonymous**: Ongoing co-creation processes rather than one single survey or focus group as you sometimes see
- **Anonymous**: Involvement in the planning, and also along the stages of the design of the plan to co create.
- **Anonymous**: Making sure that the project's management (meeting, communication ways, etc.) fits their agenda and needs
- **Anonymous**: They could be brought into a steering group so they have sight of the materials, help brief the researchers and help shape the outputs.

2. Are there inherent tensions between the rigor of scientific methodology and the adaptability required for true co-creation? How can researchers reconcile these tensions?

Mel: *There is a presumed tension between the rigid structure of scientific methods, which aim to be very objective and collect objective data, and the understanding, especially among social scientists, that data is also socially constructed. This tension arises from the scientific methodology's rigor and its aims to minimize bias, while at the same time, we work with co-creators who are a limited group of people providing us with guidance and support. This naturally raises questions about how biased the responses and guidance we receive might be.*

However, we all work within a mixed-methods approach, combining quantitative and qualitative work. The key, as someone already mentioned, is working together and upskilling our co-creators in terms of scientific knowledge and methodology. For our project, apart from the webinars and workshops, we have created a platform for collaboration and established a community of practice. This concept, while common among practitioners, is quite new for co-creators.

This community of practice allows our co-creators to come together, not only to discuss specific steps in the study design but also to build their skills. We have provided resources such as information about MOOCs (Massive Open Online Courses) and short videos explaining why we are taking specific steps in the studies. This empowers co-creators to provide competent support to the study and is beneficial for their future endeavors. It enhances their CVs and enables them to become great advocates for themselves and the vulnerable groups they represent.

This brief reflection highlights our efforts to balance power dynamics and ensure equitable expertise in our relationships with co-creators.

Key points:
- Tension exists between the objective nature of scientific methods and the socially constructed aspect of data.
- Mixed-methods approach (quantitative and qualitative) is key.
- Upskilling co-creators in scientific knowledge and methodology.
- Creating a community of practice for collaboration and skill-building.
- Providing resources like MOOCs and videos to empower co-creators.
- Enhancing co-creators' CVs and enabling them to advocate for themselves and vulnerable groups.

Rodrigo: *Scientific rigor and co-creation do not always match perfectly, as we learned through our project. Initially, we had a very structured approach for the co-creation procedures, involving schools and inviting all stakeholders in the school system to collaborate with us across the four countries where we are testing our platform. However, we quickly realized that this strict adherence to scientific rigor and methodology was not necessarily the most effective way to gather the necessary feedback at the beginning of the project.*

We had to be flexible and adapt our approach to collect as much information as possible. I would like to emphasize to other colleagues watching this that while scientific rigor is important, we must not become excessively rigid. It is crucial to be as flexible as possible during co-creation procedures. The goal is to maximize interaction with users and various stakeholders to enhance communication and obtain comprehensive feedback.

Key points:

- Scientific rigor and co-creation often don't match perfectly.
- Need for flexibility in co-creation procedures.
- Importance of not being excessively rigid to gather comprehensive feedback.
- Goal is to maximize interaction with users and stakeholders.

Mel: *I think it's important to explain the scientific process to stakeholders in a way that is understandable across different languages, age groups, and needs. This ensures that the process is meaningful to them and that they do not feel excluded. Instead, they should feel that they understand and have a reason to care about getting involved. I like the idea of fostering a sense of community where stakeholders can become part of something meaningful throughout the journey, creating a natural incentive for participation.*

We also need to be careful in how we create co-creative opportunities, maintaining the flexibility that was mentioned by Rodrigo. For example, a young person with social anxiety might not be comfortable providing feedback in a group setting or focus group. Therefore, offering more flexible opportunities for continuous feedback throughout the project and across different regions can be very useful.

Key points:

- Explaining the scientific process in an understandable way for different audiences.
- Creating a sense of community to incentivize participation.
- Offering flexible opportunities for continuous feedback, accommodating different needs.

