



Co-designing Citizen Social Science for Collective Action

#3.1

Report on Knowledge Coalition building

Mental Health Care



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List of Abbreviations

CoRe Co-Researchers

CSO Civil society organisation

CSS Citizen Social Science

EC European Commission

EUFAMI European Federation of Associations of Families of People with Mental Illness

FSMC Federació Salut Mental Catalunya

IC Informed Consent

KC Knowledge Coalition

OS OpenSystems

R&I Action Research and Innovation Action

TMS Taula de Salut Mental WHO World Health Organisation



1. Executive Summary

The CoAct (Co-designing Citizen Social Science for Collective Action) project proposes to face social global issues by placing citizens in a vulnerable situation at the centre of the research. This approach represents a new understanding of Citizen Social Science (CSS), as participatory research co-designed with citizen groups sharing a social concern.

One of the social issues targeted is Mental Health Care (R&I Action #1, WP3) and this report corresponds to Deliverable D3.1 Report on Knowledge Coalition building. The research background of this R&I Action has been constructed based of the different but complementary experiences of the two main CoAct partners involved. While the OpenSystems research group (Universitat de Barcelona) has built a research methodology based on Citizen Social Science and citizen's participation, Federació Salut Mental Catalunya has decades of experience in community mental health care activism and cooperative projects, situating the individuals with an experience of mental health and their families at the centre of this process. Based on these complementary experiences, the research has been oriented to mental health social support networks, referring to people's social environment, which is generated informally, not professionally.

The report describes the different step of the Knowledge Coalition building, formed by representatives of public administrations, civil society organisations and co-researchers, acting in representation of their institutions. After a detailed mapping of the local, national and international institutions, a comprehensive engagement process was built, that resulted in the participation of 65 individuals representing 50 institutions and the realization of a total of 6 meetings, that were conducted online due to COVID-19 pandemic. During this process, the sharing of experiences and perspectives allowed to build a rich and detailed knowledge map concerning the current situation of the mental health social support networks and of the possible future actions needed. This knowledge map will be used in the next step of the research process: the research co-creation sessions involving individuals with an experience of mental health and their families as Co-Researchers.

2. Introduction

2.1 CoAct General Concept

CoAct (Co-designing Citizen Social Science for Collective Action) is proposing a new understanding of Citizen Social Science as a participatory research co-designed and directly driven by citizens and citizen groups sharing a social concern (See Figure 1). CoAct proposes to face four “wicked” social global issues by engaging citizens in a vulnerable situation. The approach represents a new understanding of the underexplored field of Citizen Social Science (CSS), understood here as participatory research co-designed with citizen groups sharing a social concern. The joint effort will result in the implementation of new or improved science-related policies and the advancement of the CSS approach with regards to its applicability in concrete fields or research.



Figure 1: Citizen Social Science in Action, with citizen groups, a specific concern, and with the support of the Knowledge Coalition

In all CoAct R&I Actions (Mental Health Care, Youth Employment and Environmental Justice), citizens in a vulnerable situation are placed at the centre of the research and their role and dedication conceptually recognize them as Co-Researchers. In parallel, the Knowledge Coalition is a network of stakeholders who are informed about the R&I Actions’ goals, and plays an active role, either participating in or co-designing different actions, to harness Co-Researchers' efforts and implement policies and measures based on scientific evidence.

2.2. Definition of the Knowledge Coalition

Knowledge Coalitions are formed by representatives of Public Administrations, Civil Society Organisations (CSOs), educative organisations and Co-Researchers – to name a few. All R&I Actions involve people from different areas of the political, academic/scientific and social realm, according to their field of research. They strive to assure that the composition of the Knowledge Coalition reflects the diversity of actors within their field and is sensitive to gender balance and other socio-structural categories that might become relevant such as ethnicity or age. The involvement and collaboration of the Knowledge Coalition members varies according to the specific R&I Action and different actors may participate in different activities according to their expertise, interest and expectations regarding synergies with their own activities associated to the social concern. The participation of the individual parties of the Knowledge Coalition can take place in various forms and in different moments of the R&I cycle: creating a structural framework for research, participating in the actual research process, informing on corresponding issues, implementing and discussing possible solutions or getting involved in the dissemination of the project and the transformation of research results into actions according to its acting potential. Regardless of the role, each R&I Action facilitates spaces for dialogue and action with different actors promoting the creation of a dynamic network and promotes an exchange between them and building from synergies among different initiatives adding therefore to the collective effort towards transformation. In order to coordinate the network and open up spaces for deliberation, the R&I Actions use different methods and approaches, from joint discussions, workshops, expert talks and digital tools to strategy meetings, which aim at a diversity of on- and offline participation possibilities.

2.3. R&I Action #1 scope: Mental Health Care

2.3.1 CoAct Partners involved

Universitat of Barcelona (UB) is represented by the research group **OpenSystems (OS)**, <http://www.ub.edu/opensystems/> attached to the Department of Condensed Matter Physics and to the Institute of Complex Systems. OS is a multidisciplinary group that focuses

on public participation as a core element of the way of doing science. The group is involving a diversity of actors to address tailored-made research targeting social concerns mostly grounded in urban contexts. OS methodology is based on community processes and the group is committed to a horizontal research through innovation and public engagement. Computational social science, data science and complex systems science are the primary areas of expertise of the group, that have been applied to the citizen science field (Cigarini et al., 2020, Cigarini et al., 2018; Vicens et al., 2018a; Vicens et al., 2018b; Sagarra et al., 2016; Gutiérrez-Roig et al., 2014). For CoAct, OS is collaborating with Itziar González-Virós, as an expert in citizens' participation and cooperation processes. She has an exhaustive experience in cooperative and deliberative processes, such as the bottom-up transformation process of the Ramblas urban space in Barcelona and the enhancement of democratic strategies to manage prisons or wildfires (Otero et al., 2018). She has been integrated as independent researcher associated to the OS group and her work has been focused on the design of the participatory dynamics for the Knowledge Coalition and for Co-Researchers sessions.

Federation Mental Health Catalonia (FSMC, <https://www.salutmental.org/>) is a non-profit organisation that represents people with mental health issues and relatives, whose right to self-determination is performed by being represented in all decision-making levels of the organisation. FSMC has developed several projects that have been co-promoted, co-designed and co-assessed by the service users themselves, their families, professionals and administration representatives. FSMC works as well on political advocacy to promote projects in order to facilitate accessibility to care resources and programs and to contribute to policy-making.

2.3.2 Research background

2.3.2.1 Games for Mental Health

Starting point of OS-FSMC's collaboration traces back to a previous project called "Games for Mental Health" (2015-2018) that has been co-created together with representatives from mental health community ecosystem (Cigarini et al., 2018; Bonhoure et al., 2019). Relevant behavioural traits in recovery processes and community mental health care had been collectively identified: trust, reciprocity, cooperation, optimism and sense of community.

Pop-up public experiments under the form of digital games (Vicens et al., 2018a; Vicens et al., 2018b; Sagarra et al., 2016; Senabre et al. 2018) had been co-defined by OS with several groups of citizens (library users, students, CSOs members among many others) and dealing with a variety of social issues (use of public space, gender violence, climate action, housing among many others). Within this framework, social dilemmas can become an interesting approach to collectively explore behavioural traits. In particular, “Games x Mental Health” sought new ways to drive an awareness process and self-reflection on the reality of people with mental health problems and deepening in relevant social attributes involved in recovery processes (namely formal or informal caregiver, first-person or family). An innovative citizen social science methodology had been implemented for measuring the capacity and mechanisms of the ecosystem’s social integration to improve the mental health care community model.

The project had a scientific outcome (Cigarini et al., 2018) and a public policy recommendation document (Cigarini et al. 2018b) presented in a press conference underlining the importance of caregivers’ role in community mental health care and mental health recovery processes.

2.3.2.2 Local collaborative projects

Previous collaborative projects by FSMC were developed with a diversity of entities linked to different fields include the co-creation of new materials for recovery and self-management of well-being, training, empowering and support programs, mutual support guides and booklets to better accompany or the implementation and co-designing evaluation of a collaborative work model to promote integrated mental health care in municipalities.

During the last six years, FSMC co-developed an extensive project to promote that people with mental disorders and informal caregivers become active agents of the recovery process ‘Get active for mental health’ (Activa’t per la Salut Mental, <http://activatperlasalutmental.org>) promoted by the Generalitat de Catalunya, FSMC and Federació Veus (entities representing people with self-experience in mental health), in collaboration with city councils, provincial councils and local associations. The project obtained good results (Ivàlua, 2019) reaching more than 6.500 beneficiaries and building the

bases for a model to improve mental health care that is currently being developed with the public administration to include it in the public portfolio's services.

2.3.3 Ambition

Regarding the topic of mental health, there are several official recommendations from the European Commission (EC, 2016), the World Health Organization (WHO) (WHO, 2010, 2015) and the Convention on the Rights of People with Disabilities (UN, 2006) on ensuring participation of people with mental disorders and their families, at all levels, including research, design, and implementation of services and programs (European Commission & Portuguese Ministry of Health, 2010)

For partners involved in R&I Action #1, it is very important that CoAct project goes further than a better understanding of the reality of people with mental health problems and their families' community. It is essential to take into consideration that citizen participation must also translate historical demands into research processes, transformed into scientific evidenced-based policies. These policies must allow substantial social changes, improving care services, life satisfaction and a real inclusion of people with an experience of mental health.

To achieve the desired social impact, it is essential to make visible real citizen's needs, promote actions for citizens empowerment, stimulate the participation of people in situation of vulnerability to design solutions and reduce inequalities as the gap between the 'expert knowledge' and the 'real life knowledges' creating horizontal relations. Citizen participation in previous collaborative mental health research projects demonstrates that participatory methodologies contribute to better respond to the needs detected in the community, through a horizontal, flexible and self-organized space outside the health system where it is possible to express oneself without fear of being judged (Fernández et al., 2020).

Participatory approaches to mental health facilitate processes of trust, recognition, joy, social support, and health not only of the participants but of the community itself (Fernández et al., 2020), because they put the person in the centre, to co-create and implement programs to improve people's quality of life.

2.3.4 The research topic: Mental Health Care and Social support networks

The WHO states that 25% of the world's population will have mental health problems at some point in their life (WHO, 2001). In Catalonia, in 2015, more than 1 million people were visited primary care services for mental health disorders, which corresponds to 13,3 % of the total population (Generalitat de Catalunya, 2016). In 2017, a total of 235.189 people were visited in specialized mental health services; 59,6% of them were women and 28,3% were under 18 years old; 33,8% of these specialized mental health services users presented a severe mental disorder (Observatori del Sistema de Salut de Catalunya, 2017). Moreover, according to data from the Spanish Health Ministry, in Spain, 88% of the care and support tasks are carried out by informal caregivers (family, friends, etc.) (Ministerio de Sanidad, 2006)

In the last decades, there has been a change in the paradigms to address social inclusion on mental health, shifting from a biomedical approach to a rehabilitation model, and recently to a Recovery Model. In the Recovery Model, the focus is put on the life project self-definition by the person with an experience in mental health in her/his social context. Namely, the recovery model in mental health is based on principles that include self-determination, the consideration of resources beyond professional care and a community approach. In this sense, social support networks in mental health are considered a crucial point for recovery. Social support networks refer to people's social environment, which is generated informally, not professionally. All individuals need an emotional environment that provides them with love, accompaniment and support for their well-being, especially in difficult times. Families are particularly standing out, understanding that the family concept includes those people with whom close and continuous affective bonds are shared. In the case of people with mental health problems, having a social and affective environment is a key element for the recovery process. Giving support is also complex and generates specific needs in care and self-care. These issues need to be addressed in a way that benefit the accompanied person and do not cause discomfort in the accompanying person. Additionally, social support networks need to have continuity in time to be really effective.

