Lebanese Republic
Ministry of Public Health
National Mental Health Programme

Service User Participation Toolkit

FOR MENTAL HEALTH SERVICES, PROGRAMMING & POLICY

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Finally, appreciation goes to BeyondText for the design of this toolkit.

Animation

An animation for service users that encompasses some of the main themes of this toolkit was developed as a tool that can be used in tandem with this text. The animation can be accessed at: **https://lshtm.ac.uk/goal**

Citation

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Introduction

About this Toolkit

In this toolkit, we aim to define meaningful service user participation, explore its potential benefits, and present different strategies and simple, practical guidance for improving participation in the design and implementation of mental health services and policy.

This toolkit contains guidance on how to increase the meaningful participation of mental health service users in decision-making on the level of the individual service user, on the level of mental health services, and on the level of governance and policy.

Enhancing service user participation can increase the agency and independence of service users, reduce social stigma from service providers and the community, lead to better services that reflect service user needs, and improve health outcomes on the whole.

Who is this toolkit for?

Mental health service providers and practitioners

looking to increase the participation of service users in informing design and delivery of services.

Policy-makers

who strive for greater inclusivity and representation in legislation and governance and who wish to increase service user involvement in decision-making ag policies related to mental health.

Service users

wishing to advocate for their greater participation within mental health services (including the private sector, NGO sector, and government services), and in mental health policy.

"Service user participation has a lot of advantages as it conveys accurate needs and challenges that service users face."
(Service Provider)

"Engaging service users in decision-making on the level of services is a form of actual participation which is meaningful for service users and sustainable."
(Service Provider)

"Service user participation sheds light on particular things that we haven't really looked at, so it gives us a new perspective. It could show us a need that we have been overlooking and I think it leads us to create a better relationship between service providers and service users."
(Service Provider)

How was this toolkit developed?

The toolkit is a result of qualitative research around service user participation conducted as part of the GOAL project, a research project which aims to support government and partners in health system strengthening for better mental health of Syrian refugee and host communities in Lebanon. You can learn more about GOAL at: www.lshtm.ac.uk

The toolkit is intended for use in all country settings, including LMICs and forced migration settings (where GOAL research was conducted).

The contents of this toolkit are based on a combination of:

Service user lived experience, including service users from Justice for Mental Health— the first mental health service user association in Lebanon— and other documents created by service user organisations identified in our desk review

GOAL researcher and practitioner observations and anecdotal experiences from the field.

Desk and qualitative research conducted as part of the GOAL project. The toolkit is informed by a growing body of knowledge and existing global good practice from service user organisations, practitioners and policy-makers.

Positionality statement

The authors of this toolkit include TZ, a service user researcher from Lebanon working on the GOAL project. TZ is also a founding member of Justice for Mental Health. Although a service user, TZ is not representative of most average service users in Lebanon, and is privileged with having knowledge and training in academia and on the topic of participation in mental health. In addition, this toolkit was not originally written with the direct input of refugee service users.
The other authors are researchers from the GOAL project from various positionalities within academia in both Lebanon and the UK, the mental health system in Lebanon as well as the global humanitarian system.

References and further readings are found at the end of this toolkit. Our hope is to have produced a tool for sharing knowledge, guidance, and practices, for anyone who wishes to integrate service user participation into their practice.

What is service user participation?

In this toolkit, we refer to participation as the influence and decision-making power that people have when it comes to making the decisions that concern and affect them, and for the design and implementation of mental health services and policies for the population. Participation often refers to granting persons with lived experience decision-making power.

Across many sectors and disciplines, participation is recognized as a way to address power dynamics between those who provide services and those who receive it.

Participation in humanitarian settings

In humanitarian settings, mental health services are intricately linked to broader systems of aid delivery, often characterized by a top-down approach from the global “North” to the global “South”. Participation is a way to address the inherent power imbalances in humanitarian aid and knowledge production. By actively involving service users and local communities in decision-making processes, participation can be a tool for challenging these power hierarchies. In doing so, participation becomes a step towards decolonizing aid and knowledge production, and fostering more equitable and culturally sensitive approaches to mental health support in humanitarian contexts.