Celia: *I'll share an experience we had in the Bootstrap project during our first year. We have been developing an assessment app to identify young people at risk of problematic internet use. To achieve this, we prepared an assessment with many psychological scales that are very rigorous from a psychometric point of view. We need thousands of young people in schools to use the app over the next six months so we can conduct studies and develop an effective algorithm for diagnosing risk.*

The challenge is to engage young people, aged 12 to 16, to use the app and complete these long and potentially boring questionnaires over six months. We adopted a co-creation approach for technology, involving young people in multiple steps of the app's development. These user

representatives helped us design the assessment app to ensure its usability and appeal to the final users.

Three perspectives could potentially cause tension: the psychometric team insists that all questionnaires must be completed in a specific context, the IT technology team faces time and budget constraints, and the young users express reluctance to use the app. In one workshop, a young participant candidly said they would start but never continue using the app because it was too boring.

Our interdisciplinary approach has been key to addressing these challenges. In addition to online focus groups for early feedback, we organized a face-to-face camp where all researchers and young people worked in small interdisciplinary groups. This allowed young people, developers, and psychometric researchers to understand each other's perspectives and provide suggestions to make the app more engaging. For instance, ideas like storytelling or gamification were proposed, but from a psychometric point of view, turning the app into a game would alter how people use it, affecting the assessment's validity.

We explained these limitations to the young people, and researchers realized the need to make the app more user-friendly. This led to a negotiation where each party understood the others' points of view because of their interactions and discussions. Although the project involves multiple countries and is quite large, we strive to consider each other's perspectives.

This interdisciplinary approach, supported by previous training, has been a valuable component and a positive experience for us.

Key points:

- Challenge: Engaging young people in long and boring assessments.
- Adopted a co-creation approach for technology development.
- Three perspectives causing tension: psychometric team, IT technology team, and young users.
- Interdisciplinary approach with face-to-face camps for better understanding.
- Negotiation and understanding of different viewpoints to make the app user-friendly.

Kate: I wanted to give two quick examples: one on the tension between scientific rigor and cooperation, and the other on the issue of timelines.

One of the things we want to collaborate on with adolescent co-researchers is the outcome measures for our trial, which is a double-blind randomized controlled trial. There are clear limits to what we can do with outcomes within a trial. It feels key to us to be completely open with the young people and ensure they have appropriate training to understand what we are discussing. This ties into what Moe mentioned earlier. For instance, if we agree on a specific outcome measure with the young people, we need to clarify the limited scope for changes. However, in principle, we could alter wording if something is unclear to them. They need to understand the principles of rigorous scientific measurement to contribute effectively.

The second example is about timelines, which often come up when co-creating technological solutions with young people. There is always tension between different sources of input. It is important not to shy away from the fact that everyone involved has different kinds of

expertise. In our case, the design team, which already has experience collaborating with young people to develop a prototype of our technological intervention, leads the process. Ignoring their experience and starting from scratch with a new group would mean losing valuable insights informed by previous collaborations with young people. Openness about this helps everyone understand the expertise they bring to the process, which helps us move away from rigid paradigms.

Lastly, tech development is very timeline-driven. Being completely clear about these timelines from the start is essential to meet the deadlines that are crucial for the tech developers.

Key points:

- Tension between scientific rigor and cooperation.
- Importance of being open and training young people to understand scientific concepts.
- Clarifying the limited scope for changes in outcome measures.
- Timelines: balancing input from various sources and recognizing different expertise.
- Openness about expertise and experience helps in understanding and collaboration.
- Importance of clear timelines in tech development.

Audience inputs (via Slido):

- **Anonymous**: I think the legislation created more tensions than the scientific methodology. Obtaining informed consent for adolescents to be involved in co-creation from their parents required a lot of time (communication, reminding parents multiple times to sign even if they were onboard when we explained the objectives, etc.)

- **Anonymous**: I think they are but it requires communication with all stakeholders, but really work the extra time for communication into the framework. Work with stakeholders to define reasonable timing for each step where they are involved and be prepared to be flexible about involvement.