Research on social support networks in mental health is important because people with self-experience in mental health and their families claim the importance and effectiveness of social support networks as facilitators of the processes of recovery and the improvement of

the quality of life. People's social support in case of emotional suffering is a determinant element for evolution and recovery (Knapp et al., 2007; Pernice-Duca, 2010; Cocke, 2015;). Positive family environment is identified as a key protective factor against the risk of exclusion and homelessness (Mental Health Europe, 2008). Studies show that people living with mental illness who are provided with well-planned, comprehensive support in the community have a better quality of life, develop an improved level of functioning and social contact, and have fewer relapses (Merton & Bateman, 2007). Federació Salut Mental Catalunya and Activament Catalunya Associació reports (FSMC & Activament Catalunya Associació, 2017) showed that people with self-experience point to social support networks (family and friends) as key elements for recovery, well-being and crisis management. However scientific research on family and other social support networks role in recovery model is still scarce.

Recovery goes beyond professional care and is supported through relationship and social networks formed by family members, peers, providers, faith groups, community members, and other allies form vital support networks. Through these relationships, people leave unhealthy and/or unfulfilling life roles behind and engage in new roles that lead to a greater sense of belonging, personhood, empowerment, autonomy, social inclusion, and community participation (SAMHSA, 2012). Family members have assumed additional responsibilities and tasks, especially in situations where resources transferred to community mental health systems have been insufficient. Considering "The caring for caregivers survey report" (Vermeulen et al., 2015), elaborated by the European Federation of Associations of Families of People with Mental Illness (EUFAMI), regarding "satisfaction with support received", 39% of the family caregivers are dissatisfied with the support from doctors, but another 39% are satisfied. It must be said that considering the selection of participants, they found out a highest satisfaction for the support received from patient and caregiver organisations (58%).

Mental health problems account for approximately 20 per cent of the total disability burden of ill health across Europe (WHO, 2004), but receive much lower proportions of total health expenditure, often below 5 per cent. Indeed, disability burden calculations of this kind could be underestimated as they overlook the broad impact that mental health problems can have on many aspects of life including physical health, family relationships, social networks, employment status, earnings and broader economic status (Magliano et al., 2007).

Our research focuses thus on social support networks considering people with an experience in mental health as experts in the field. The research outcomes should be scientifically valuable but also should contribute to the mental health community, take control of their own lives and help others to achieve this control. In line with these concepts, the R&I Action #1 was renamed “**CoActuem per la Salut Mental**” (**CoAct for Mental Health**) to facilitate the local communication and engagement actions. Furthermore, based on the first steps of the research process (see below Section 4), tentative research goals would be related to:

1. To have a better understanding of social support networks and to identify opportunities and strengths of social support networks. Broad questions related are: What do we understand as social support networks in mental health care? Which are the contexts and the situations that make social support networks especially relevant? Can we reinterpret the given roles in mental health care in terms of social attributes? If so, which are these social attributes (e.g. trust, cooperation, reciprocity...)?
2. To boost collective intelligence problem solving approach to enable collective evidence-based actions or support with evidence specific policies.

2.3.5 Groups involved

CoAct for Mental Health is involving different groups:

The Knowledge Coalition (KC) is formed by representatives of public administrations, civil society organisations, educational organisations and co-researchers, acting in representation of their institution. As described in the next section, we prioritized relevant institutions considering their commitment in mental health care improvement at different levels. It includes professionals, people with self-experience in mental health and relatives.

Co-Researchers (CoRe) includes people with self-experience in mental health and relatives, acting as experts in the field. In this case, experiencing themselves (or somebody closed to them) mental health problems place these individuals in a socially vulnerable position. The purpose is that they co-create, together with OS and FSMC researchers, a collective research tool in the form of collective digital conversation (planned as a chatbot in Telegram). The collective digital conversation content, namely micro stories, are built through co-design

mechanisms that allow to reach consensus and agreement among participants while including different perspectives and viewpoints. They then will analyse and interpret the final results gathered with the collective digital conversation, deliver them to the Knowledge Coalition, and/or autonomously trigger specific collective actions.

Citizen Scientists are the participants to the Collective Digital Conversation (planned as a chatbot in Telegram). This conversation is a safe space for collective and anonymised conversation established through mobiles of all registered participants belonging to the mental health care community. Safety is defined by the fact that participants anonymity is maintained, as well as their privacy as the individual positions are not exposed in front of any other participant. The participants receive micro stories, namely dilemmas and scenarios, that will be co-created by the CoRe. All micro stories are planned to be posed to self-express the participants own perspectives based on their own experiences. The platform aims to provide continuous feedback considering community inputs and in an adaptive and personalized manner. The goal is to collectively generate new interconnected and multi-layered data able to embrace the complexity and the diversity of the mental health social support networks. The results then can be transformed into evidence-based actions.

3. Knowledge Coalition formation

The creation of the KC is one of the key points of the project, since it allows to kick-off the framing of the research on mental health social support networks. In particular, the KC is meant to contribute to the mapping and identification of the concerns and problems of the mental health community in terms of access to and provision of social support, which will then be validated by the CoRe. Members of the KC were also expected to support and facilitate the creation of the CoRe by participating in the CoRe open call. Finally, the KC is intended to play a crucial role in the final translation of the evidences collected into policy proposals (in 2022).

The KC includes representatives of the main public administrations engaged in the community of Mental Health Care, like municipalities or members of the regional government, representatives of health professionals and academic researchers but also Civil Society

Organizations (CSOs) like bottom-up associations of people with an experience of mental health and their relatives, associations for the labour insertion of individual with an experience of mental health, or association for education and social inclusion of marginalized communities, namely migrants and homeless. The KC has been designed as a horizontal and collaborative space, where the voices of the representatives of people in a social vulnerable situation (in this case representatives of bottom-up associations linked to the mental health community) are equally considered as the voices of any representative from professional, academic or public administration institutions. This network of representatives from different organizations and fields offers a space to create synergies and contribute to the construction of knowledge enriched by the diversity and complementarity of voices.

3.1. Local context mapping

From February to May 2020, the CoAct partners involved in CoAct For Mental Health (OS and FSMC), met regularly in order to progressively build a map of possible local, regional, national and international stakeholders.

The first mapping (see Table 1 for a summary of the main dimensions considered) was mainly designed thanks to FSMC experience in the territory, enriched throughout more than twenty years working hand in hand with the network of stakeholders involved in mental health, especially in Catalonia, but also in Spain and, although to a lesser extent, in Europe. In the creation of the Knowledge Coalition, this background has been the key to identify relevant representatives of the Generalitat de Catalunya (regional government, main mental health care provision responsible), provincial and city councils, health and social services, civil and academic organizations, involved in mental health, more or less directly, the majority of whom FSMC had established previous alliances.

First mapping has been also possible due to FSMC active role in political advocacy for the creation of community action programs and the inclusion of services in the Generalitat de Catalunya public portfolio, the participation in work teams of the Strategy of the Mental Health and Addictions Master Plan (Generalitat de Catalunya, 2017) and the Integral Care Plan (Generalitat de Catalunya, 2017) for people with mental disorders and addictions and the

development of the Taules de Salut Mental (TSM) model (FSMC & SPORA, 2015, 2017)., a space for reflection, exchange of resources and collaborative work to promote integral mental health care in the territory. The currently 26 TSMs in Catalonia with approximately 800 people committed seek the involvement of all agents related to mental health care in the territory: civil social organisations (associations and / or federations of families and people with mental health problems), entities that provide mental health services, local public administration (councils, services and resources), the regional administration, provincial councils and the territorial representation of councils or bodies of the Generalitat de Catalunya. de Catalunya. The result of the space for debate and reflection and further e-mail interactions, translated into a first list of institutional representatives involved in different mental health areas that was shared with the rest of the CoAct For Mental Health research team (early March 2020). In this second phase, the list of stakeholders was completed with profiles that were considered important to enrich the network, such as researchers involved in health services evaluation, social sciences researchers and NGOs having a main focus not directly associated with mental health but that could be possibly related (social exclusion, AIDS and LGBT activists and youth-targeted socio-educational projects). We must mention that in middle March 2020 the health crisis broke out in Spain due to the COVID-19 pandemic and the home confinement decreed on March 13, slowed down the ongoing process (see following sections for further details).

This first joint work allowed us to define the main characteristics of the profiles we aimed to include in the KC. The process was guided by the five main dimensions shown in Table 1. We carefully included potential KC members in order to guarantee a balanced distribution of the different categories of the five dimensions. We also considered a balanced distribution considering a gender perspective. We then obtained early April 2020 a wide list of possible candidates to participate in the KC under the form of a large table that characterized each possible candidate in terms of the five dimensions being mentioned.

REPRESENTATION	<ul style="list-style-type: none"> • People with self-experience • Families • Health professionals • Policymakers • Researchers
TYPOLOGY	<ul style="list-style-type: none"> • First persons and family associations • Educational and social inclusion activist organisations • Academia • Health professional associations • Government & public administrations • Health service providers
ORGANIZATIONAL CONSTITUTION	<ul style="list-style-type: none"> • Federation • Foundation • Association • Public administration • Consortium • University
ACTION SCOPE	<ul style="list-style-type: none"> • Sanitarian • Social • Research
LEVEL	<ul style="list-style-type: none"> • Local • Regional • National • International

Table 1: Dimensions that guided the KC constitution process, as the main coordinates to build a KC map and identify potential members.

3.2. Knowledge Coalition constitution process and building of the research framework

The COVID-19 crisis deeply affected the CoAct R&A #1, due to the pandemic serious consequences. The lockdown started in Spain on March, 16th 2020 and lasted in Barcelona until July, but despite a period of relative relaxation in summer, contingency measures have continued since then. When starting the Knowledge Coalition constitution process, beginning of April, we were still envisioning meetings in physical spaces and the possibility to deploy face to face dynamics. However, as the COVID-19 related situation had not improved enough in May, we finally decided to focus exclusively on online processes in order to build the Knowledge Coalition.

However, the COVID-19 crisis has also represented an opportunity to learn from and participate to bottom-up projects. In an attempt to respond to this crisis in an adaptive and flexible manner and to anticipate future research steps with the CoRe, we submitted an initial idea to FrenaLaCurva digital hackathon. The CoAct For Mental Health research team thus developed the CoActFrenalaCurva project devoted to investigate the mental health informal support networks in times of COVID-19. We took the opportunity to check the general interest in our approach and to test co-creation dynamics through digital platforms in a hands-on manner (as an exploratory prototyping phase).

3.2.1 CoActFrenalaCurva in a Digital Hackathon as a prototyping process

CoActFrenalaCurva was among the 10 finalists of the Common Challenges call of the FrenalaCurva (Slow down the Curve, <https://frenalacurva.net/>) initiative, which is a citizen platform where volunteers, entrepreneurs, activists, social organizations, makers and laboratories of public and open innovation, cooperate to channel and organize social energy and civic resilience in the face of the Covid-19 pandemic giving a response from civil society complementary to that of the government and essential public services.