What makes participation ‘meaningful’?

Meaningful participation is the ability of actors ~~to have a tangible impact within~~ to have tangible impact within relevant decision-making spaces, on decisions that affect them directly or the broader population. Sometimes, practices are labeled as participatory, but are tokenistic ‘ticking the box’ activities in reality. In our research and experience, reported examples of common tokenistic ‘ticking the box’ activities included:

☑ Inviting service users to be a part of committees without ensuring mechanisms for their feedback to be taken into consideration or giving them real decision-making power

☑ Requesting feedback from service users on the last stage of a project (e.g., a media campaign) without involving them in any earlier phases of the project

☑ Inviting service users to participate by speaking only to give a testimony about their own mental health and life story, rather than about other topics of their own choice or making decisions

In order to avoid involving actors as tokens, it is important to ensure that their participation is active and meaningful, rather than passive or even manipulative.

Service user participation

Service user participation refers to the involvement of service users in the range of decisions that concern them.

This involves service users participating in decisions on a micro-level, such as on the individual level, to the level of designing and improving services, and even to the macro-level of policy and legislation.

Examples of decisions include:

- the decision to seek services
- decisions related to treatment options
- the ability to give feedback about and contribute to service design and delivery
- setting research and policy priorities for mental health, contributing to discussions around legislation...

Expert by Experience

Certificate of Lived Experience

Meaningful service user participation constitutes an active partnership between service users, mental health professionals, researchers, and policy-makers, where service users are able to have an impact on decision-making. In a review of academic literature about service user participation, service user participation is defined as

> *An active partnership between service users and mental health professionals in decision making regarding the planning, implementation and evaluation of mental health policy, services, education, training and research. This partnership employs a person-centred approach, with bidirectional information flow, power sharing and access to advocacy at a personal, service and/or societal level.*
>
> (Millar et al., 2015)

Why service user participation?

“Nothing about us, without us”

This slogan from the disability rights movement has been adopted by service users and persons with lived experience in mental health around the world, and refers to the idea that no decisions and actions related to mental health can be taken without the meaningful, active, and full participation of those who are most affected by the outcomes of those decisions.

Experts-by-experience

Service users are persons with lived experience: they have personal knowledge about mental health gained through direct, first-hand experience. As such, they are often considered to be **experts-by-experience** within healthcare systems, who must work alongside traditional experts.

The participation of service users in mental health policy, planning, and service provision **is increasingly recognized to have benefits in health system design and governance.**

Research has found that service user participation has many benefits:

For service users themselves:

- Improved service user knowledge
- Greater chances of recovery
- Better experiences of care
- Increased agency, independence, and autonomy
- More inclusion

In services:

- Increased quality of services
- Reduced human rights violations within services
- Reduced social stigma
- Enhanced evidence-based decision-making within mental health services leading services that more accurately reflect needs
- Better outcomes of activities
- More realistic activities and better outcomes

In policy:

- Service user participation is central to:
- Addressing power imbalances in policy-making
- Setting priorities for mental healthcare on a national level
- Providing an evidence-base for legislation and decision-making

Providing an accurate representation of needs

“Service users are key stakeholders and should be part of the decision-making process.”

How can service users be involved?

Peer Support

Service users can provide support to other peers who also have lived experience with mental health, either through one-to-one support or peer groups. Peer support can take place through sharing personal experiences, providing empathy and understanding, and offering practical advice. A growing body of evidence in research strongly supports the positive values and outcomes of peer support in mental health, especially within humanitarian emergency settings.

Research

Service users act as experts-by-experience and can inform mental health research priorities as well as the design and scope of research projects. Service users can participate in all stages of the research process, including determining if methods are suitable and evaluating the research project outcomes. Service users can participate in research in groups, such as through Community Advisory Boards. Service users can also be trained to become 'service user researchers', who can then actively participate in research activities.