- **Sophie Bertocchi (YouthGems)**: Respect the difficulties of workers with mental health disorders, understanding their needs. The company I'm working with understands my struggles but it's not that common.

- **Anonymous**: There will always be tensions but my experience is that communications, verbal and written, are key. It is ensuring that everyone is brought along on the journey together and receive information they need in the right format at the right time. It needs regular check-ins to help with understanding.

3. Is co-creation worth it? How do we measure the success of co-creation efforts in mental health research beyond traditional metrics such as publications and grant funding? What alternative indicators of impact should we explore?

Kate: *Why do we do it? Because everything is better with co-creation. This inherently makes measurement difficult, but for me, measurement comes down to impact. If we take the impact plan designed in our application and consider it in a context where we haven't done co-creation, the vast majority of that work would not be possible. We need buy-in from all stakeholders at all stages to create the kind of impact we want. Therefore, the measurement of co-creation and the measurement of impacts are completely intertwined. We should consider how we measure impact, though that is a topic for another discussion.*

Key points:
- Co-creation improves overall project quality.
- Measurement of co-creation is intertwined with impact.
- Buy-in from all stakeholders is necessary to achieve desired impact.
- Measurement of impact is a topic for further discussion.

Mel: *The benefit of co-creation is that it is an essential part of understanding and addressing needs. The solution must be built around these needs, and the only way to achieve this is through co-creation. In terms of how to measure it, there are three main aspects to consider.*

First, there is the output of the co-production process itself, which includes the end product and its impact. This can be measured by the uptake of the product and the benefits experienced by those using it.

Second, there is the experience of participating in the process for the beneficiaries or end users. This can be assessed through interviews, focus groups, and other methods to understand how they felt during the process.

Third, we should consider the longer-term effects on the participants. Being involved in the process can provide them with confidence and skills that they can use in different aspects of their lives.

Key points:
- Co-creation is essential for addressing needs effectively.
- Three main aspects of measuring co-creation:
    1. Output of the co-production process (end product, its impact, uptake, and benefits).
    2. Experience of participating in the process (interviews, focus groups).
    3. Long-term effects on participants (confidence and skills gained).

Arlinda: *In the work we are doing, developing interventions without co-creators means creating solutions that may not be acceptable, accessible, or usable, rendering them ineffective. Therefore, it is essential and imperative that we engage in co-creation.*

In terms of evaluation, it is important to assess satisfaction with engagement levels and the involvement of stakeholders in the co-creation process. This helps us improve and refine our

methods for future projects. The quality of relationships and partnerships formed through co-creation is also crucial. Evaluating indicators such as trust, mutual respect, and collaboration among stakeholders, co-creators, and research teams is essential.

These factors can significantly impact policy and practice, which is the ultimate goal of our research. Co-creation allows us to assess the extent to which these effects influence the development of services and clinical practices. This can be documented and evaluated.

Additionally, empowerment and capacity building are vital aspects. We aim to upskill and build capacity in our co-creators, so measuring the impact of these efforts is important. It ensures cultural and contextual relevance for the solutions we create. Finally, assessing the ethical and social impact, including ethical considerations and social implications of our co-creation efforts, is essential.

Key points:
- Interventions without co-creators may be ineffective.
- Assess satisfaction with engagement and involvement.
- Quality of relationships and partnerships (trust, respect, collaboration).
- Impact on policy and practice.
- Empowerment and capacity building.
- Assessing ethical and social impact.

Rodrigo: *I need to mention one point that is being emphasized here, which is acceptability and acceptance. There is a gap between us as researchers and our methods, and what we think is the best solution versus what actually is the best solution. We need input from various stakeholders—in our case, adolescents, teachers, and parents—while designing our solutions and throughout all stages of the process.*

Regarding how to measure and assess the impact, apart from the options highlighted here, we can also develop a log to track the actual changes in the program. This log can document how co-creation procedures impacted the course of the project. Additionally, an online platform or section dedicated to different methodologies and types of reports could be very useful. It would support external reporting and allow other researchers to benefit from the lessons learned and understand how projects are evolving.