During one-week digital hackathon, from 26th of April to 2nd of May of 2020 (See Figure 2), a wide range of people collaborated: from individuals with an experience of mental health and health professionals, to web designers and visual artists, to representatives of administrations or activists, from Europe to Central and South America (fully reported in

Spanish, <https://festival.frenalacurva.net/coact/>). Telegram was used for daily communications, coordination and feedback while jit.si video conferences were used as spaces for discussion, decision-making and validation throughout the different phases of the co-creation process.

The project aimed at co-creating a citizen social science prototype platform (<http://coactfrenalacurva.net>) to collect personal stories and strategies of care in order to map the network of informal social support for mental health during and after the pandemic. The methodological approach followed citizen social science CoAct principles, giving project members an equal seat at the table through active participation since the very beginning of the co-creation process.

Feedback from participants, collected by CoAct partner ZSI, showed that the digital tools helped to create a space for collective learning about more communal values of collaboration and solidarity, a recurrent theme across participant assessment of the impact of the process. The broad variety of expertise and geographical origins, which would hardly be possible in physical settings, helped to amplify the scalability and reach of the initiative while creating a community of committed ambassadors for the future project development. Contrary to physical settings, however, digital tools posed extra challenges to coordination among geographically dispersed and heterogeneous forms of participation, hinder empathy generation, and require the design of tools information access and sharing that is to be adapted to distributed knowledge settings. Besides, participants of FrenaLaCurva were also invited to join the KC.

All this effort has helped to better design KC activities and anticipate challenges that may have a negative impact in later stages of the R&I Action.

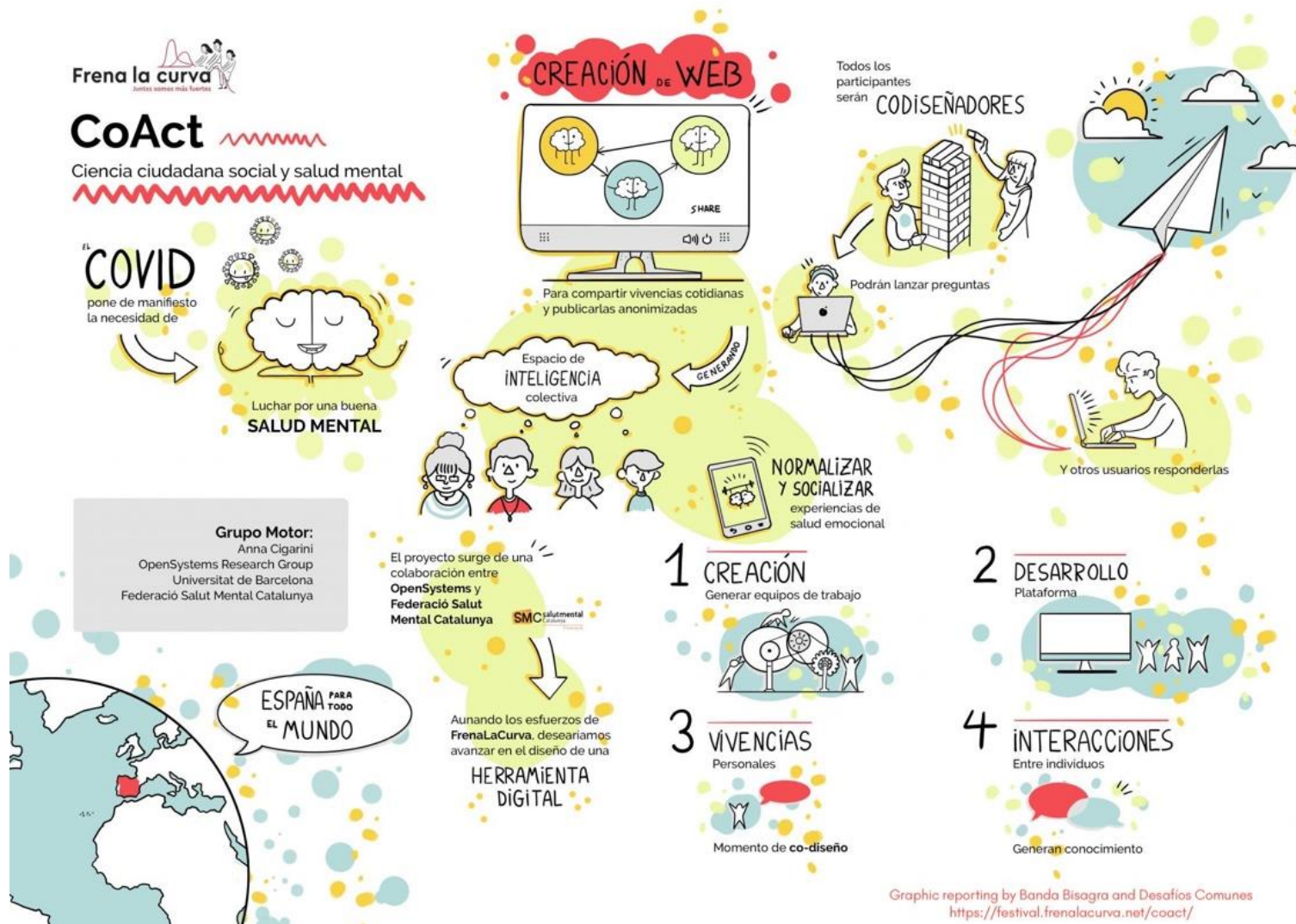


Figure 2. Summary of the CoActFrenaLaCurva project, that can be considered as a first prototype of CoAct For Mental Health.

3.2.2 KC Members recruitment

The next step (end April 2020) consisted in establishing a first contact with the people of the list through two representatives of the FSMC management team. The director of the FSMC and the director of "Get active for mental health" contacted the potential members preferably by phone, but also by e-mail, to invite them to participate in a first informative meeting where the project would be explained in detail so that they could finally decide whether to be a part of it or not. OS also personally contacted the institutions they previously worked with or were in contact.

The potential members, once they confirmed their interest, were formally invited and informed of the date and schedule of the kick-off meeting (2nd of July) by the CoAct For Mental Health research team (May-June 2020), through a personalized letter in which we thanked their interest (Annex 1). To design the invitation letter, we agreed that it should be articulated following two aims. The first aim was to present the "what" (CoAct For Mental Health as a research project on social support networks in mental health) and the "how" (through citizen social science) of the project. The second aim was to recognize the value of the entity represented, considering their commitment and their experience in the field of mental health. Finally, we included a brief agenda and logistic information to attend the meeting.

Together with the formal invitation letter, potential members were also asked to fill a brief paper questionnaire with important information for the mapping of the KC:

- Confirmation of the person attending the kick-off meeting on the 2nd July and its role within the organisation or institution.
- Geographical field action of the represented entity.
- Brief presentation of the organisations or institution and its objectives in relation to mental health.

Once we received the questionnaire completed, we sent a second personalized letter to confirm their participation in kick-off meeting remembering logistic issues.

3.2.3 KC composition analysis

The response to the KC invitation was overall very positive and of the 69 (35 -51%- women and 34 -49%- men) potential KC members contacted and invited, 58 (28 -48%- women and 30 -52%- men) said that they would attend the kick-off meeting. In cases where the person contacted showed interest but was not available or considered that there were other members of his team more suitable for the proposal, we were offered to directly contact another person from the entity or they personally contacted with the candidate, to delegate their participation. Although some of the initial 69 finally declined to continue involved in the project, others joined after the kick-off meeting, resulting in 65 final participants up to now (34 -52%- women and 31 -48%- men), who participated in at least one meeting and did not communicate us their intention to withdraw from the project.

Currently, there are **65 people involved in the KC, representing 50 organisations**, as shown in Figure 3. These 65 members of the KC have either participated in at least one meeting or have confirmed that they would participate in the project and kept email contact with the research team (but were eventually unable to attend the meetings). Yet, none of the 65 actual members expressed his/her willingness to withdraw from the project. The 50 organisations are made of 17 association/entity of people with self-experience and relatives, 12 government & public administrations, 9 association/entity representing health professionals, 5 academic institutions, 4 educational and social inclusion activist organisations and 3 health providers.

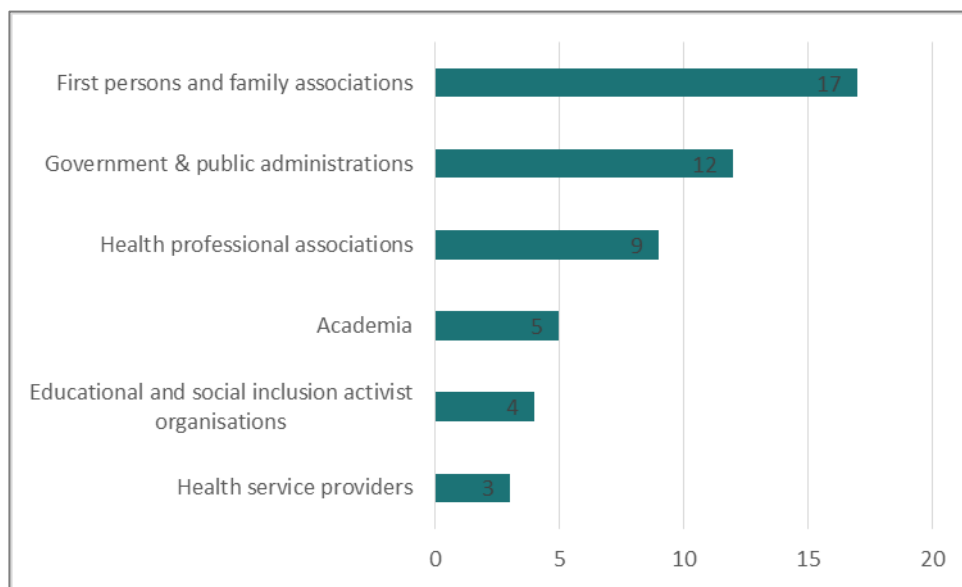


Figure 3: Number of entities represented in the KC, distributed by typology.

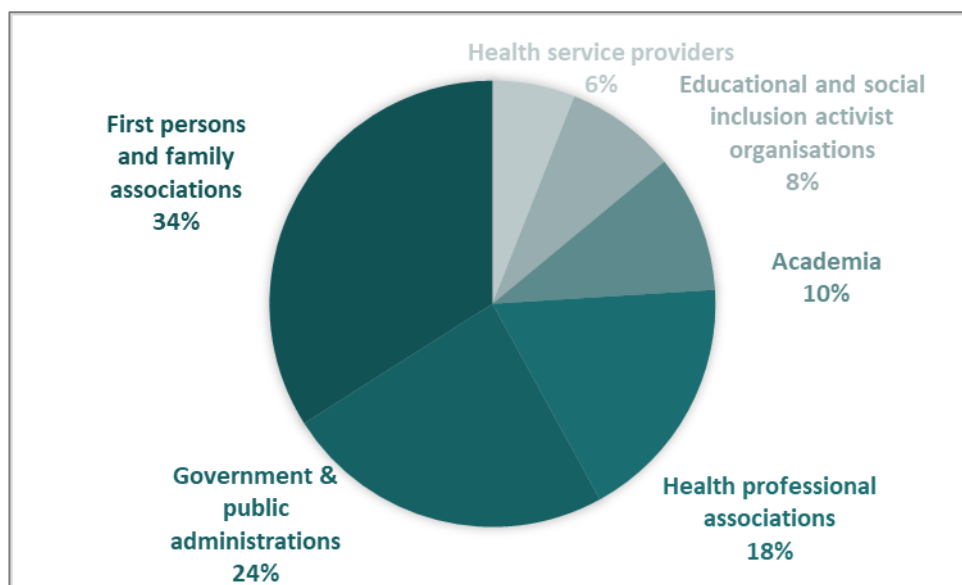


Figure 4: Percentage of representation according to typology.