Advocacy

The lived experience of persons who use mental health services provides valuable and irreplaceable insights for advocacy agendas on mental health. Their unique perspectives help shape policies and practices that truly reflect the needs of those who use the mental health system. Service users can work as individuals or in groups to advocate for their rights on the individual, service, and policy levels. The service user association 'Justice for Mental Health' in Lebanon is one example of a service user advocacy group.

Policy and Legislation

Service users and persons with lived experience can form powerful lobbying groups, challenging discriminatory legislations and pushing for more inclusive policies. Around the world, service users have come together to form service user associations that are then involved in policy influence and decision-making.

Designing and improving services

Increasingly, mental health service users are being considered experts in the training of service providers and evaluation of mental health services due to their first-hand lived experience.

Principles of service user participation

1. **‘Do no harm’:***Ensuring service users are protected, particularly in settings where they may be exposed to societal stigma by speaking out*

2. **Accessibility and accommodations:** *Ensuring service users can easily access mechanisms for participation*

3. **Available opportunities:** *Making different mechanisms for participation known and available to service users (such as feedback mechanisms, invitations to meetings, etc.)*

4. **Addressing power imbalances:** *Actively creating space for service users to participate and inviting service users into closed decision-making spaces, where few ‘power-holders’ (such as policy-makers, or high ranking officials) typically are in charge of decision-making without outside consultation*

5. **Addressing stigma:** *Addressing stigma and misconceptions towards service users through capacity strengthening of policymakers and service providers, as well as service users and their caregivers*

6. **Two-way information-sharing:** *Gathering feedback and information from service users and informing service users of the outcomes of their participation*

7. **Equity:** *Granting all service users an equal voice and seat at the table*

8. **Respect and dignity:** *Respecting the right of service users to participate as experts-by-experience, and treating them with dignity*

9. **Representation:** *Ensuring that service user voices are as representative as possible by age, gender, race, nationality, and socioeconomic status of service users in the community*

“Do no harm” - a message from Justice for Mental Health

One of the most important principles of service user participation is ensuring that service users are protected from stigma, discrimination, and harm. It is crucial to consider the societal context in which service users participate, to ensure that their involvement poses no risk in environments where such disclosure could lead to negative consequences due to stigma. For instance, in some cases we have encountered, giving feedback to some services and providers might result in retaliation or harm. It is also vital to safeguard service users from being harmed or disrespected when other participants in a service, project, or advocacy campaign could pose a threat or trigger them. For example, there have been cases where service users from Justice for Mental Health were asked to collaborate on activities with traditional experts who had previously violated their rights or made derogatory comments about them. When not done carefully, service user participation can unintentionally reinforce existing disparities among service users. Ensuring safe and respectful participation requires careful planning and a commitment to protecting the well-being and dignity of service users.

“Participation can’t happen if the processes aren’t in place: There needs to be a clear process of participation in terms of the design, and in terms of giving the opinion and giving the recommendation about the service received. That way, we can collect decisions in a way that would be participatory. This needs to be mainstream within all the mental health service providers at the level of the institution and management. It needs to be part of the main strategy of each NGO, each service provider.”
(Service Provider)

Examples of accessibility and accommodations

These points were adapted from existing good practice guidance documents, in addition to GOAL research findings, and guidance from the service user association in Lebanon Justice for Mental Health.

