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Co-Designing Citizen Social Science for collective action



POLICY BRIEF ON MENTAL HEALTH CARE

Brief on policy recommendations to promote and strengthen mental health social support networks

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1. Executive Summary

This policy brief tables recommendations to strengthen mental health social support networks, as a result of the design and implementation of a new Citizen Social Science (CSS) project. Social support is a positive factor within mental health recovery, while also acting against social exclusion. However, evidence on how to fully harness its potential is still lacking. The "CoAct for Mental Health" project has been co-designed and directly driven by Co-Researchers, people with mental health problems and their families. The intrinsic and transformative value of personal lived experiences of mental health problems is extended with the methods and tools presented. CSS makes it possible to implement an inclusive and multi-level participation model, based on cooperation. This involved launching a chatbot to invite all citizens to participate in the CSS research and deploying collective data interpretation methodologies to include Co-Researchers in the results discussion and in drawing conclusions to make recommendations and support specific demands. Within the local context of Catalonia, specific recommendations are made, which will be mainstreamed within the National Mental Health Pact. At a more global level, recommendations to include CSS tools and methodologies are made to the mental health research community.

2. Introduction

CoAct understands **Citizen Social Science** (CSS) as participatory research co-designed and directly driven by citizen groups sharing a social concern. CoAct has brought together and further developed methods to give citizen groups an equal 'seat at the table' through active participation in research, from the design to the interpretation of the results and their transformation into concrete actions. **Citizens act as Co-Researchers and are recognised as in-the-field competent experts**. Multi-stakeholder collaborations have formed **Knowledge Coalitions** to enable the provision of socially-robust scientific knowledge to promote social change. One of the CoAct Research and Innovation (R&I) Actions took place in Catalonia (Spain). It focused on mental health care and, more specifically, social support networks in mental health. This R&I Action was CoActuem per la Salut Mental (**CoAct for Mental Health**).



Figure 1

Citizen Social Science in Action, with citizen groups, a specific concern, and the support of the Knowledge Coalition.

3. Rationale for action

"Too many people living with mental health conditions are not getting the care they need and deserve... Business as usual for mental health care simply will not do."

Source: Word mental health report. Transforming mental health for all (WHO, 2022).

The World Health Organisation (WHO) advocates for urgent change in mental health care. Despite the emphasis on the need for accessible community-based health services since 2001, "the global shift towards care in the community has been very slow and truly multisectoral initiatives remain few and far between... We must intensify our collective actions to reform mental health systems towards comprehensive community-based networks of support." (WHO, 2022).

One way to change this mental health care provision paradigm, is to shift from a biomedical approach to a recovery model based on principles that include self-determination, resources beyond professional care, and a community approach. "Recovery is widely accepted as an important aspect of person-centred care in community-based mental health services [...] People with lived experience have long challenged the assumption that having a mental health condition means you cannot live a productive and satisfying life, arguing that recovery can occur even as symptoms persist. [...] The idea of personal recovery emerged to mean a way of living a satisfying, hopeful and contributing life despite the limitations that experiencing mental health problems can impose. Recovery-oriented care is not about treatment of symptoms but about empowering people to have control of their own lives." (WHO, 2022).

3.1 Why are social support networks important?

"Social support refers to one's social bonds, social integration, and primary group relations – all concepts central to sociological theory and research. Social bonds and supportive relationships with others are essential to mental health;"

Source: Social Support and Mental Health. In A Handbook for the Study of Mental Health: Social Contexts, Theories, and Systems. (Turner & Brown, 2009).

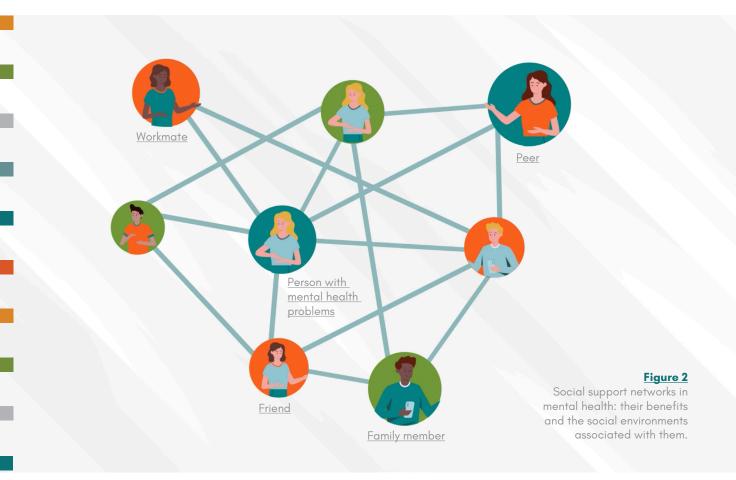
"Social support is a broad construct that describes the network of social resources that an individual perceives. This social network is rooted in the concepts of mutual assistance, guidance, and validation about life experiences and decisions. This social system plays a role in providing a number of forms of support, including informational, instrumental, and emotional support."