Looking at the percentage of representation according to typology (see Figure 4), more than half of the institutions correspond to first persons and family associations or government and public administrations, respectively representing 34% and 24 % of the institutions. This high representativity is associated with the importance of the two institutions’ typologies in CoAct For Mental Health. Firstly, as individuals with an experience in mental health and their

families are at the centre of the project, it is thus highly relevant to involve the associations that are representing them. Secondly, as one of the main expected outcomes of CoAct For Mental Health is to transform scientific results into collective and/or political actions, it is highly desirable to deeply involve government and public administrations in the KC, engaging them in such a way that they will be willing to implement the actions collectively proposed.

The least represented group is the one of organizations of health service providers, although it can be said that the voice of health professionals is also collected through their professional organizations. Moreover, professionals have voice in other participatory spaces and at different levels. CoAct For Mental Health has opted to emphasize leadership of collectives with usually less decisional power (people with self-experience in mental health and relatives) that certainly were well represented in the KC. Also, half of the organizations of the KC (50%) operate at the local level (i.e. Barcelona), 38% at the regional level (i.e. Catalonia or Andalucia), 4% at the national level (i.e. Spain), and 8% are members of international organizations (as shown in Figure 5). We put a strong emphasis on involving local members since, originally, the co-creation sessions with the CoRe were intended to be off-line. Therefore, as we expected the KC to support us in the CoRe's group call and building, we counted on the greater involvement of local organizations and public bodies (at the level of Barcelona Metropolitan Area) than national or international members. Yet, in the next stages of the project we will make a stronger effort to involve national and international members.

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 XARXA AGENTS / CARTOGRAFIA

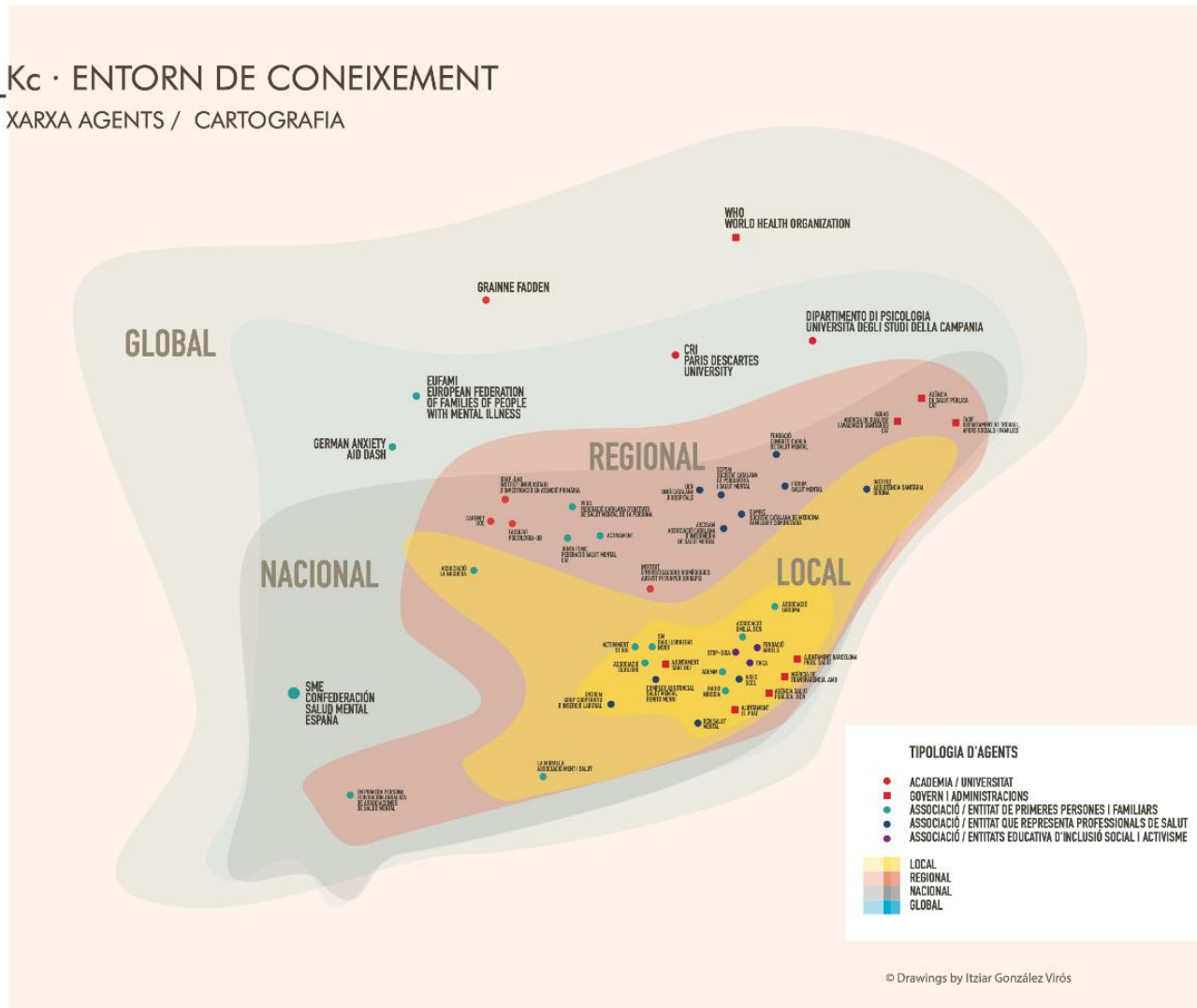


Figure 5: Knowledge Coalition mapping.

4. Knowledge Coalition in action

4.1. Knowledge Coalition Activities

The KC building process was articulated through three online meetings, taking place in July and September 2020, as summarized in Figure 6. These meetings were carried out in a relatively short period of time in order to generate efficient dynamics, able to quickly generate an appropriate research framework. While the kick-off meeting was understood as a presentation of the project and a slot to lay the foundations of the Knowledge Coalition engagement, the second and third meeting were conceived as work sessions to define the framework of the research (social support networks complementary definition and collaborative objectives identification). We exhaustively describe below the preparation and the dynamics of the meetings with the KC.

Kick-off meeting 2nd July 2020	Second meeting: work session 23rd July 2020	Third meeting: work session 17 & 22 September 2020
<ul style="list-style-type: none">•Presentation of CoAct•KC engagement•Hosting and encountering space	<ul style="list-style-type: none">•Social support network definition•Colaborative objectives identification•Representatives expectations	<ul style="list-style-type: none">•Social support network definition reviewed, completed and reorganised•Colaborative objectives identification reviewed and completed

Figure 6: Knowledge Coalition meetings in 2020.

4.1.1 Knowledge Coalition Kick-off

Kick-off preparation

While receiving confirmation of attendance and the brief questionnaire filled by interested KC members, we also prepared the kick-off meeting (May-June 2020). Several detailed graphic representations were created to clarify the explanation of the project for representatives and to facilitate the process of building a cohesive and committed research community. The principal challenge was to transform the meetings that we had previously conceived in face-to-face format into virtual form.

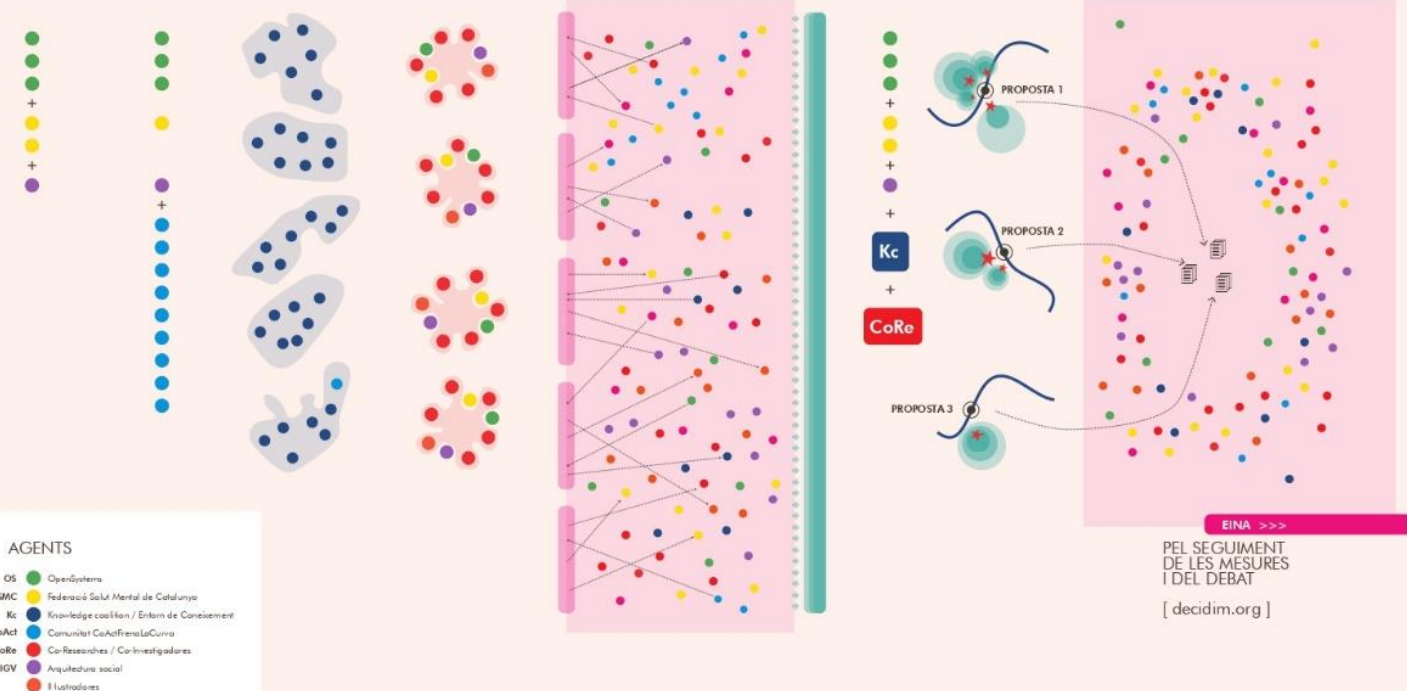
The agenda to define the different parts of the KC kick-off meeting was collectively prepared and the dynamics carefully designed, in order to create two different workspaces, one with the full group and another with different breakout rooms for small groups discussions.

We also decided to convene participants in two differentiated spaces, one for national representatives in Spanish and another for international representatives in English to facilitate the development of the sessions.

We conceived the kick-off meeting as a first presentation of CoAct as a whole and of CoAct For Mental Health. We also conceived it as a starting point to lay the foundations of the KC. We put a great effort into the preparation because we were aware that this first meeting should also provide the KC potential members with all the necessary information to decide whether to opt in or out of the project. This is reason why we also elaborated materials with an attractive design, like a graphic representation for the construction process of the research community and a roadmap (see Figures 7 and 8). These materials were created with the aim of facilitating the comprehension of the process, differentiating the involvement of the KC and the CoRe. We also wanted to clearly present the estimation of the time and effort needed considering the different participation slots and the different phases of the project (see Figure 8). The illustration situates KC in phase 1: KC is being constituted to frame research. Phase 2 corresponds to the codesign of the chatbot with CoRe. Phase 3 starts when chatbot is launched and finally all together we will interpret data and organise a large assembly in phase 4.