Ensuring involvement during all phases of the project: Involving service users in initiatives as early as possible in the process as well as through different phases of the process to ensure their consistent influence and to enhance their feelings of ownership

Co-production of terms of reference: Involving service users in designing terms of reference, roles and responsibilities for their participation in the given initiative / process

Accessible meetings: Having clear procedures for meetings that are shared with service users beforehand, creating contingency plans for service users who are unwell and unable to be present (eg, the option to attend remotely, or participate with written feedback)

Accessible language: Sharing the aims and purposes of meetings in a clear and accessible manner and indicating how the issues discussed are related to service users' lives,avoiding technical jargon

Flexible meetings: Incorporating regular breaks into meetings and incorporating flexibility in schedules as well as any deliverable dates, being accommodating and flexible with any service user who has obligations such as caregiver roles or work obligations (eg, taking their input for convenient meeting times, compensating them for any time taken off work, supporting in finding childcare or allowing children into meetings)

Compensation: Providing equivalent compensation for service users' time and labour, including transportation or internet data if applicable

Representation: Accounting for diversity in gender, age, nationality, disability, and socioeconomic status (eg, mobilizing service networks or social media channels to help recruit service users); ensuring that all service users are equally informed about participation, have access to information about the project, and have access to accommodations. Ensuring equal voice to all service users to ensure equitable participation and influence, and to avoid perpetuating existing disparities based on intersecting vulnerabilities amongst different groups.

Providing options for participation: Providing multiple forms of information including verbal, written, visual, etc. as well as providing multiple forms of participation including written or verbal forms of communication such as focus groups, comment boxes, questionnaires, phone calls, etc.

Attitudes: Open and welcoming attitudes and behavior that are inviting for service user participation

Capacity strengthening: Providing training and capacity building opportunities for service users, practitioners, policy-makers, and service providers on service user participation

“I am the one responsible for myself and I take my personal decisions. Others may affect me, of course they will, but I’m the one who takes the decision.”
(Service Provider)

“I trust myself to take this decision to see what’s better for me.”
(Service Provider)

“Having someone that supports you is very important, because the emotional side and emotional support are very important”
(Service Provider)

Strategies to improve service user participation

Research, including desk research and the findings of GOAL qualitative research (see references and key resources) has highlighted enablers and strategies that may allow for more meaningful participation of service users.

Individual level

Social support:
Some service users expressed the importance of seeking social support from friends and family in decision-making

Awareness-raising:
Service providers and service users emphasized the importance of raising awareness and providing information about mental health to facilitate decision-making among potential service users

Campaigns to address stigma:
Service users can participate in awareness-raising campaigns to address stigma both in the community and within services

Empowering vulnerable groups:
Service users and service providers discussed the importance of supporting and empowering vulnerable groups including women and refugees, for example, by providing information and resources in an accessible format, and connecting vulnerable service users to other existing supportive networks and services

"It's true that sometimes one has to consult someone else or his therapist in order make a decision; more than one opinion is better" *(Service Provider)*

"It's good to get final input because its participatory, but at the same time, it doesn't include people from the first moment. Ensuring inclusion from the beginning leads to more meaningful participation."

"The therapist brought us together into a group meeting and explained to us about different mental health conditions, this helped me make more decisions in my treatment plan"

Services level

Information:

- Ensuring service users are well-informed about available treatments and services, can access information easily, and have the opportunity to make decisions about their service and treatment

Service provider advocacy:

- Service providers can advocate for more service user participation in decision-making

Accessibility (timing and location):

- Service users having input in the location and timing of services can be a facilitator for participation

Involving service users in the treatment process:

- Providing treatment options for service users (eg. medication, therapy…)
- Engaging service users in their treatment plans and discussing their goals

Opportunities for service user feedback:

- Making feedback mechanisms freely available and sharing information about feedback mechanisms: For example, over the phone, or through comment boxes
- Conducting focus groups or satisfaction surveys with service users
- Ensuring a bi-directional flow of information where service users are involved in decision-making also informed of how their feedback was taken into account
- Ensuring meaningful participation in M&E processes by incorporating service user feedback into final service design and planning

Opportunities for service user participation in the treatment process:

1. Informed decisions:

Providing access to all information related to decisions regarding service users' health (symptoms, risks, comorbidities), treatment, and recovery.
This includes information about treatment options, side effects of medications, alternatives, and available services in the community.
Information can be available on easily accessible platforms such as social media.
Using tools such as WHO QualityRights to ensure the participation of service users in the treatment process

2. Supported decision-making:

Service users can be informed of their right to appoint a person of support of their choosing to help in decision-making. When needed, support can be offered to service users in decision-making, through a trusted person of support designated by the service use.
Supported decision-making is not the same as substitute decision-making, or taking a decision on behalf of someone else.