Source: Social Support. In Encyclopedia of Quality of Life and Well-Being Research. (Zhou, 2014).

Based on these generic definitions, an exhaustive characterisation of mental health social support networks has been further discussed within CoAct for Mental Health (see Annex 1). The different co-defined characteristics are listed below:

- WHAT do we mean by social support networks? WHO configures them? WHERE do they meet?
- WHAT are social support networks for? WHAT is their functionality?
- HOW do or should social support networks work? HOW do we connect or accompany them?
- HOW should we approach their creation, promotion and access?
- What DIFFICULTIES do we encounter in creating, accessing, and maintaining social support networks? What NEGATIVE circumstances can interfere within social support networks?
- What ELEMENTS characterise social support networks? What PRINCIPLES or VALUES govern them?

SOCIAL SUPPORT NETWORKS IN MENTAL HEALTH



BENEFITS

PROTECT against mental health problems

FACILITATE empowerment and recovery processes

IMPROVE quality of life and well being

ACT against isolation and social exclusion

CONTEXTS

CLOSE ENVIRONMENTS: Personal life experiences, the closest family and extendend family, close friends and intimate relationships

PROFESSIONAL AND INSTITUTIONAL ENVIROMENT: Social support networks in mental health services

SOCIETY ENVIROMENT: Social relations, activism and empowerment, learning spaces and meaningful occupation / working places

Social support has proven to be a positive factor within mental health recovery (e.g. Cooke et al. (2017)). Federació Salut Mental Catalunya and Activament reports (2017) also show that people with personal experience in mental health consider social support networks (mainly family and friends) to be key elements for recovery, well-being, and crisis management. Social support networks not only improve people's quality of life. They are also a preventive factor against isolation and social exclusion (WHO, 2022). The COVID-19 crisis has indeed shown the extent to which formal and informal community support has a protective role (e.g. Schug et al. (2021)). Although the importance of social support networks is increasingly acknowledged, we need new research approaches to fully understand how they work and how to promote and strengthen them. Scientific evidence-based reactions are needed to fully deploy their capacity to improve mental health at a wide scale.

3.2 Window of opportunity in Catalonia

In Catalonia, in 2015, more than 1 million people visited primary care services for mental health problems (Generalitat de Catalunya, 2016). This figure is consistent with the worldwide (WHO, 2022) estimates that 13% of the global population is living with mental health problems.

Catalonia presents some specific features compared with other Western European regions. Catalonia is reported to be especially active in progressive approaches to mental health care and support, including the implementation of community-based mental health care and the recovery model (Eiroa-Orosa & Rowe, 2017). There is a beneficial coexistence of organisations that provide institutional representation of people with mental health problems and families (e.g. *Veus*). Particularly important to this report is a federation of associations (*Federació Salut Mental Catalunya*, Catalonia Mental Health Federation), since the Federation is one of the CoAct partners and co-authors of this report. There are also territory-specific anti-stigma campaigns, driven by civil society organisations (e.g. *Obertament*).

In Catalonia, as in other European Regions, the population's mental health has been strongly affected by the COVID-19 pandemic. The European Union (2022) and the WHO (2022) both report a significant increase in anxiety, depression, and serious mental health problems. The recovery process for people diagnosed with a mental health problem has also been affected, as well as the health of people who play a support and care role.

The Parlament de Catalunya (Catalan Parliament) held a plenary session to discuss mental health in December 2021. The chamber voted, with unanimous cross-party support, to create a programme to be drawn up by the Pacte Nacional de Salut Mental (National Mental Health Pact; NMHP). The NMHP is the interdepartmental and intersectoral instrument of the Generalitat de Catalunya (Catalonia Government) which, aligned with the recommendations of the WHO, promotes mental health in all areas of action of the Government and society (Generalitat de Catalunya, 2022). The NMHP has a communitarian spirit and is currently in a phase of promotion and creation, gathering ideas and proposals from citizens, organisations and associations, family members or people with mental health problems. The NMHP is the first Catalan government interdepartmental action that identifies mental health as a priority to be tackled collectively by all government ministries. The NMHP will issue policy recommendations in December 2022. These recommendations will then be prioritised and progressively implemented by the Catalan ministries.