CoAct PROCÉS DE CONSTRUCCIÓ DE LA COMUNITAT RECERCA

PROCÉS COOPERATIU RECERCA CIUTADANA DE SALUT MENTAL



- AGENTS**
- OS ● OpenSystems
 - FSMC ● Federació Salut Mental de Catalunya
 - Kc ● Knowledge coalition / Entorn de Coneixement
 - CCoAct ● Comunitat CoActFrenadaCurva
 - CoRe ● Co-Recerca / Co-Investigadores
 - IGv ● Arquitectura social
 - Il·lustradors ● Il·lustradors

© Drawings by Itziar González Virós

Figure 7: Illustration of the development of the research community to help KC to get the large picture of CoAct for Mental Health.

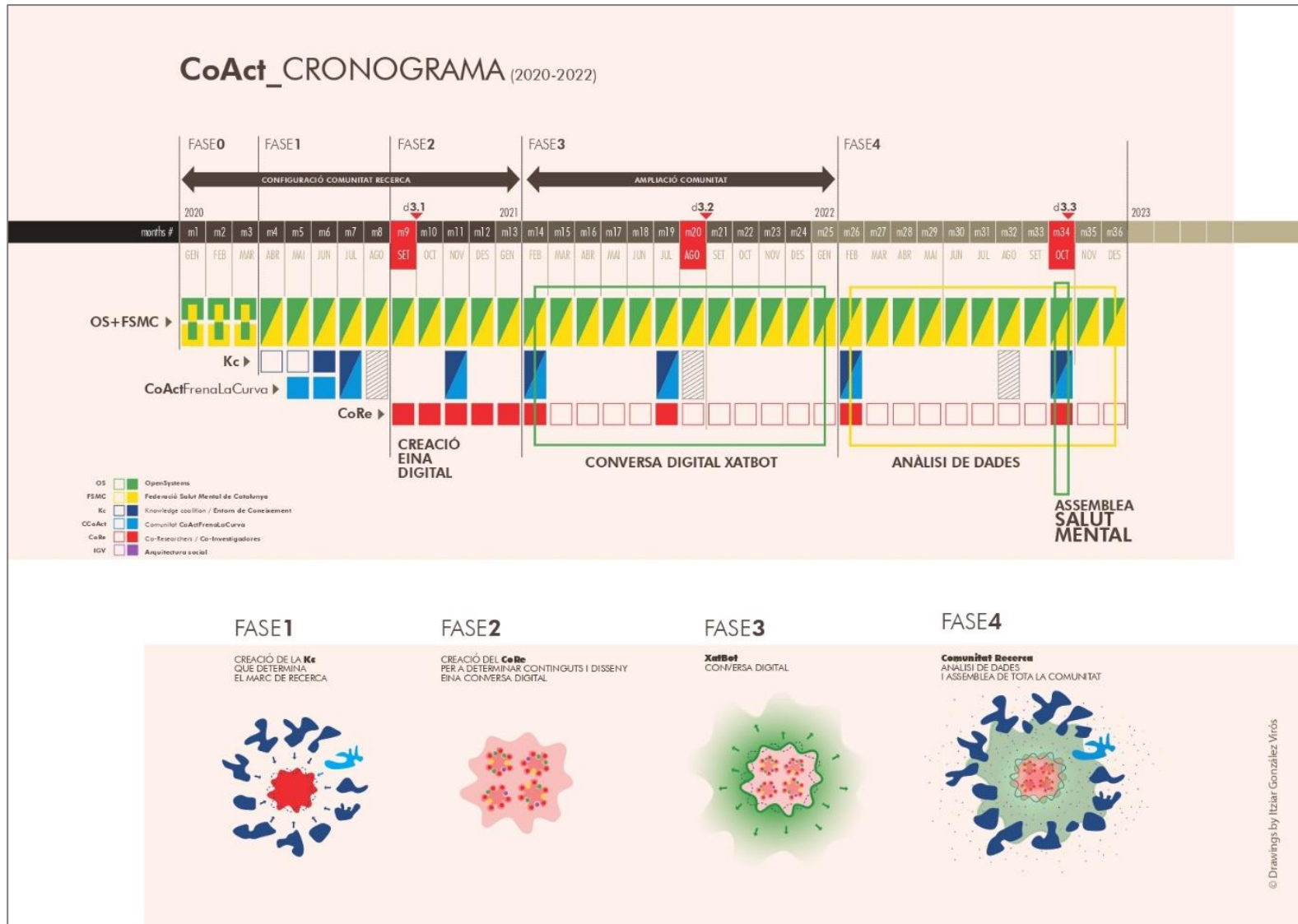


Figure 8: Roadmap and phases of CoAct For Mental Health.



Kick-off meeting dynamics

The main objective of the kick-off meeting was to present the project, clarify doubts, gather previous expectations, and validate the Knowledge Coalition mapping proposed by the CoAct for Mental Health Research Team. Overall, 43 members (49% female and 51% male) participated in the session. We first gave an explanation of the theoretical framework and methodologies of Citizen Science, and the vision of Citizen Social Science and presented the objectives of the European project CoAct.

We also presented the framework and context of CoAct for Mental Health and an explanation of the phases of the process of construction of the research community: (1) creation of the KC that defines the research framework; (2) creation of the group of CoRe and work sessions; (3) data collection process through the chatbot; (4) data analysis and final general assembly for results interpretation and definition of recommendations. The objectives and expectations of project were also discussed.

During the second part of the meeting, we worked in five small groups, moderated by FSMC and OS members, to clarify doubts and reflect on the role of the KC and the participants' commitment and involvement with the project, especially in relation to the methodological and data analysis part.

Within small groups the participants had the chance to present themselves and get to know each other. The attendees further shared their perspectives and current work and initiatives in the field of social support networks in mental health. The need to approach mental health in a broad sense, taking into account diverse groups, such as people with drug addictions, was also discussed as well as the importance of the discourse on social isolation. The social support networks in relation to mental health care provision and the search for specific indicators that could be deployed were highlighted. The participants discussed how to generate interaction within the social support network and highlighted the current lack of information on the social support network in mental health. They pointed out the limitations of the current system that does not take into account the aspects that the project wants to explore and the need for a psychological and social approach to mental health was also highlighted, to facilitate a better understanding and management at the public health level. The obstacles of collaborative

projects and the need to promote genuine and transparent cooperation in all phases of the research process were highlighted as well, putting at the centre and valuing the contributions and expertise of the communities involved. The need to give a relevant and active role to the CoRe was also emphasized and the value of the participation of relatives of individuals with an experience of mental health was addressed. The need to obtain concrete results with the evidences collected was also placed at the centre, which might have a return for the people involved but at the same time a political incidence. Doubts were addressed regarding the impacts and personal returns for participants involved in the project, and regarding the impacts in the political sphere. In particular, the need to consider family members and members of the mental health social support network not only in terms of accompaniment in the recovery process, but rather as agents with their own needs and desires, was emphasized. There emerged a general agreement on the relevance of addressing and emphasizing the role of social support networks in mental health, giving great value to the knowledge and expertise of individual with an experience of mental health and of the members of their proximate social environment. The discussion reflected the importance of social support in mental health and the need for cooperation between different agents to understand mental health from a more communitarian perspective.

A discussion on the possibility of incorporating new actors not represented in the KC mapping also took place. The participants pointed to some missing associations and local entities that could be interested in participating in the project as KC members. The proposals of possible candidates to join the KC were collected and evaluated by the CoAct For Mental Health Research Team to integrate them to participate in the next meeting.

Finally, the comments and reflections of each subgroup were shared in the general group, and questions and doubts were addressed, and we opened a discussion related to the dynamics of follow-up, work and planning with the KC. The possibility of monitoring the project was discussed through a periodic newsletter via email and general meetings (approximately three per year). To end up we clarified next steps and invited them to the second meeting of the KC.

After the kick-off meeting, we send a gratitude letter to all people invited, both those who could not attend and those who took part of the first meeting. To those who could attend we also attached the links to three documents: a summary of the project in the form of “most frequent questions” (appendix 3), the slides of the presentation and the Knowledge Coalition mapping.

4.1.2 KC Collaborative work

The Kick-off meeting was framed mostly as an informative meeting, in order to allow the potential KC members to understand the project and to freely decide to join the project, based on the detailed information we provided us. Second and third meeting were focused on establishing the framework of the research, to obtain a social support networks complementary definition and to identify collaborative objectives from the perspective of institutional representation to compare and complement it with the perspective of the co-researchers as self-experience representatives.

4.1.2.1 Informed Consent procedure

Firstly, an initial proposal of Informed Consent (IC) was elaborated by the Research Team, included in the Deliverable D9.2 and positively reviewed by the Ethics Committee of the University of Barcelona. From April to June 2020, as the Knowledge Coalition building process was further defined, the IC was revised by OS and reviewed by UNIVIE in order to fulfil as much as possible the plain language rules. Useful discussions in the frame of the CoAct IC working group helped us to clarify some issues and to spot the important ethics points to be included and made very clear. The document was translated in Catalan, Spanish and English, in the form of a pdf file.

The document was sent to the Knowledge Coalition participants by email after the Kick-off meeting, insisting on the fact that they could send us any question they may have. The document was framed as a way to clarify the terms of cooperation within the Knowledge

Coalition and as a way to follow the principles of an ethically responsible research. We asked them to sign it and send it back by email, should they understand it and agree.

In addition, in order to make sure that all participants understood the document, we explained the IC in an online meeting in simple terms and we gave another opportunity to the participants to ask questions. One participant took this opportunity to ask for some clarifications. The virtual meeting was also used to collect the oral consent of those who couldn't send us a signed copy because they did not have a printer and/or scanner. In order to complete the IC collection, we wrote further emails to the participants who didn't send us the copy and couldn't attend the meeting.

4.1.2.2 KC Community building dynamics

Following the path of the Kick-off meeting, we designed the communications and the interaction with the KC members. We established a communications protocol in order to provide personalized information to all KC members, to share documentation and to foster the members participation during and in-between the meetings. We thus pretended to generate a clear vision of the work needed and positive dynamics in order to achieve the goals needed.

The different steps of the communications and engagement protocol were:

- Send a personalized invitation to the work meeting, explaining carefully the goal of the meeting at least xx days before and a reminder the day before.
- Carefully analyse and process the work done during the previous meeting in order to produce new material, to be shared during the meeting.
- During the work meetings, always include breakout rooms, in order to have the possibility to work in small groups and to foster an active participation of all members.
- At the end of the meeting, clearly explain the next step of the dynamics and what the KC will have to do before the next meeting.
- After the meeting, send an email with very complete information about the work done, including minutes of the meeting and all slide presentations.

- Constantly maintain an open communication channel, through the email of the project (coactuem@ub.edu) where possible doubts and questions were immediately answered.
- Implement open, flexible and inclusive dynamics. If some KC members could not attend a given meeting, they could anyway catch up by reading the minutes and the presentations and could easily participate to the next meeting.

4.1.2.3 KC second meeting

Preparation

For the second meeting, we completed the KC by contacting and inviting those representatives proposed during the kick-off meeting by the KC members.

Before the meeting we analysed the information collected through what the attendees have expressed in the questionnaire they filled previously to first meeting and the information collected during the small groups' discussion at the kick-off meeting, the 2nd of July 2020. This analysis allowed us to obtain a new cartography based on five identified approaches: social inclusion, defence of rights, awareness, provision of services and improvement of care (See Figure 9). We pretended to collect and segment the interests and objectives of the entities represented, to work in five small groups in the second session with related entities. However, we detected that some entities covered several dimensions, so we decided to include them in the one that represented their main area of activity and they were given the option of moving to the work subgroup where they felt most comfortable with.