Communicating these findings, not only the scientific community but also the general public, is essential. This transparency can help bridge the gap between research and real-world applications, ensuring that our solutions are more effective and widely accepted.

Key points:
- Importance of acceptability and acceptance from various stakeholders.
- Develop a log to track changes and impact of co-creation.
- Online platform for different methodologies and reports.
- Transparency in communicating findings to both the scientific community and general public.

Celia: *What I want to emphasize is that we need to integrate this knowledge and experience into the scientific community. We are talking about citizen science and involvement in science. So,*

instead of questioning the ways we can show the impact of involving citizens in science beyond applications, we need to create publications and inform the scientific community by writing scientific papers.

We should document this way of working, including its impacts, difficulties, limitations, best practices, and outcomes. By doing so, we can build a rigorous scientific body around this new method. Citizen involvement should not be considered optional or non-scientific. It is a valid methodology that deserves recognition and rigorous study within the scientific community.

Key points:
- Integrate knowledge and experience into the scientific community.
- Create publications to document impacts, difficulties, limitations, best practices, and outcomes.
- Recognize citizen involvement as a valid scientific methodology.

Claudia: I want to emphasize that measuring success is truly a work in progress. In the scope of ADVANCE, we are trying to do this together with our societal advisory groups, which are leading the co-creation efforts. These groups are composed of 10 to 12 people representing end users, practitioners, policymakers, and mental health organizations from each of the seven participating countries.

For us, the benefits of co-creation are measured in terms of whether the interventions implemented bring a better understanding of users' needs, are usable, are taken up, and whether their results are sustainable. Success must also be measured by whether participants feel empowered both personally and professionally, and whether co-creation inspires cooperation and nurtures both existing and new relationships for collaboration.

The indicators of co-creation impact should be co-created as well. We hope that within our project, we can develop these with our societal advisory groups. A good sign of producing important impact is whether co-creators sustain their involvement throughout the project. These are long projects, so nurturing involvement is crucial, bringing us back to the importance of relationships and maintaining them well.

Key points:
- Measuring success is a work in progress.
- Societal advisory groups lead co-creation efforts.
- Benefits of co-creation: understanding users' needs, usability, sustainability.
- Measure empowerment, cooperation, and relationship building.
- Indicators of co-creation impact should be co-created with stakeholders.
- Sustained involvement of co-creators is a sign of impact.

Audience inputs (via Slido):

- **Anonymous**: Articles in more mainstream places - magazines, blogs, social media, newspapers and their reach.

- **Anonymous**: Acceptance of treatment, outcome measures, impact on implementation (we should aim to document co-creators influence), new understanding of the topic (which are often found in these projects)

- **Anonymous**: I'm saying this as a subjective personal view, and as someone that joins many different communities with people affected by problems related to mental health. For me, seeing success in a project of these scopes would be seeing the target audience of said studies to feel heard, and to see hope in a future where these researchers can influence the system for them to have lives where they feel as a part of the broader community, not being afraid of being open about their needs. As Arlinda said, having an impact on the influencing of policies and changes of that regard.

- **Anonymous**: Most often, we focus on the large-scale impact of the program however we should start with the co-creation group themselves. how this activity improved/impacted them and if the process brought any benefit to them, then it has an impact as well.

4. Questions from the Audience:

Q1: The engagement of different stakeholders in co-creation needs to be sustained and nurtured, but this can be challenging because research projects are often quite long. We've heard from you that it's important to build co-creation from the beginning and continue it through to the end. What challenges have you faced in supporting this sustained engagement, and what strategies have you put in place that you can share with us? Specifically, how can we support the engagement of all stakeholders, including specific groups such as young people, people experiencing mental health problems, or other vulnerable groups?