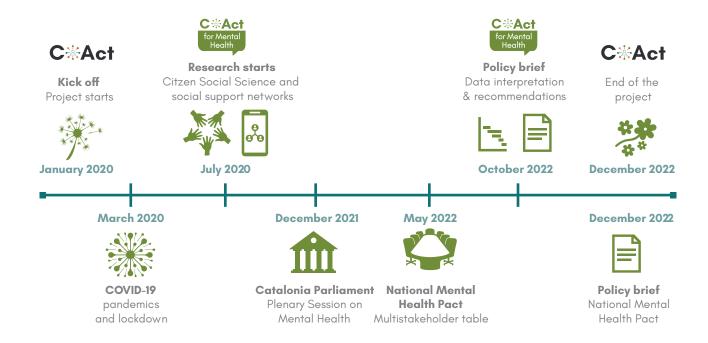


Figure 3

Timeline of policy actions and strategy in Catalonia in relation to CoAct and CoAct for Mental Health.

4. Citizen Social Science for Mental Health

"Valuing the insight of people with lived experience of mental health conditions, and giving them voice, choice and influence in multiple aspects of the mental health care system, is a vital step towards transforming mental health worldwide."

Source: Word mental health report. Transforming mental health for all (WHO, 2022).

The participation of people with lived experience of mental health conditions is key to transforming mental health worldwide (WHO, 2022). There are also several official recommendations to ensure participation of people with mental health problems and their families, at all levels, including research, design, and implementation of services and programmes (EC, 2016; UN, 2006).

Citizen Social Science (CSS), defined above as participatory research co-designed and directly driven by citizen groups sharing a social concern is a conceptual framework that can easily be applied to research on mental health social support networks. In that case, it has been proven to be an inclusive and multi-level participation model.

A three-level participatory research process was structured, as detailed in Table 1, to promote cooperation and trust among all participants:

- The first and most intense role was taken by the **CO-RESEARCHERS**, 32 people with first-hand experience of mental health, or family members.
- Research framing to enhance its impact on mental health care provision was one of the tasks undertaken by the **KNOWLEDGE COALITION**, made up of 65 representatives of organisations involved in mental health care provision (civil society organisations, universities, governments, public agencies, etc.).
- Anyone motivated to improve mental health, acting as **CITIZEN SCIENTISTS**, can contribute to the research by listening and responding to lived experiences shared by the Co-Researchers.

<u>Group</u>	Who	<u>How</u>	Why
CO-RESEARCHERS	People with lived experience of mental health problems and their families. 32 people with lived experience in mental health: 24 people with mental health problems 8 relatives 2 people with a double profile	Co-Researchers were invited to join through an Open Call (Catalonia).	- They have the most valuable knowledge on how social support networks work as they are at their centre. - Their personal lived experiences have a transformative intrinsic value.
KNOWLEDGE COALITION	Institutions: public administrations, civil society organisations, educational organisations, academia, and coresearchers. 65 representatives from 50 institutions joined the project.	Based on local, national, and international mapping, representatives of a wide range of institutions were invited.	- The institutions have practices and knowledge able to frame the research. - The institutions can implement concrete actions.
CITIZEN SCIENTISTS	Citizens from different countries and with different profiles, motivated by mental health improvement, subscribed to a chatbot currently available in 4 languages (Catalan, Spanish, English and German). 75% of the Citizen Scientists experience or have experienced mental health problems. 30% of the Citizen Scientists are	704 people signed the informed consent to actively participate through the collective research tool (chatbot). Data from 2022-10-23.	 A safe space is needed for collective and anonymised conversation. Diverse life experiences are listened to. Awareness is enhanced and empathy generated. New ways of gathering data and information from society at large are made possible.

<u>Table 1:</u> Description of the three groups participating in CoAct for Mental Health.

informal caregivers.

The research legitimacy is mostly grounded on the Co-Researchers and the Knowledge Coalition groups. However, crowd-sourced citizen science practices can further increase legitimacy by extending the research to the general public. Anyone, with or without a mental health problem, can subscribe to a Telegram chatbot to receive messages and respond to them. These participatory practices thus enlarge public awareness and triggers public discussion on mental health-related issues. By reaching a large number of participants, it is also possible to obtain large, new datasets on mental health from the population at large.

5. Methodologies and tools

5.1 Cooperation as an umbrella

The Co-Researchers and Knowledge Coalition were invited to participate from the earliest steps in the research process. A careful and articulated cooperation process was followed, promoted by a participatory expert facilitator, collaborating with the research team. In addition, a contact person was in charge of promptly replying to any communication by participants. All participants were dealt with individually to enhance mutual trust, and to recognise each contribution. They became key players able to influence any decision throughout the research and to reorient research plans if necessary. This process was eased by the facilitator who acted as a go-between to balance the different groups' contributions. This horizontality implied the emergence of a new scientific, institutional and citizen community that has worked together over the course of three years and that, once the research is finished, will continue to promote actions and deliver recommendations to the bodies responsible for implementing them.