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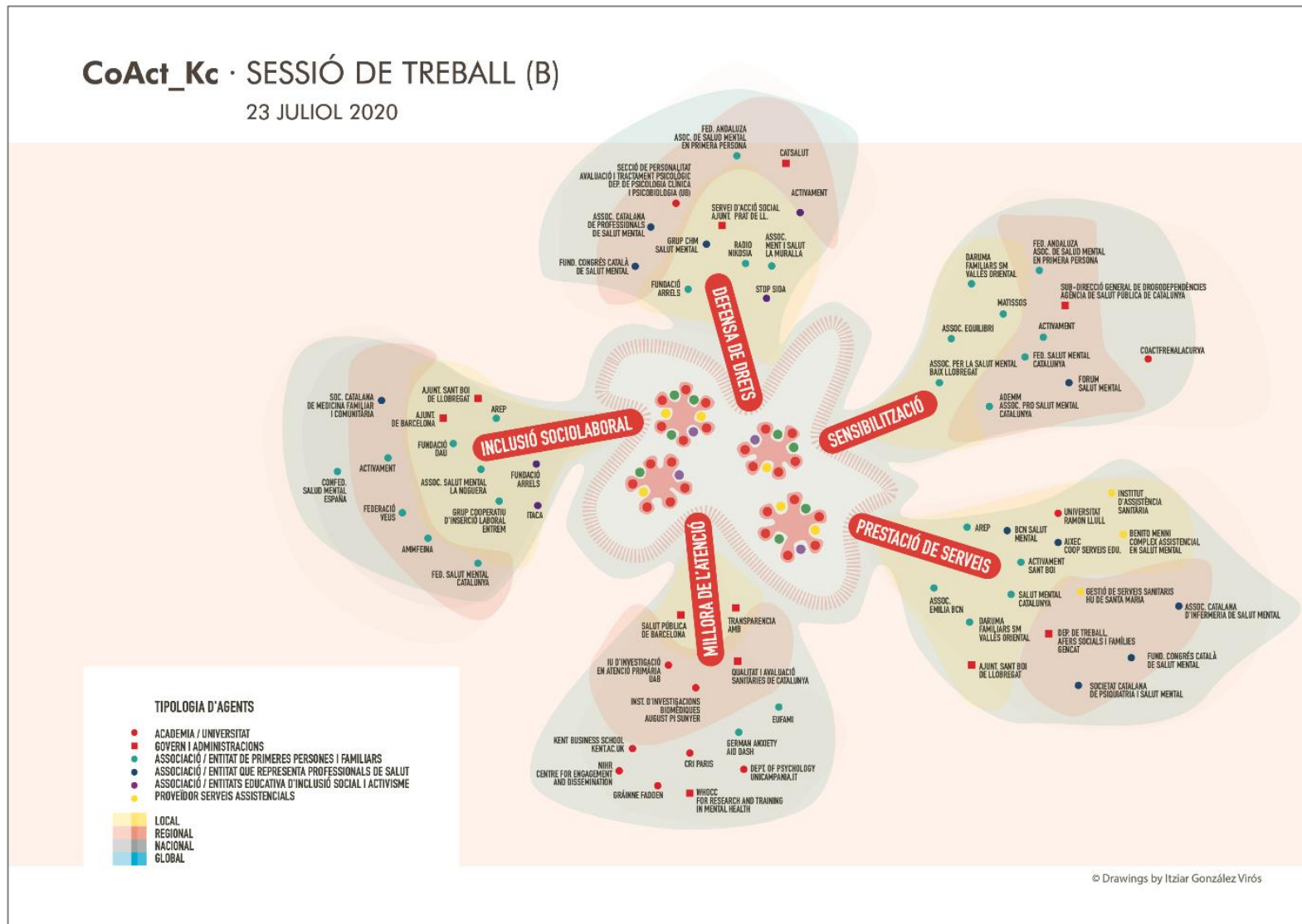


Figure 9: Mapping of the approaches to mental health work and research.

Work session

The aim of the second meeting was to open the discussion to obtain a social support networks complementary definition and to identify collaborative objectives from the perspective of institutional representation. Finally, 30 participants attended the second meeting. Both international and local attendees were present, as we included English subtitles for the international attendees.

As the research process was starting with this work session, at the beginning of the session, we carefully explained the information contained in the IC, to be fully sure that all participants understood the project and agreed with the personal data treatment (see 4.1.2.1).

The new cartography (see Figure 9) representing different complementary approaches to mental health work and research (social inclusion, defence of rights, awareness, provision of services and improvement of care) was presented.

The work in subgroups was targeting several questions in relation to social support networks in mental health:

What do we understand as social support networks? *What is actually being done? What should be done?* The aim was to find out the working areas of the CoRe, to detect common struggles and identify the wishes of each member of the Knowledge Coalition community. In other words, the objective of the groups was to help configure the thematic axes of the research that would be worked on by the CoRe, ensuring that the digital conversation includes the expectations and struggles that the members of the Knowledge Coalition are fighting for. In particular, the first question: What do we understand as social support networks? was intended as a collective exercise to build a common language around the definition of social support networks in mental health, acknowledging its complex and multi-faceted dimensions. The second one: What is actually being done? was intended as a mapping effort to collect from KC members all the initiatives, materials, researches, projects or actions carried out to facilitate access or strengthen social support networks. The third one: What should be done? was intended as a starting point for the identification of the main needs of the mental health community when it comes to improving access or strengthening social support networks.

Back to the main room, discussions and insights from each group were shared and summarized.

Overall, the attendees were very participative, and the work done allowed the research team to prepare a first collaborative document on social support networks that we worked on internally during the next month and a half until the third meeting.

During the second meeting we also opened a channel to collect participants' expectations. A representative from the Centre for Social Innovation (ZSI) in Vienna asked the attendees to fill out a *padlet* board to express the expected results of the project based on their role and perspective. The *padlet* was left open for all people who had not been able to attend.

4.1.2.4 KC third meeting

Preparation

We decided to convene participants in two differentiated spaces (as we did for the kick-off meeting), one for national representatives in Spanish (17th September) and another for international representatives in English (22nd September) to facilitate the development of the sessions.

We dedicated a consequent effort to organize all the information collected during the second meeting in relation to the questions exposed: *What do we understand as social support networks? What is actually being done? What should be done?* However, for the third meeting we focussed on two of them, namely *What do we understand as social support networks? And What should be done?*, redirecting the mapping exercise of current initiatives, materials, researches, projects or actions carried out to facilitate access or strengthen social support networks to a web repository currently under development. The reason was that we considered essential to review and complement the definition of social support networks and the collective objectives to define the research framework

After analysing and reorganising the information we obtained a digital document ready to be presented to the participants in a clearly and comprehensive format in order to facilitate the work in the third session. All KC members inputs and contributions to the definition of social

support networks were thus categorized into six dimensions, namely: 1) community/social relations, 2) good practices, 3) place/service, 4) challenges, 5) values and 6) other. The same categorization exercise was done for the collaborative objectives, which were grouped into eight main objectives (see section 4.2).

Work session

The session with local and national members of the Knowledge Coalition, was carried out from the beginning in two parallel groups (virtual rooms) and the second part of the session we met the complete group. Overall, 22 participants attended the third meeting.

The third session was meant to follow-up on the work of the second session, leaving more time for discussion and debate so that everyone could give his/her opinion. Digital document was shared, representing the internal effort to summarize and provide a first grouping of the contributions made by the members of the Knowledge Coalition during the second meeting. Each group reviewed and commented on a shared digital document that was intended as a starting point for revision and validation of: (i) a broad and complementary definition of the concept of "social support network in mental health", (ii) the collective objectives of the research. In the meeting we aimed at: (a) better understanding what we mean by social support network, (b) mapping expectations and collective objectives of the research. The fact of having worked on the collection document of the second session facilitated the presentation and organisation of the information and allowed us to complete the definition of social support networks and deepen into the collaborative objectives (*What should be done?*). The idea behind the discussion of a definition of mental health support network and of the collective objective was to help define the thematic axes of the joint research that the CoRe would carry out. The document would finally be revised and validated by the CoRe, who would start the co-creation sessions in November. It also aimed at prioritizing the research objectives and the actions that could be taken based on the results.

The first part of the discussion was about the grouping of dimensions that made up the definition of a support network. Attendees commented on the grouping and suggested some new keywords. They also commented on the need to rename some tags / dimensions so that they could better represent the keywords included. Attendees suggested that some

dimensions / keywords were very general, that they should be more specific, and that it was not clear whether it was a definition related to mental health or to society in general.

The second part of discussion was about collective objectives. Attendees commented on the need for more specification since the dimensions and grouping looked too abstract and generic. The attendees further commented on the abundant overlap of concepts and pointed to the need to further include the idea of support networks into collective objectives in very pragmatic terms (such as support when accessing certain services, including services as specific as public transport).

The opportunity was given to make the last suggestions online and the members of the Knowledge Coalition positively appreciated being able to offer this feedback afterwards. Comments and suggestions would be included and returned in a new document for final revision and validation. The objectives of the offline work were to validate a broad and complementary definition of social support networks in mental health, and to prioritize actions to transform the research results into concrete proposals and actions.

At the end of the meeting we gave an explanation about the call to build the CoRe group in two complementary ways:

- A) Open call: the material would be published on a web page accessible to everyone and would be disseminated through various channels (twitter, newsletters, etc.).
- B) Call with the support of the Knowledge Coalition: the members of the KC would receive the details and material to be shared with their contacts so that any interested participant could contact the project coordinators.

Finally, we informed about the development of a website to centralize the materials from the sessions and all the communications related to the co-creation process, also functioning as a repository for materials, initiatives and resources that already exist in relation to social support networks in mental health. Attendees were also informed that they would receive information about the co-creation process through a periodic newsletter and that they might contact the coordinators for further information and follow-up through the project email coactuem@ub.edu. We end up the meeting wishing to meet them at the fourth meeting of

the Knowledge Coalition planned for March-April 2021, once the co-creation process is its final phase.

After the meeting, the attendees were invited to comment, revise and validate the working document on social support networks which was left open until October 4, 2020.

The response was very rich, both in terms of new comments and the assessment of the collection document. However, several criticisms were collected in relation to a specific aspect: the organization by dimensions of the definition of social support networks. Therefore, we worked on the part of the document focused on the complementary definition of social support networks distributed in six previous sections: 1) community/relations, 2) good practices, 3) place/service, 4) challenges, 5) values and 6) other. The result obtained was a restructuration of the information in five new axes trying to answer the questions related to: 1) meaning, 2) purpose, 3) functioning, 4) difficulties and 5) values and principles (see section 4.2).

Once the work had been done, we sent the new document with the aim of giving them back the work carried out so far and requesting them to assess and review it together with the CoRe in spring 2021.

4.2. Knowledge Coalition members' participation analysis

We present below relevant data of KC members' participation and a brief explanation of the work done in the first participatory sessions with the KC.

Participation

The barplot (Figure 10) shows the level of participation of Knowledge Coalition members throughout the three meetings of the Knowledge Coalition building process. Despite the exceptionality of the circumstances, which obliged us to turn to online sessions, 45 participants attended the first meeting on July 2nd 2020, 30 participants attended the second meeting of July a 23 2020, and 22 attended the third meeting of September 17 and 22, 2020. Beyond those who could attend the meetings, overall 65 KC members have shown their

interest in keeping engaged in the project, either by participating to the sessions or keeping email contact while not able to attend the meetings.