Arlinda: *It is really important, and I also wanted to address one of the questions from the Q&A regarding sustainable co-creator involvement without incentives. When we think about equity, co-creators are part of our team, and their contributions should be compensated fairly. It is more than fair and equitable to provide incentives, including financial compensation, for their time. However, I understand there may be challenges in terms of funding and limitations.*

There are other incentives to consider beyond financial ones. For example, we agreed to provide funds for upskilling. If co-creators wanted to take specific research-related online courses, we could pay for them. Additionally, we discuss with the co-creators what incentives they would like to receive, such as CV support and references, depending on whom we are working with. Incentives and fair compensation for their time are crucial.

Regarding challenges, we face specific issues because we are working across eleven countries, with eleven cultures and eleven languages. We wanted to create a community of practice, but to do so, we needed a common language. We decided to use English, which means we are excluding some important, vulnerable co-creators. To address this, we created a cascading approach with a core group of co-creators who speak English. This core group includes many who have joined us today, which is wonderful to see.

Additionally, we stratify for the vulnerable groups we are working with. For example, we work with older adults for whom the digital divide is a significant issue. We have a core group of co-creators

and also local groups of co-creators, all working together to support us. This is how we address this challenge.

Key points:
- Importance of equitable compensation for co-creators, including financial incentives.
- Consider other incentives beyond financial compensation (e.g., funds for upskilling, CV support, references).
- Challenges due to working across eleven countries with diverse cultures and languages.
- Created a community of practice with a core group of English-speaking co-creators and local groups for vulnerable populations.
- Addressing the digital divide for older adults by having core and local groups working together.

Rodrigo: *During the project proposal preparation, we invited teachers and student associations to be part of the project. Although they were interested, they sometimes faced difficulties such as unexpected challenges and bureaucratic problems. We wrote the proposal in 2021, but the project started in 2024, and they had regulatory obligations that prevented them from committing to something three or five years in advance. Because of these regulatory issues, it was impossible to have them officially included in the project to receive funds directly for their contributions.*

To address this problem, we need to think of collaborative solutions. One approach we considered involves being specific about the knowledge needed at particular moments in time. We identify potential supporters for the co-creation procedures and specify their investment to ensure more continuous participation. Not all individuals need to be engaged from the beginning to the end of the project; instead, they can contribute at specific time points to be more productive and effective with their time.

Additionally, recognizing that they have other interests and commitments, we must find ways to acknowledge their participation without requiring a three- or four-year commitment. As Alina suggested, we can ask them how they would like their participation acknowledged. This could include certificates of participation in research, training in specific content helpful for their professional development, or certificates for teachers, parents, or students that can be recognized in their practice.

Key points:
- Invited teachers and student associations faced challenges due to regulatory obligations and timing.
- Proposed solutions include identifying knowledge needs at specific times and specifying investments for continuous participation.
- Not all individuals need to be engaged throughout the project; contributions can be made at specific time points.
- Acknowledging participation without requiring long-term commitments (e.g., certificates of participation, training for professional development).
- Asking participants how they would like their contributions acknowledged to ensure meaningful recognition.

Q2: How can we take into consideration the needs of mental health workers and researchers, given that the workplace is not always accommodating for people experiencing mental health issues? Their needs are often not respected. In the scope of our current research discussions, could we even co-create solutions to address mental health issues in the workplace?

Mel: *Many times, as projects evolve, we focus on creating opportunities for participants and end users of the products, but we often forget about the team we're working with. Perhaps co-creation should start at the team level, identifying whether there are aspects within the team that are reflected in the work being done and addressing the needs of team members. This includes supporting those who come in and out of the wider team along the way. By implementing good practices from the start, we can demonstrate to other co-creation members how we approach the projects. It's a good point to raise and for teams to consider as they move forward.*

Key points:

- Co-creation should start at the team level, identifying aspects within the team that are reflected in the work.
- Addressing the needs of team members is crucial, including support for those who join and leave the wider team.
- Implementing good practices from the start demonstrates effective approaches to other co-creation members.