1: Framing the research: KNOWLEDGE COALITION & CO-RESEARCHERS



2: Writing microstories through a research diary: CO-RESEARCHERS



3: Sharing them through a chatbot and engaging a wide public: CITZEN SCIENTISTS



4: Collectively interpretating data and proposing actions: CO-RESEARCHERS & KNOWLEDGE COALITION



5: Deliberating through an assembly: CO-RESEARCHERS, KNOWLEDGE COALITION & CITZEN SCIENTISTS

Cross-cutting Principles:

SUSTAINABILITY, RESPECT, INCLUSION, CONFIDENTIALITY.

Figure 4

Key steps, actors and principles of CoAct for Mental Health.

5.2 Research co-creation and transformation of results into actions

1. Framing the research

This first step made it possible to create the two main groups (Knowledge Coalition and Co-Researchers) but also to carefully examine and reflect on ethics and personal data protection. After receiving approval from Universitat de Barcelona's Ethics Committees, the informed consent procedure and the data protection framework were progressively explained to the participants and organically integrated in the research process. During this step, collaborative documents and definitions were also collectively prepared, to establish a common, shared basis. Finally, the participants' initial expectations and goals were collected, within a 3-year co-evaluation process.

2. Writing microstories through a research diary

The Research Diary. Hardcover publication to guide the Co-Researchers during the process of writing microstories based on their own personal experiences and related to the different social environments of social support networks.

Source: Quadern de Recerca CoActuem per la Salut Mental / Research Diary CoAct for Mental Health. Zenodo. (Perelló et al., 2021)

The Co-Researchers were invited to write personal stories about their lived experiences of social support, accompanied by a professional writer and a professional graphic artist who illustrated most of the stories. The Research Diary was meant to be used as physical supporting material after, during and between the online sessions. In this way, it has encouraged and guided the Co-Researchers' offline work, as an individual and self-reflective process, thus making it possible to maintain a more continuous relationship with the project. The experience was then shared in online meetings and the texts themselves were shared with the research team.

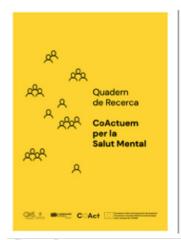








Figure 5
Sample of *Quadern de Recerca* (Research Diary) content. Source: (Peter et al., 2021).

The process of writing microstories is not a straightforward task, especially when these stories deal with mental health issues. For this reason, a warm and personalised style fostered **closeness and appropriation**. The Research Diary was designed as **a standalone**, **accessible document**. Therefore, all aspects of the project were carefully explained, and plain language guidelines were followed. The document also clarified the **terms of the collaboration**, **defining** what the Co-Researchers would have to do, when they would have to do it and on which terms, including how their personal data would be handled. The Research Diary includes contents that were collaboratively produced with the Co-Researchers during previous sessions, thus enhancing **work recognition and traceability**.

3. Sharing them through a chatbot and engaging a wide public

The Chatbot. A Telegram mobile-based messaging tool to send the microstories written by the Co-Researchers to the Citizen Scientists. Citizen Scientists can answer using buttons and in a structured manner over a long period of time, once or twice every day. The chatbot consists of a python3 code package and includes several content blocks.

Source: CoActD3.2: Digital and non-digital tools for conducting research. Zenodo. (Peter et al., 2021)

A Telegram Chatbot with the name CoActuem per la Salut Mental (CoAct for Mental Health in English) was co-designed. It facilitates the collection of responses from hundreds of participants over a long period of time via the Telegram messaging application **in private conversations** with the chatbot. A chatbot is an automated conversation generator that can be included in quite different digital environments, for instance for customer support on enterprise websites or, in our case, a chatbot to moderate an automated conversation in a messaging application such as Telegram. For many purposes it might be helpful to create replies to customers or followers by making use of Natural Language Processing and Artificial Intelligence to simulate a real conversation. This effect was not desired here: the participants needed to be conscious of **contributing to scientific data collection** by relating to microstories provided by the Co-Researchers. Especially for the topic of mental health, it is important for the chatbot not to fake being a real conversation partner, or even a friend. All content sent from the chatbot is written by humans as illustrated in Figure 6.

Using a chatbot for participatory research has several benefits, especially for CSS: the participants can answer the question when it is most convenient for them, thus **integrating research participation into their daily routines**. As the Telegram application that hosts the chatbot can be installed on smartphones and desktops, the participants can answer in **private and safe surroundings**. The participants can thus take their time to answer, collectively nourishing a rich and well-thought-out dataset of answers.

Furthermore, the chatbot ran over a long period of time, more than a year. The chatbot is therefore also seen as a medium to explore how to increase **long-term engagement**, which is generally challenging in citizen science projects. The chatbot source code is openly accessible in Creative Commons licence in Github repository (Peter et al., 2021). The chatbot will be functioning at least until December 2023 (see Annex 2 for instructions how to join the chatbot through Telegram).