From the 42 people that participated in the first meeting, a total of 38 people participated either in the second or the third meeting, which demonstrated a strong interest and engagement of the KC members. Some representative also participated with written contributions to the third meeting although they couldn't attend neither the second nor the third meeting. As represented in Figure 11, the distribution of the participation during the three meetings has been very similar in relation to geographical level.

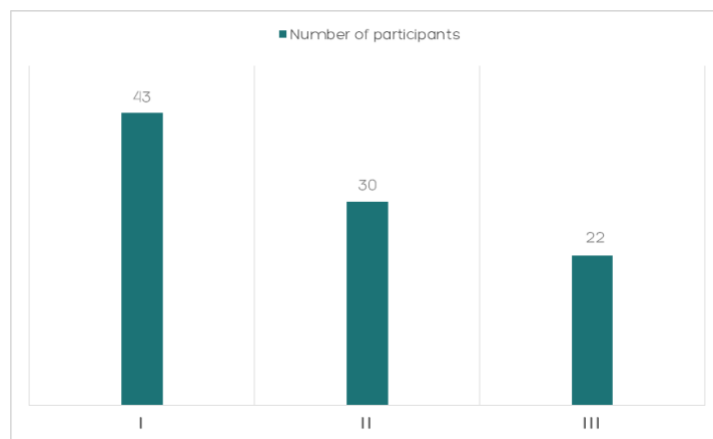


Figure 10: Number of participants during the three meetings of the Knowledge Coalition building process (July – September 2020).

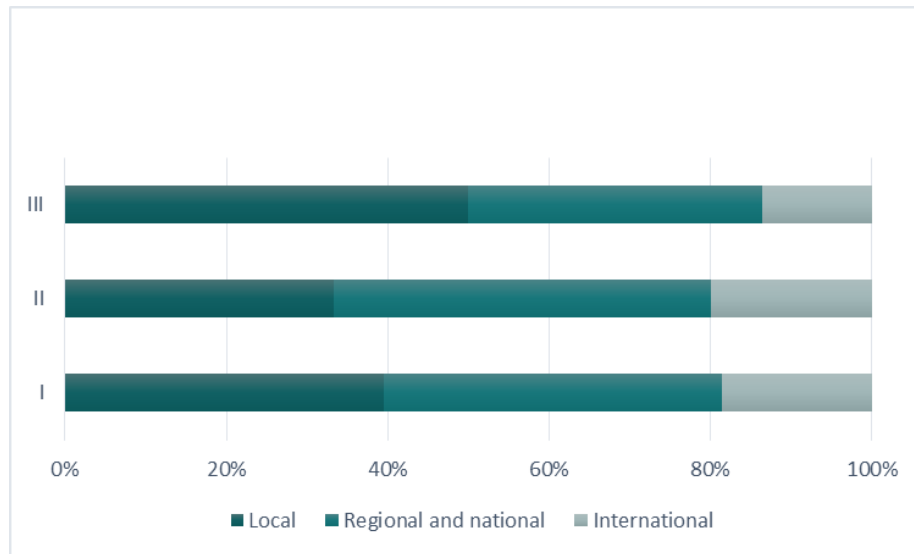


Figure 11: Percentage of participants by geographical level during the three meetings of the Knowledge Coalition building process (July – September 2020).

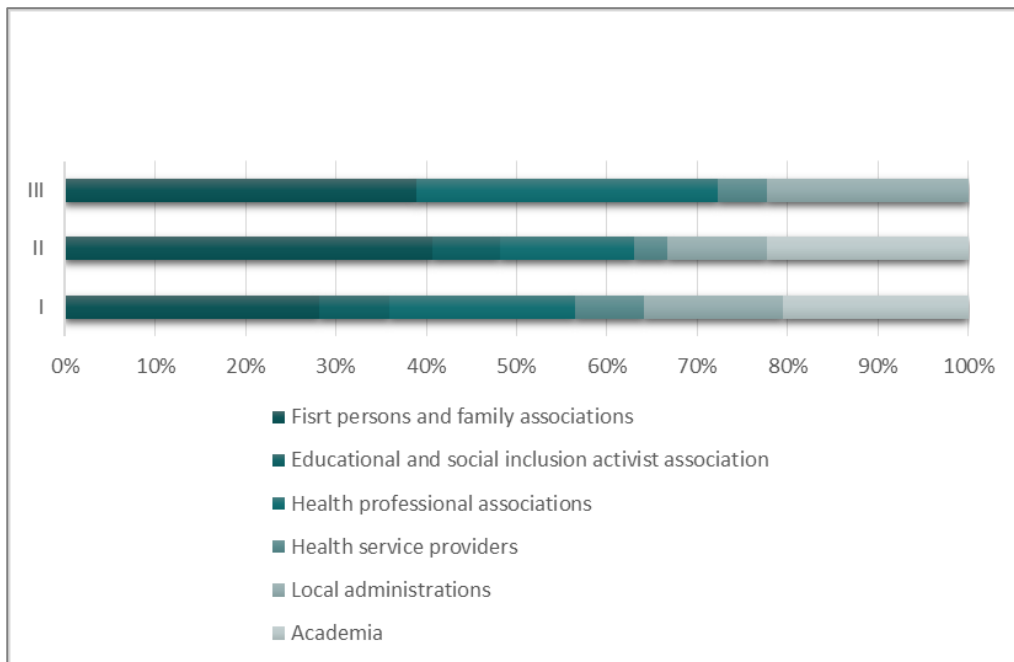


Figure 12: Percentage of participants by typology during the three meetings of the Knowledge Coalition building process (July – September 2020).

The percentage data in relation to the typology (see Figure 12) showed us a fairly balanced distribution in general, although in the third meeting we couldn't count on the participation

of representatives from the academic and educational/social inclusion activist association field. A relevant fact is the high and sustained participation of representatives of people with self-experience in mental health and their relatives.

Co-evaluation

At the end of the second meeting with the Knowledge Coalition, attendees were asked by a member of the Centre for Social Innovation (ZSI) in Vienna to express their expectations of results of the project. The contributions were collected in an online padlet board that was accessible to all members and left open for all people of the KC, who had not been able to attend the second meeting. The exact wording of the question was: What are the most important results that you expect from the project for your organisation (or for you)?

The contributions were then collected in a *padlet* board with different sections, to obtain a map of expectations of the participants based on their role and perspective. The different sections were referred to the type of representative's participation: academia, health service provider, government & public administrations, association/entity representing health professionals, association/entity of people with self-experience and relatives, association/educational entity for social inclusion and activism and, the last one, related to individual interests.

After the third meeting ZSI elaborated a more specific on-line questionnaire to learn more about the expectations of participants, but also about their experiences with the participatory process so far. The results from this feedback will flow into further project planning but also into further reflection processes.

4.3. Knowledge Coalition in times of COVID-19

One of the most relevant issues in the constitution process of the KC has been the changing and uncertain context we have dealt within the last seven months. The fact of having to work in totally anomalous and changing circumstances has forced us to be flexible, adapting the work rhythms constantly and designing a work plan that would allow us to overcome the obstacles that were arising, especially in relation to the limitations of the social contact. This

has affected both the coordination meetings of the research team and the biannual meeting with the rest of the CoAct partners and, above all, has conditioned the organization and development of the meetings with the representatives of the KC that we expected to perform face-to-face. On one hand, we consider that face-to-face contact facilitates group cohesion, work dynamics and the creation of bonds between people. Regarding this, the impossibility to meet face-to-face has been a handicap to build a solid, effective and committed community. But, on the other hand, we consider that holding online meetings has encouraged the participation of people from outside Barcelona, who were able to participate without having to move.

Another of the main challenges of the KC constitution has been to involve the public administration, which since last March had been focused on managing the social, health and economic crisis, and the civil organizations that have been trying to respond to emerging social needs and sustain the emotional wellbeing of citizenship. In the end, we have obtained a positive response, although we will have to work to achieve greater involvement and participation of prominent mental health stakeholders. The good news is that today (November 2020), the importance and value of social support networks (our research focus) is being highly validated and reinforced.

The exceptional situation derived from the pandemic has also represented an opportunity to learn and practise alternative participative online methodologies. FrenaLaCurva Digital Hackathon allowed us to use the platform as a prior and complementary test bed to the work carried out with the KC and to that planned with the CoRe. Three working groups (contents, technological issues and communication) were generated to create a first tool that allows co-creating stories for the future chatbot. Thanks to the effort and work done with volunteers from Spain and South America, we now have a web prototype. The intense work carried out entirely in an online format also allowed us to test the dynamics to follow in future sessions with the KC and the CoRe, considering the current pandemic situation. Thus, this prior training helped us to design the first virtual meeting with the KC, while the call for possible candidates was launched.

Despite the unexpected difficulties, we are satisfied with the results obtained so far and we believe that the co-evaluation work carried out in parallel by ZSI can help us to collect and analyse the feedback from the representatives of the KC to improve aspects of the participatory process in ahead. At the current point of the research, we have a working document that will help us to approach the next phase with the Co-researchers committee and we trust that the experience acquired in the online environment will help us to do a good job of cooperation and co-creation.

By the time we are writing this report (November 2020), we are dealing with the new COVID-19 outbreak so the face-to-face research co-design process with CoRe has been also designed through on-line co-creation sessions.

5. Concluding remarks

The main objective of the KC building process was the definition of a common language around the concept of social support networks in mental health, and the identification of the main social concerns perceived by those associations, public administrations, health service providers and academic institutions represented in the KC.

As described in section 4.1.3, during the second and third meeting with the Knowledge Coalition, we've been working to try to answer three different questions in relation to social support networks: *What do we understand by social support network? What is actually being done? What should be done?*

Based on the work done, we have obtained a document that is not currently public, as it is still under review and co-construction. In addition, the same participatory work process will be carried out with the CoRe in order to compare and complement approaches from both participation slots. However, we present some of the preliminary reflections and results.

The collective definition of social support networks in mental health has helped to promote a space for reflection regarding what are social support networks for, how do they work, what value do they have and what challenges do they entail. The discussion has helped to visualize the mechanisms, and the different social support needs that may emerge among community

actors. Overall, many KC members pointed out the relational dimension of social support networks, often understood as the community and interpersonal bonds of the individual with his/her external environment, or the spaces that facilitate social interactions, including the bar, the kiosk, or the church, social clubs or other cultural and leisure activities. While these interpersonal bonds may be related to leisure activities, they also present a more functional, every day, instrumental aspect, such as facilitating access or coverage of basic needs. Indeed, KC members consider that socializing individual suffering and reducing social isolation is a major function of social support networks. Actors of the social support networks are also understood as facilitators of access to very basic services such as transport and mobility. However, one of the main challenges identified by KC members is the risk for social support networks of being perceived by individuals with a mental health experience as an imposition, harmful and unintentionally overwhelming causing stigma and low self-esteem.