Q3: You all mentioned in different ways the importance of creating a safe space, emphasizing openness, respect, and transparency. How can we create a safe space for co-creating mental health research?

Kate: We need to think carefully about who the people are that we are doing co-creation with. In our case, as I mentioned, we have several different groups. I just talked about three examples of young people, but we have many other groups as well. It's important to design the infrastructure to be tailored to their needs. Part of the co-creation process involves understanding the individuals' needs. Even if we have an initial idea, we can still keep adapting it.

This approach emerged from our work with the Unicorn Theatre group. Before establishing the group, we visited the young people's schools and asked them to show us around from their perspective. This gave us real insight into their views and allowed the creative professionals at the theatre to start thinking about how to design a safe space. Every week, as the young people come in, they continue to actively think about that question, gather feedback on an ongoing basis, and mold the design of each session to meet those evolving needs.

Key points:

- Careful consideration of who the co-creators are is crucial.
- Involving several different groups, not just young people, is important.
- Infrastructure should be tailored to the specific needs of each group.
- Understanding individuals' needs is a key part of the co-creation process, requiring ongoing adaptation.
- Example from Unicorn Theatre:
    - Visited young people's schools to gain insight from their perspective.
    - Creative professionals used this insight to design a safe space.

- Weekly sessions involve continuous feedback and adaptation to meet evolving needs.

Q4: In your experience, what could be the most meaningful forms of acknowledgement of the contribution for end users in the co creation process?

Kate: *Again, it depends on who we're talking about. For our young people involved in game design, it would be much more attractive for them to be acknowledged as part of the game's development team, similar to credits at the beginning of a film. For adolescent co-researchers involved in all aspects of the project, giving them the opportunity to be involved in a publication and be named within it towards the end of the project would be particularly valuable. So, it really depends on the group and their specific context.*

Key points:
- Acknowledgment should be tailored to the specific group involved.
- For young people in game design:
  - Being acknowledged as part of the game's development team (similar to film credits) is attractive.
- For adolescent co-researchers involved in all aspects of the project:
  - Opportunity to be involved in a publication and be named within it towards the end of the project is particularly valuable.
- Acknowledgment strategies depend on the group and their specific context.

Q5: How do you think we can ensure diversity in co-creation so that those we involve represent the perspectives of the entire community? How can we practically integrate that at the beginning of the project?

Celia: *It is a very important question because while we emphasize the importance of involving citizens, we need to carefully recruit and select our team. Who are these citizens that will work with us? Although I don't have all the answers, we should ask ourselves this question when planning the project.*

This is absolutely key because involving researchers and citizens in research requires designing the research protocol accordingly. We should treat this with the same rigor as we do when considering our sample. Currently, we often view this as something separate or optional, but it is not.

We need to think about the stratification, profiles, and inclusion and exclusion criteria for the co-researchers, just as we do for the researchers selected for the project. Co-researchers should also go through a selection process, especially if they will be involved on a day-to-day basis and not just at one step.

Proper planning is crucial and should be done before the research project starts, during the application phase.

Key points:
- Importance of careful recruitment and selection of the co-creation team.
- Critical question: Who are the citizens that will work with us?

- Designing the research protocol to include both researchers and citizens with the same rigor as sample selection.
- Consider stratification, profiles, and inclusion/exclusion criteria for co-researchers.
- Co-researchers should go through a selection process, especially for ongoing involvement.
- Proper planning should be done before the research project starts, during the application phase.

Arlinda: *It is important for us to think about this very thoroughly in MentBest. We created standard operating procedures throughout the 11 countries where we worked, putting a lot of thought into mapping our stakeholders. We aimed to cover all the different characteristics we wanted in our co-creators.*

A significant amount of work went into this mapping process across the participating countries in the research. Having very clear standard operating procedures was crucial. We did not approach this ad hoc, as it might seem when just selecting co-creators. Instead, it has been a very clear and strict process for us.