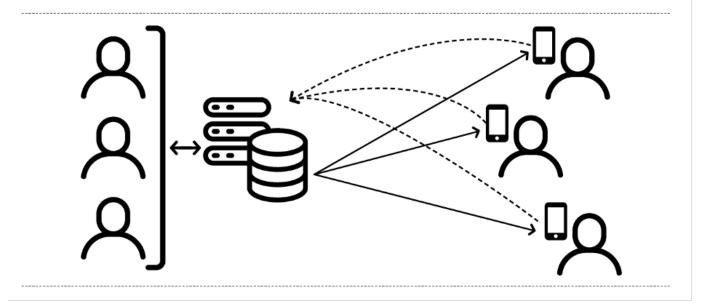


Figure 6
Human-written contents (left-hand side) sent from the CoActuem per la Salut Mental chatbot (centre) to the volunteer participants (right-hand side). Source: (Peter et al., 2021).

4. Collectively interpretating data and proposing actions

Carefully designed face-to-face sessions (3 hours each) with Co-Researchers were conducted to explain the nature of the different data collected and to collectively interpret the results obtained. Using several techniques including gaming, data visualisation and scenario planning, the data were critically discussed and concrete actions to fully deploy the benefits of mental health social support networks were designed. Following transparency and traceability principles, all sessions were carefully documented. After all sessions, the participants received the corresponding documentation to promote their continued engagement. Moreover, permanent communication was maintained with the NMHP to guarantee win-win collaboration and ensure the actions proposed could be implemented.

5. Deliberating through an assembly

The final step is the configuration of a mental health community and holding an assembly (November 2022) with Knowledge Coalition members and Co-Researchers. It is open to anyone who has participated in the chatbot or has an interest in mental health. The document resulting from step 4, in the form of a proposal, will be delivered to the commissioner of the NMHP. The document will include: a collaborative definition of what we mean by social support networks in mental health and the proposal for the most urgent goals, recommendations and actions to be implemented by administrations. The assembly is structured like a parliamentary committee with officials and a facilitator who gives the floor to the various members who wish to make changes to the text, deliberation, and the final joint proposal that will be submitted to the Parliament of Catalonia by the Co-Researchers' representative. The assembly is intended to continue functioning as a "lobby" and a scientific, institutional and citizen community that can monitor compliance by the Government of Catalonia with the agreements reached.



I often think work is one of these places where there are a lot of people in my situation, with a mental health problem. But at the same time it's an environment where it's very hard to say it and show it. People are afraid of losing their job. I miss a place to share some things emotionally. It would be very good for me and we'd all stop having so many prejudices.





I have three friends who are my therapy. My son suffers from a lot of anxiety. There are days when he says he'd rather die. Sometimes I can't go on, I think I can't take this situation any more. The fact that I can talk and they listen, they take in my fears, makes me feel lighter and stronger to help my son.

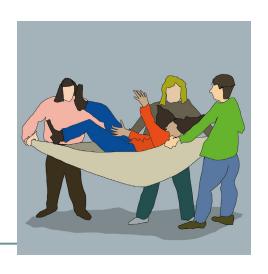


Figure 7
Two examples of chatbot illustrated microstories written by the Co-Researchers.
Drawings Pau Badia.

6. Policy recommendations

Based on the methodologies and results explained above, a set of recommendations are issued. These recommendations are provisional. During step 5 "Deliberating through an assembly", changes and nuances proposed by the Co-Researchers and the Knowledge Coalition Members will be included. The final version will be debated and approved during the final assembly, taking place in November 2022.

RECOMMENDATIONS FOR MENTAL HEALTH RESEARCH

- 1. **PROMOTE** Citizen Social Science methodologies in the field of mental health research. Why? To open up mental health research to the whole of society.
- 2. **INVOLVE** people with lived experience of mental health conditions and their relatives in mental health research. Why? To produce highly-situated and socially-robust knowledge.
- 3. **ARTICULATE** the research through different participants' groups. Why? To harvest different solutions for the complexity of a given problem, while facilitating their future implementation.
- 4. **CONSIDER** citizens a reliable source of information on mental health social support networks. Why? To fully consider the importance of lived experiences in mental health.
- 5. **INTEGRATE** the research into daily routines, through a mobile-based messaging tool and make it accessible to all. Why? To lower the accessibility barrier while acting against mental health stigma.

Several recommendations are made for the three environments of mental health social support networks (see Figure 2). Some of the scientific evidence collected with the chatbot that supports these recommendations is shown in Figure 8.

704 people entered the Telegram chatbot, signed the informed consent and paticipated in the research.

The vast majority of the 32 questions in the sociodemographics cannot be compared with any open data for Catalonia.