3. Advance directives:

Advance directives are a detailed plan that service users can develop and set with their service provider or person of support, or even on their own.

- Advance directives detail the actions a service user would like to be taken in the case that they are temporarily in a state where they are unable to make decisions.
- Communicating wishes beforehand can help ensure that no actions will be taken against a service user's will, in situations where they are unable to cannot communicate their preferences.
- These advance directives can become part of the service user's treatment plan

4. Training medical teams to seek service user opinions and engage them in the treatment process:

- Design and planning services

1.
Setting organizational policies for service user participation

2.
Gathering service user opinions on organizational strategies through assessments

3.
Ensuring access to services as a first step towards participation

"Now definitely when we are talking about mental health and about engaging service users in their treatment plan, if we want them to reach recovery, we stress on the field teams to engage the service users in decision making. Making them choose their goal, to set their goal, to the role of our staff is only to guide or to support the beneficiary in defining their roles, but they are the ones who should set their own goals and the objectives"

"The role of the service provider is to explain to the service user that they have the right to participate in setting this treatment plan because it involves their personal life. This is [service provider's] job. "
(Service Provider)

"There should be a committee for the service users with a clear structure and hierarchy. And it's like a shadow unit that would have clear roles and duties and different levels and with different functions."
(Service Provider)

Policy level

Integration of service users into existing mechanisms:
Policy-makers can work to actively incorporate service users and service user groups into coordination and planning meetings:

1.
Inviting service users and service user groups to operational and coordination meetings

2.
Consulting service user and service user groups in advocacy and strategies

3.
Creating MOUs (memorandum of understanding) with service user groups

4.
Using informal channels such as social media to gather service user opinions

5.
Integrating service user feedback into policy design and legislation

6.
Incorporating participation mechanisms into governance structure

Service user groups:
Service users can work on advocacy through service user groups.
Around the world, mental health service users have come together to form associations or organizations. These organizations are run by service users and through them, service users work on raising awareness about mental health and more importantly, on advocacy for their rights to be active participants in making decisions. For example, these service user associations can be consulted when working on any legislation on mental health, as service users are seen as experts by experience that have input on all decisions regarding their rights.

Practitioners and policy-makers can play an integral role in facilitating the creation of these spaces for service users:

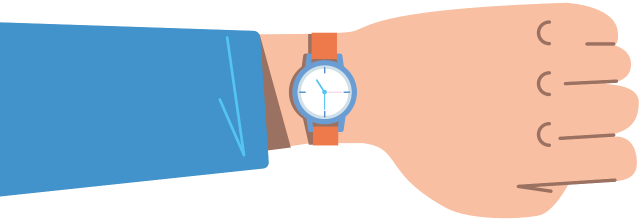
1.
Consulting service user groups on decision-making related to service planning as well as policy and legislation

2.
Facilitating the communication of service user groups with other service users within your services (for example, for recruitment)

3.
Integrating mechanisms for the inclusion of service user groups as major stakeholders in higher-level mental health decision-making (for example, inviting service user groups to coordination group meetings, creating channels of communication with service user groups, creating advisory boards and committees, involving service users in policy design, implementation, and evaluation)

Some challenges you might face

Potential challenges	Proposed solutions
Limited information and knowledge provision to service users	Making sure a two-way flow of information is always in place, where service users are informed of their rights and options as well as the outcomes of their participation
Perception of service user participation as being too costly and time-consuming	Allocating an adequate budget and accommodating service user participation during service design and planning from the beginning, raising awareness about how service user participation can lead to more effective services and outcomes, and advocating for participation to be an essential step, rather than optional
Stigma around the mental capacity and expertise of service users among professionals	Ensuring that mental health professionals and policy-makers have access to adequate information and, if possible, capacity-building around service user participation, consistent advocacy for service user participation
Existing power differentials between different stakeholders	Actively creating spaces for service user participation and inviting service users into otherwise 'closed' decision-making spaces, equipping service users with accessible information in the topics they are participating in, advocating for treating service users with dignity and respect, and integrating standard practices for service user participation into all processes and intentionally seeking to reduce these power imbalances