Key points:
- Emphasizes the importance of thorough planning in MentBest.
- Created standard operating procedures across 11 countries to map stakeholders.
- Ensured coverage of all desired characteristics in co-creators.
- Clear and strict processes for selecting co-creators, avoiding ad hoc approaches.

Mel: *I think the issue of diversity is fraught with problems because some diversity categories tend to rise to the top, leaving others unseen. This is why it is crucial to cast the net widely in the recruitment strategy and consider the different types of incentives that various people need to get involved. Building and fostering a sense of community across diverse groups will make people more likely to want to participate.*

I agree with Celia about the importance of planning. The recruitment strategy must be built from the very beginning. By planning carefully, we can ensure that the communities we recruit from naturally have the diversity we need, rather than recruiting for specific categories. This approach encourages a broader range of individuals to come forward.

Key points:
- Diversity issues can leave some groups unseen; cast the net widely in recruitment.
- Consider different incentives to engage diverse groups.
- Build and foster a sense of community across diverse groups to encourage participation.
- Agree with Celia on the importance of planning the recruitment strategy from the beginning.
- Ensure natural diversity in recruited communities rather than targeting specific categories.

Claudia: *Very briefly, I agree with the proposals and considerations that have been made. Just to emphasize that we need to be very humble. An important question to ask our co-creators is, "Who is missing?". We should then actively engage in efforts to bring those voices into our discussions.*

Key points:
- Emphasize humility in the co-creation process.
- Important question for co-creators: "Who is missing?"
- Actively engage efforts to bring missing voices into discussions.

Q6: When talking about flexibility in co-creation, how do we strike a balance when findings deviate from the proposed project? How do we handle this with ethical review boards and funders?

Liuska: *We've seen a bit of this already—negotiating, finding compromises, and being transparent about how certain input is taken onboard or not. We also share this message with funders, encouraging them to create conditions that make this flexibility easier and possible.*

Key points:
- Importance of negotiating, finding compromises, and being transparent about how input is incorporated or not.
- Communication with funders to encourage the creation of conditions that allow for flexibility.

Claudia: *I think we also need to engage more with ethics committees, not just funding agencies. One recommendation we can make is to amend the project with a strong case for why deviations or new methods are being used. From personal experience, these processes are lengthy, taking considerable time not just to frame the amendments but also to receive a response. This often goes beyond the project timelines we've discussed before.*

Therefore, there should be some reconsideration of how co-creation is done, how it is funded, and how it is understood—not just by funding agencies but also by ethical committees.

Key points:
- Need for greater engagement with ethics committees, not just funding agencies.
- Recommend amending projects with strong cases for why deviations or new methods are used.
- Lengthy processes for amendments require considerable time, often exceeding project timelines.
- Reconsideration of how co-creation is done, funded, and understood by both funding agencies and ethical committees is necessary.

Final recommendations:

Mel: *I think it's really important for researchers to approach co-creation with the mindset that they might genuinely learn something from their co-creators. They should not engage in co-creation just for the funding or because they think they should, but rather with an open mind, acknowledging that these people have lived with the circumstances in question. The key is to consider what valuable insights and knowledge can be gained from them.*

Key points:

- Researchers should approach co-creation with an open mind, ready to learn from co-creators.
- Co-creation should not be pursued just for funding or out of obligation.
- Acknowledge that co-creators have lived experiences with the circumstances being studied.
- Focus on the valuable insights and knowledge that can be gained from co-creators.

5. Other questions answered via chat

Q6: What are the challenges faced in sustaining the involvement of co-creation groups without financial/incentives? and how to mitigate them.

Kate: I think the main challenge is that people always have a lot going on in their lives and we are asking time people to spend time on this. If there are no financial incentives then this challenge comes into play even more. For me, the key mitigation strategies are to build strong relationships and to think as broadly and creatively as possible about how to design the process of involvement in a way that is going to give the involved people skills and experiences they will enjoy and that will serve them well in their lives.

This question has also been answered live by Arlinda.