3 out of 4 chatbot participants experience or have experienced **mental health problems.** People without or with mental health problems respond to the chatbot with the **same level of commitment**.

3 out of 10 chatbot participants identify themselves as **caregivers**.

7 out of 10 chatbot participants are **women.**

2 out of 3 people with mental health problems say that people in their **neighbourhood do not know about their problems.** 1 in 3 people with mental health problems say that their work environment does not know about their problems.

1 out of 2 microstories talk about mental health **stigma**.

Stories about **positive aspects of social support networks** are
experienced by 1 in 5
chatbot participants.

According to people with mental health problems, the people who are **most involved in their well-being** are...

- 1. The people they live with
- 2. Close friends

According to people with mental health problems, the people least involved in their well-being are people in their neighbourhood.

I felt so lonely when it all began! I didn't know what to do or where to go for help. Lots of visits to the Emergency Department for nothing. I don't understand why, if all the doctors could see what the problem was, none of them told me that apart from doctors and hospitals there were resourses and people whi had gone through something similar and could help me.

1 out 2 chatbot participantes has had the same experience.

I couldn't get up; I just wanted to sleep, to stop thinking, to stop feeling—feeling what? I don't know... But I couldn't go in, I couldn't go on feeling like this. I didn't want to feel. I didn't want to go on. I didn't want to be. I didn't want to exist.

7 out of 10 chatbot participants who have mental health problems have had the same experience.

Figure 8

Some of the scientific evidence collected through the chatbot that supports the policy recommendations.

Data from 2022-10-23.

POLICY RECOMMENDATIONS FOR MENTAL HEALTH SOCIAL SUPPORT NETWORKS

In the CLOSE ENVIRONMENT:

- 1. **GUARANTEE** the support and basic needs of people throughout the different stages of life, preserving self-determination and promoting literacy and defence of rights. Recognition and training of people with lived experiences in mental health, as experts in-the-field.
- 2. MAKE VISIBLE the role of the close social environment and ensure that families have support, information, resources, and tools as subjects of care, for care and self-care, especially in families with children, adolescents, and young and elderly people. Promote the training of the close social environment to learn to accompany, and so that people can build their own social support network.
- 3. **DEEPEN** the definition of "mental health caregiver" and promote recognition, support and training, without presupposing the existence of rigid identities of "caregivers and cared people". Insist on cultural change for a greater involvement of men in care and self-awareness of need for help.

In the PROFESSIONAL AND INSTITUTIONAL ENVIRONMENT:

- 1. **PROMOTE** a paradigm shift to analyse and work on social determinants and structural causes of mental health discomfort. Work with a community approach (with and in the community) to promote transverse and comprehensive interventions, and promote good practices, aligned with the recovery model.
- 2. **EXPAND AND IMPROVE** mental health services to promote social support networks and guarantee that, rather than just provide care treatment, professionals offer listening, good personal treatment, information and resources that facilitate access to social support networks and act as connectors.
- 5. **EXPAND** training and care spaces for professionals. Consider levels and types of needed support and personalise interventions throughout the life cycle and throughout the territory (greater resource equity), based on a real interconnected and accessible network of resources and services. Improve intervention protocols and guarantee humanisation of care (skills and attitudes).
- 4. **FACILITATE** accessibility to social support networks, according to particular needs. Increase insufficient formal and informal social support networks. Expand, make services and resources more flexible and visible (platform) to work and accompany people's relationship with the social environment and improve support. Promote research with qualitative methodologies to identify how to improve social support networks.
- 5. **PREVENT AND ADDRESS** the discomforts and suffering of the population. Focus on the issue of suicide and the social emergency it represents in terms of mental health.

In the **SOCIETY ENVIRONMENT**:

- 1. **PROMOTE** individual and collective empowerment activism and mutual support (deployment and systematisation) and consider social support networks as strategic for empowerment and recovery. Take into account people who do not access spaces for social participation and activism or digital tools.
- 2. **FIGHT AGAINST** stigmatisation with the media as allies. Promote awareness and prevention, especially in educational environments, for a social transformation sensitive to diversity, for the emotional well-being of citizens.
- 3. **ACTIVATE** the community at multiple levels. Eradicate the differentiation between an "other" and a "we" in the ecosystem of mental health and society in general, in favour of "all citizens" and "community". Promote mutual support and prevent loneliness. Guarantee measures for co-responsibility versus the current feminisation of care. Insist on social education in new masculinities.
- 4. **TRAIN** society in the educational, labour and neighbourhood fields to prevent discomfort, to develop coping and emotional management strategies and to train professionals. Promote the creation of a seal of approval for premises and centres that are "friends of mental health". Promote spaces for relationship and real inclusion. Identify needs and obstacles to obtain social support from the nearby environment. Training in mental health in workplaces and promotion of an ISO seal to guarantee the quality of management of mental diversity.
- 5. **HIGHLIGHT** and make visible the positive aspects of social support networks in mental health, the benefits and positive experiences. Recognise the social strategic function of PEER to PEER. Promote the use of chatbot stories in social, educational and therapeutic spaces.
- 6. **CREATE** an Observatory on mental health data and prioritise actions such as the preparation of a thematic survey on mental health, access to diverse data on mental health (not only from specialised health systems but also from primary care and other social and educational service systems) or studies with qualitative methodologies that allow learning about experiences and identifying how to improve social support networks and the needs and obstacles to achieving social support in the immediate environment.e for a greater involvement of men in care and self-awareness of need for help.