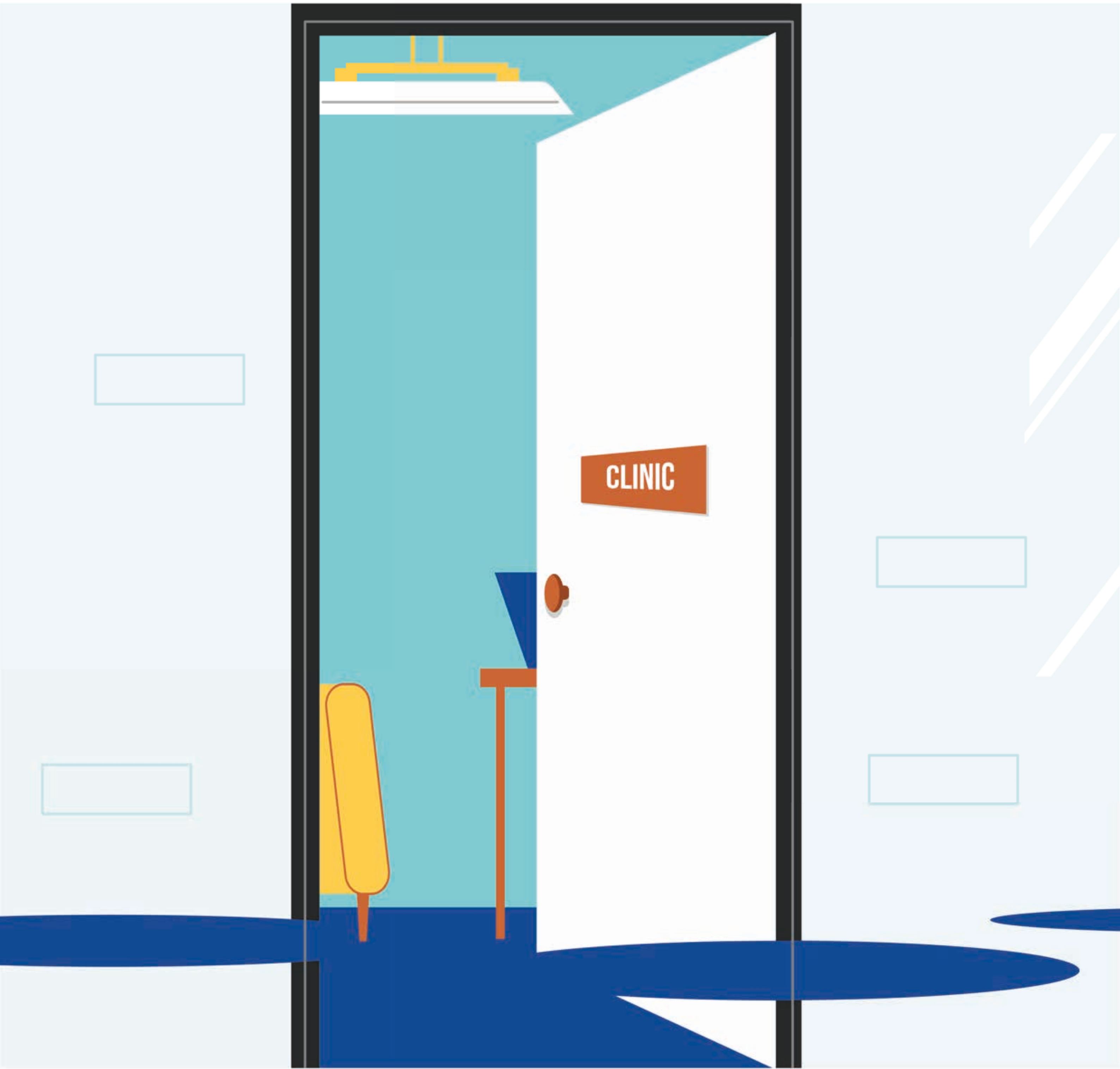


Potential challenges	Proposed solutions
Tokenism (for example, which can take the form of the consultation of service users without the intention of their full collaboration, or inviting service users without involving them in decision-making):	Ensuring that service user participation is integrated into the final decision-making process, and that service users are informed of the outcomes of their participation
Community and societal stigma	Providing accessible information around service user rights and service user participation and actively seeking service user involvement in the design of awareness and advocacy campaigns to set priorities and tackle societal stigma
Lack of resources for capacity-strengthening of service users	Allocating an adequate budget for the capacity strengthening of service users and investing in the creation of accessible educational tools about service user participation
Lack of accommodation in decision-making spaces	Actively seeking information about service user experiences and needs when involving them, and providing the necessary accommodations to allow for the full participation of all service users
Poor economic conditions and other competing priorities	Developing tools and material that can be disseminated to stakeholders in low-resource situations, integrating participation into standard practice within services and policy
Social, cultural and material barriers to accessing services (for example, financial costs, refugee status, or gender)	Prioritizing addressing barriers to access within services, as well as consulting service users to better understand these barriers and how to tackle them

Potential challenges	Proposed solutions
Lack of systemic mechanisms for participation	Investing in integrating participation mechanisms within service planning as well as on the policy level, such as advisory boards, internal policies that prioritize participation, and other two-way feedback mechanisms and ensuring information about these mechanisms is freely available
Community and societal stigma	Providing accessible information around service user rights and service user participation and actively seeking service user involvement in the design of awareness and advocacy campaigns to set priorities and tackle societal stigma