Q7: How important is it to have people with lived experience of mental illness/distress represented on the research team? Or alternatively do you think it's useful (and can contribute to preventing tokenism) if members of the research team disclose their own lived experiences of mental ill health at the beginning of the process?

Mel: This is a topic I have been discussing with my team as I think the openess of the team is the first step in breaking down stigma to create an open space for people to contribute to knowledge.

Q8: I'm a young biomedical engineer and I suffer from a mental health disorder. I want to spend my life to help and raise awareness about mental health, how can I do that? Do you have a website where I can find projects?

You can contact EURO YOUTH MENTAL HEALTH. If you have any difficulties in this contact, please feel free to contact me in my email: celiasales@fpce.up.pt

Q9: In child and adolescent mental health research, what should be the minimun age of a co-creation group member? any evidence on this?

Kate: I'm not aware of any evidence on a minimum age. I would say it comes down to how well you can design methods that are going to enable the children to collaborate.

Karthrin: We have a Child Advisory Board in another project with children as young as 6 years.

Q10: What about informed consent etc

Arlinda: We have Terms of Reference for our co-creators as we consider them our colleagues not study participants.

Karthrin: Informed consent might become necessary if you are collecting personal data (e.g. required for financial compensation) or if you are audio-/videotaping the co-creating sessions'

Q11: Is there any initiative that addresses / aims at cultivating mental health and wellbeing of people in European organisations? I am a certified trauma-informed relationship coach pursuing my career within HR, on a mission of fostering employee mental health and well-being in companies. But I found very little to none initiatives in organisations that prioritise this important topic.

Maria: Regarding mental health and wellbeing in companies, you can check EMPOWER project, a platform of mental health in the workplace: https://empower-project.eu/ It also has an anti-stigma campaign: https://antistigma.empower-project.eu/

You can look at https://www.mentuppproject.eu/ and https://www.prosperh.eu/about/

Q12: when talking about flexibility in the co-creation process, how to strike a balance between findings of co-creation group if it deviates, let's say 180degrees, from the proposed project. How should this be dealt with ethical review boards and funders.

Karthrin: In our project, we explain in the beginning the boundaries of the co-creation process and where they come from.

Annex

Program

- **Introduction** (program & expectations – *2mins*)
- **Welcome message** (*3-5mins*):
    - Mirjam BORSTNIK GERGELY, Deputy Head of the Health Research Unit, HaDEA
- **Lightning talks** (*20mins*)
    - Along the co-creation pathway, how can we actively prevent tokenism and ensure that individuals with lived experiences of mental health problems are not merely seen as a diversity checkbox, but as equal collaborators in developing solutions?
    - Only 2-3mins each to answer = this is the 'lightning talks' part.
    - Start with a short intro: *My name is … I am the (role) of (name of project)*
- **Moderated discussion** (30mins)
    - *Are there inherent tensions between the rigor of scientific methodology and the adaptability required for true co-creation? How can researchers reconcile these tensions?*
    - *How do we measure the success of co-creation efforts in mental health research beyond traditional metrics such as publications and grant funding? What alternative indicators of impact should we explore?*
- **Q&A with the participants** (20mins)
    - via Zoom Q&A tool
    - + 2 on camera questions/ reflections
- **Final messages** (10mins):
    - Panel: Recommendations for the Scientific Community.... also to mental health practitioners, policymakers, innovators and citizens – choose 1 (1 minute each)
    - Facilitator: Announcement of the webinar series starting September 2024

Links

Event announcements:

- https://advancementalhealth.ku.dk/news-and-media/news/2024/how-to-get-co-creation-right-in-mental-health-research/
- https://hadea.ec.europa.eu/events/webinar-how-get-co-creation-right-mental-health-research-2024-05-15_en
- https://www.mentalhealtheurope.org/emhw-event/how-to-get-co-creation-right-in-mental-health-research/

Webinar Series Registration:

- https://ec.europa.eu/eusurvey/runner/JointWebinar2024

Webinar Series Announcement



Intro Slide



Event poster