7. Transferability

CoAct for Mental Health is a project that offers several possibilities for re-use in different contexts. It could be replicated anywhere, as it does not depend on the local health system and because mental health social support networks are crucial community-based mechanisms all around the world. On the methodological side, the strategy could be easily replicated for other widely-shared health or public health issues or societal problems. The present work has demonstrated the soundness and the feasibility of the methodology.

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Annex 1: Collaborative definition of mental health social support networks.

AXES

KEY CONCEPTS AND IDEAS

WHAT do
we mean by
social support
networks? WHO
configures
them? WHERE
do they meet?

Community of people / Healthy community.

They make up community support.

Interaction of the individual with **help network** / Support relationships in the **coverage of basic needs** (housing, food, etc.).

Interconnected nodes from which we obtain: support, listening, understanding, company and soothing.

Meaningful relationships that generate a sense of belonging.

Network: a set of relationships that accompany you in good times and that sustain you in difficult ones.

Social and interpersonal liaison / Interpersonal ties that are stable and close.

Linked to 1) **leisure**, joy, support, connectivity, being a citizen, security 2), daily, instrumental **functional** aspect.

Formed by active agents, not receiver-passive people.

People we walk alongside.

Recovery facilitated by **welcoming public spaces** and services that **accompany** citizens. Social support networks **formed by**: family, friends, study and/or work colleagues, neighbours, associations, spaces for activism and militancy, and spaces for mutual support between individual or group peers.

Local relationships: neighbours, co-workers, neighbourhood, the bar, the kiosk, facilities and community spaces (church, clubs, cultural and leisure activities, for example, choirs).

They are those that the person **feels and wants as support** in a subjective way, not those that the environment offers, if the person does not feel them as such.

Special relevance of mutual support.

WHAT are social support networks for? WHAT is their functionality? Socialising individual experiences, socialising suffering, although not always included.

Accompanying people in their process of **recovery** and social **reintegration**.

Facilitating social **inclusion** (society adapts) instead of social integration (the person adapts) and **social cohesion**, creating a community and ensuring well-being.

Spaces for **listening / Emotional and psychological support, material, instrumental and practical /** Ensuring care, coverage of **basic needs**.

Sharing in general and in particular: desires and objectives, satisfaction, and happiness with the achievement of desired goals, hopes and dreams, etc. Being able to talk about problems, about what is difficult for us.

Facilitating the **exercise of rights and opportunities** in a manner more shared with others.

Giving and receiving understanding of difficulties. Lending a hand when someone needs it.

Trusted social network that promotes **social capital** and reduces isolation.

Communities that can **sustain people** beyond individual relationships and **in their context**.

Offering healing environments, providing health, and serving as a preventive factor / Slowing environment.

Enriching the **quality of life**, contributing to **personal identity**, feeding self-concept and self-esteem, and valuing one's own skills.

Making up for the lack of social interaction of people with mental health and family problems.

Purpose not closed or structured.

HOW do or should social support networks work? HOW do we connect or accompany them?

HOW should we approach their creation, promotion and access? **Third sector entities** as backbones and promoters of the organisation and management of social support networks / Importance of **strengthening and supporting associationism** in mental health.

Members of the support network as **supporters and facilitators** of access to services (health, but also transport and mobility, among others), the associative movement and information.

Importance of **services as a bridge** (when there is no social, informal, natural support environment) and **community-based**.

Networks as **a platform for virtual and face-to-face approach with** stable and basic support.

There is a need to facilitate **knowledge and accessibility** to social support networks.

Respect for the need for the **socialisation** of each person. Differentiating difficulties in social interaction and linked social isolation from preferences regarding the degree of desired social interaction and **healthy retraction**.

Changes in the **role** of the agents involved are required by putting themselves in the place of the other, and collaboration between peers and others.

There is a **need for training** for people with lived experiences, family members and professionals in social support networks and values education throughout society (solidarity, equality, fraternity, etc.).