Difficulties finding service users to engage	Using informal channels, such as social media, using service networks to meet or recruit service users, providing appropriate compensation and accommodations for participation, as well as organizing events and disseminating information about participation within services and related organizations
Difficulties finding representation of a range of service user perspectives	Mobilizing service networks that cover different regions, populations and needs, collaborating with service user associations which, in turn, have active policies to promote diversity and ensure inclusion to capture a range of different needs and backgrounds (eg. diversity in gender, age, SES, refugee status, disability status, sexual identity, etc.)

Conclusion

Ensuring the meaningful participation of service users in mental health decision-making remains an ongoing journey, and we recognize that there is still a considerable distance to cover. We hope that the suggestions, insights, and experiences shared in this toolkit can serve as valuable resources in advocating for more participation. By prioritizing service user engagement, we can collectively work towards creating more inclusive, responsive, and effective mental health systems. Together—service users, service providers, and policy-makers—we can continue to advocate for the rights and voices of service users, ensuring that their perspectives shape the future of mental health systems.



Key Resources

Accompanying Animation

An animation for service users that encompasses some of the main themes of this toolkit was developed as a tool that can be used in tandem with this text. The animation can be accessed at: www://lshtm.ac.uk/goal

Justice for Mental Health service user association in Lebanon

Website:
www.justiceformentalhealthlb.org

Social media:
www.instagram.com/justiceformentalhealth.leb
www.facebook.com/JusticeForMentalHealth.LB

Best practice guides

Health Service Executive Ireland (2010) Achieving Excellence in clinical governance: Service user involvement

Turning Point Scotland (nd.) Good practice guide: Service user involvement

Voices of Experience (VoX) (2007). GOOD PRACTICE IN SERVICE USER INVOLVEMENT GUIDANCE NOTES.

UNICEF (2022) Young People's Participation and Mental Health: A Protocol for Practitioner.
www.unicef.org/reports/young-peoples-participation-and-mental-health

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