Intersectional perspective: considering different aspects of social inequalities that make some people more exposed to systems of oppression (this allows us to consider that needs and demands are different between populations; for example, migrants, in disadvantaged socioeconomic situations, without family support).

There is a need for common and horizontal spaces **for self-reflection** for self-evaluation and the promotion of inter-relationship improvements (at all levels).

It is essential to promote the systemic approach to mental health services.

The **fight against stigma** at all levels is essential to promote and strengthen them (media, education system, legislative level, family environment, etc.).

What DIFFICULTIES do we encounter in creating, accessing, and maintaining social support networks? What NEGATIVE circumstances can interfere within social support networks?

Perception of imposition / They can be harmful, drowning without having that intention / Hyperprotection and paternalism.

Existence of **hidden**, **unclear**, **disorganised and confusing** social support networks.

Stigma and self-stigma / Low self-esteem / Shame.

Lack of personal resources to establish or maintain social support networks. **Lack of knowledge** that there are resources and support networks complementary to specialised mental health services.

Precariousness and scarcity / Territorial inequity / Lack of flexibility.

Accessibility difficulties because information from mental health social support networks does not reach those who need it. Lack of proactivity to reach those who need help, especially those who find it difficult to ask for it.

Non-prioritisation of social support networks.

In **a crisis situation** (pandemic) many support networks were suspended, did not adapt to the new circumstances, and it was even more difficult to access them.

Horizontality (between peers, without hierarchies) can be understood as **a difficulty or a challenge** that can be overcome and transformed into value. Horizontality for some can mean letting yourself be helped (without fear) and sharing responsibilities (it is easier to say what to do). It is a problem for both "sides" (users and service providers).

Free oneself from threats or coercion.

Breakdown in family support.

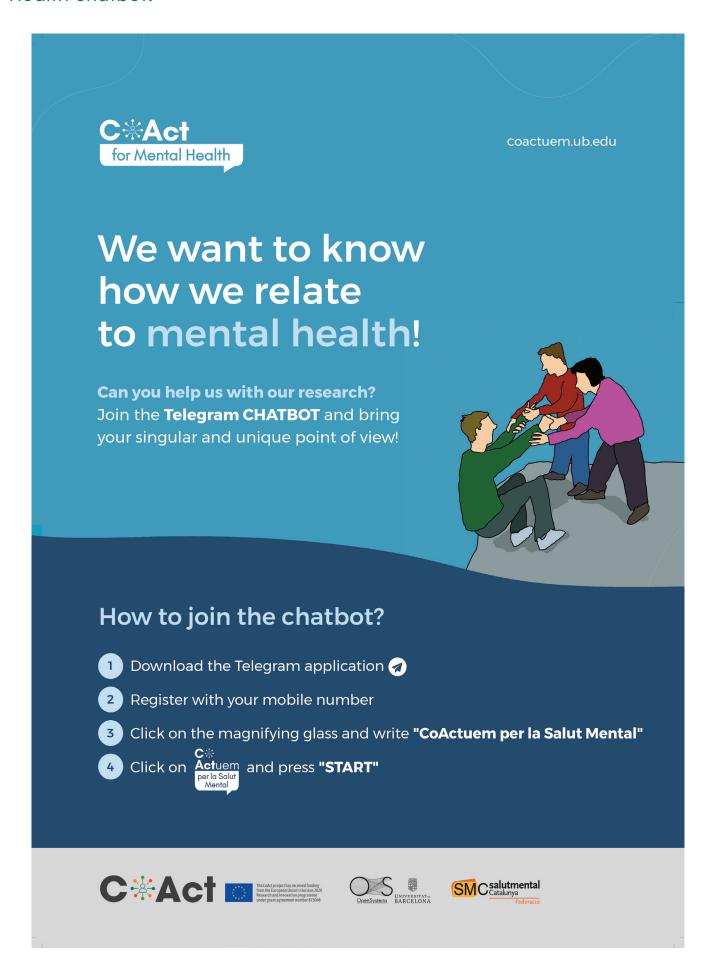
Questioning the **unconditional nature of families' support**, which may put their own mental health at risk.

Doubts and even disagreements about why to differentiate between social support networks (such as non-professional and informal networks made up of family, friends and colleagues, etc.) and institutionalised support networks (such as professional and formal networks made up of health and social services) and how this can contribute to **lack of coordination** and failure to work in parallel.

What ELEMENTS characterise social support networks? What PRINCIPLES or VALUES govern them?

Links / Affection / Solidarity / Leisure / Dignity / Happiness / Process / Hope / Respect / Rights / Self-realisation / Flexibility / Horizontal perception / Maintenance / Citizenship / Security / Trust / Self-esteem potential / Co-participation / Equality in the approach / Community / Interconnection

Annex 2: Poster inviting the Citizen Scientists to join CoAct for Mental Health chatbot.





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