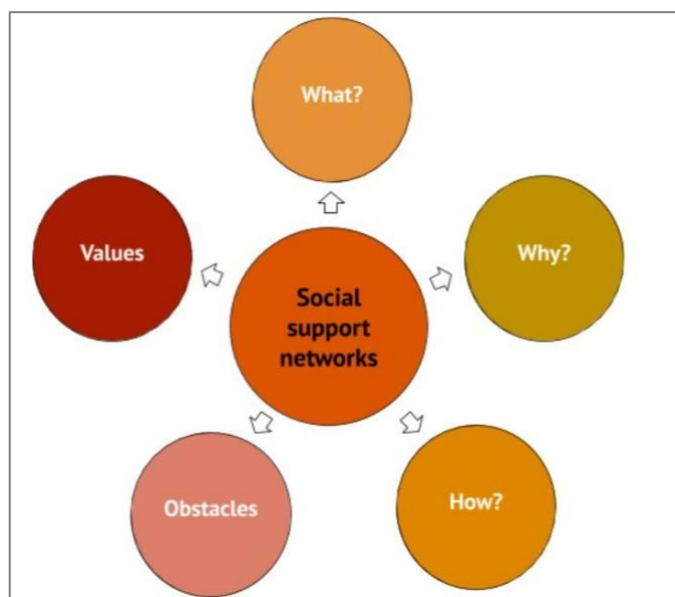


Figure 13: Axes identified in the collective definition of social support networks in mental health through the work carried out in the meetings of the Knowledge Coalition.

Similarly, the social concerns and expected objectives of the KC related to social support networks were identified and summarized into eight main points (see Table 2). The social concerns and expected objectives that emerged during the KC meetings address problems of accessibility to social support networks (namely language, lack of skills, gender, lack of self-

confidence, impact of anxiety, lack of assertiveness), the need for making social support networks visible and facilitating contact from inside the network. The objectives identified also point out the need of care and prevention of young collectives, or the promotion of existing activities and initiatives that may constitute important resources and elements of the network. The need to make visible the role of the family and of the proximate environment was also pointed out, as well as a necessary shift in health professional’s role and perspective towards more active listening. Finally, the need to identify and publicise local 'champions' in the professional community in order to gain wider 'but-in' from peer, or to address the issue of communication and awareness in general, to work on the “causes” of stigma and, therefore, of the lack of social support networks at the community, was emphasized.

O.1	Improve accessibility to social support networks
O.2	Make visible the role of the family and of the immediate environment
O.3	Expand and improve the management and provision of mental health services in their role of promoting social support networks
O.4	Train professionals and professional caring practices
O.5	Expand services for them to be able to work and monitor people's relationship with the social environment
O.6	Promote individual and collective empowerment
O.7	Influence the training of people in the support network
O.8	Act at multiple levels in the community

Table 2. Table of the collective objectives identified during the meetings of the Knowledge Coalition.

The document is an ongoing open effort to build a complementary definition of social support networks in mental health, and to identify the main objectives and needs that the R&I Action ought to address. It also constitutes a starting point of discussion for the CoRe. During the co-creation session, indeed, the CoRe will be addressed the main question: What do we understand as social support networks in mental health?, which will then be contrasted and complemented with the definition proposed by the KC. The CoRe will be further asked to

refine and prioritize the collective objectives which will function as dimensions and main themes of the micro-histories co-designed during the co-creation process.



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7. Appendix

Appendix 1

KC Invitation letter

Barcelona, XXX June 2020

Dear XXX,

We are writing to invite you to participate to the project **CoActuem per la Salut Mental** (CoAct for Mental Health) that OpenSystems research group (University of Barcelona, Spain) and the Catalan Federation of Mental Health (Barcelona, Spain) are leading. **CoActuem per la Salut Mental** is a citizen social science project about mental health social support networks. It places at the centre of the whole research process the lived experiences of individuals with mental health issues and their families. The project is part of the European project CoAct (2020-2022, <http://www.coactproject.eu>).

We highly value the support of your organization. Citizen social science engages citizens who share a social concern and recognizes the value of their experience as co-researchers and co-actors in the research process. Organizations like XXX, which you are part of, are the knowledge coalition that can best indicate how the research could be framed, while finding greater value in the final results.

In order to explain you the project in more details, and to discuss the planning and methodologies we have devised, we would like to invite you to an online session* on July 2, 2020 from 16 pm to 17 pm (CET). The session will consist of a brief presentation of the leading team, as well as an explanation of the content and purpose of the research, together with the mapping of the knowledge environment that we have developed and of which your organization is part.

Thank you so much for your attention and interest in attending the July 2 session. We would be very grateful if you could confirm your attendance, or the person you are delegating, and fill out the attached form before June 22nd.

Yours faithfully,

CoActuem per la Salut Mental research group

*link to the on-line session: <https://eu.bbcollab.com/guest/1f3ff6fa877748b49a3ada761245a2fc>



Appendix 2

Informed Consent

Signing this document means that **you voluntarily agree to take part** in the CoAct for Mental Health project and that **you understand your role in this project**. We want to give you important information before you decide if you want to participate.

We invite you to take part in the CoAct for Mental Health research project.

The goal of this project is to strengthen social support networks in mental health through participatory research and citizen social science. During this process, the mental health community and the research team will work together. We are especially interested in what individuals with an experience of mental health and their families want to express and the support they need. The project has received funding from the European Union's Horizon 2020 research and innovation programme and will last 3 years, from 1st January 2020 until 31st December 2022. What we do in CoAct for Mental Health is described in the attached document "Frequently Asked Questions".

We ask you to be part of the Knowledge Coalition.

The Knowledge Coalition is formed by a diversity of stakeholders related to mental health: local and international Non-Governmental Organizations, professional associations, public institutions and professional researchers.

Your role will be to frame the research, based on the experience of your organization.

We want to map the complementary and diverse approaches of social support networks in mental health. We invite you to be part of this process. You will be involved in periodical meetings (no more than 4 every year and each with a duration of 2 hours maximum) and will receive periodical updates on the project. You will be invited to the collective data interpretation and their transformation into actions. The meetings of the Knowledge Coalition will be audio/video recorded for research purposes only.

Your inputs will contribute to the research co-creation.

Your inputs will be used for the cooperative work with the Co-Researchers. The Co-Researchers are individuals with an experience of mental health and their families. They will co-create material in the form of microhistories based on their lived experience. This material will be shared through a collective digital conversation within the research frame provided by the Knowledge Coalition. We will invite anyone concerned about mental health to interact through this digital conversation.

Your participation will mean the following benefits:

- Participate in a first level European research project
- Enrich your organization's network with local and international contacts
- Be involved in a pioneer citizen cooperation research process

No risks are foreseen. You are only asked to be available to participate.

Information about your personal data.

Personal data includes personal information about you such as your contact details, your personal opinions or video/audio recordings. Other **non personal data** recorded during the project will include general information about the mental health community and existing resources on social support networks.

- The University of Barcelona is in charge of collecting, storing and anonymizing your personal data (contact details, personal opinions and video/audio recordings). If you want to have more information, you can contact the person in charge: General Secretary of the University of Barcelona, Gran Via de les Corts Catalanes, 585, 08007 Barcelona / email: secretaria.general@ub.edu.
- Your personal data will only be used for research purposes. Additionally, if you agree, we will send you information about the events we are organizing.
- Your personal data will be used only if you sign this Informed Consent. You have the possibility to decide not to participate anymore, without any negative consequence. In that case, you can contact the Principal Investigator (Josep Perelló, josep.perello@ub.edu) and your personal data will be immediately deleted.
- After we collect your personal data, we will de-personalized it. This means your identity will be hidden. After 10 years, all personal data will be deleted.
- Only the research team will have access to your personal data, and it will not be shared with anybody, neither inside or outside the project.
- Only data where your identity is hidden may be shared with other partners of the project.
- Data where your identity is hidden may be used to write scientific publications. You will always be informed prior to the submission of the publication to the scientific journal.
- You can ask to see your personal data anytime, ask to correct or delete your personal data and ask for restriction of your personal data processing. To this aim, you can write to Principal Investigator (Josep Perelló, Universitat de Barcelona, C/Martí i Franquès, 1, Barcelona E-08028 (Spain) / email: josep.perello@ub.edu, attaching a copy of your ID card.
- If you feel like we missed something that is important for you, you can contact with University of Barcelona Data Protection Officer (Gran Via de les Corts Catalanes, 585, 08007 Barcelona / email: protecciodedades@ub.edu)
- You can send a complaint to the Catalan Data Protection Authority www.apdcat.cat: C/ Rosselló, 214, Esc. A, 1r 1^a, 08008 Barcelona / email: apdcat@gencat.cat

Contact person

If you have further questions concerning your role in this project, you can contact the Principal Investigator, Josep Perelló (josep.perello@ub.edu).

Informed Consent

Confirmation



Your participation in this research is only possible if you freely sign this Informed Consent document to authorize us to use the data you provide.

I hereby declare:

- I am 18 years or older and am competent to provide consent.
- I was informed about the goal of the project CoAct for Mental Health.
- I understand that it is not compulsory to participate. If I decide to participate, I understand that I can decide not to participate anymore at any time.
- I have read the attached document “Frequently Asked Questions” and I had the opportunity to ask more questions. All my questions have been answered.
- I agree that I will be audio/video recorded during my participation in this research project.
- I understand that no recordings will be replayed in any public forum or made available to any audience. The recordings will not be shared with the other partners of this project.
- I understand that information where my identity is hidden may be shared with the other project partners.
- I have no objection if data in which my identity is hidden are used in order to write a publication in a scientific journal if I am previously informed.
- I understand that I can refuse to answer any question during this research project.
- I have received a copy of this agreement.

If you want to participate in this project, then check the first box below. In addition, if you want to receive information about future events of the project, you need to check the second box.

1) Regarding to the processing of my personal data with the purpose of executing the project, I give my explicit consent checking the following box:

2) Regarding to the processing of my personal data with the purpose of sending information about future events of the project, I give my explicit consent checking the following box: (Optional).

Name and surname of participant:

Place, date and signature of participant:

Appendix 3

CoAct for Mental Health FAQs

Project name: *CoActuem per la Salut Mental* / CoAct for Mental Health



Keywords: mental health, social support networks, citizen science, co-creation, digital conversation, participatory research, open data

Research team: The [OpenSystems](#) group of the University of Barcelona, [Catalonia Mental Health Federation](#) and the social architect Itziar González Virós.

Funding: The European project [CoAct](#), which places groups of citizens in vulnerable situations at the center of research, belongs to the Horizon 2020 research and innovation program of the European Union with contract 873048.

What is the goal of *CoAct for Mental Health*? It is a citizen science research project which places individuals with an experience of mental health and their families at the center. CoAct for Mental Health wants to strengthen social support networks in mental health through a participatory research, within the so-called social citizen science.

What is citizen social science? It refers to a scientific research co-created and led by groups of citizens who share a social concern, in this case related to mental health social support networks. Citizen science is a model of scientific research carried out through the active participation of the general public. Citizen science is gaining momentum globally. It includes top-level academic research that combines scientific advancement with social transformation and the improvement of public policies.

What is so special about social citizen science? It involves citizens who share a social concern as co-researchers and co-actors in the research process. Their experiential knowledge is valued at the same level as that of professional researchers.

What are social support networks in mental health? They refer to the individual's social environment, which is generated informally, and which is not professionalized. We all need an emotional environment that provides us with love and support, especially in difficult times. In this sense, our families stand out, including all those with whom we share close and continuous emotional ties. As for individuals with an experience of mental health, the social and affective environment is a key element in the recovery process. Yet, support is complex, and it generates specific needs of care and self-care. These issues need to be addressed in a way that benefits both who is caring and who is being cared, without generating discomfort. Moreover, social support needs to be continuous overtime.

Why is research on social support networks in mental health important? Because individuals with an experience of mental health and their families advocate for the importance and effectiveness of social support networks as facilitators in the recovery process. Social networks act as a preventive factor in situations of isolation and social exclusion. Yet, scientific research on the role of the family and other social support networks in the recovery process is still scarce, lacking evidence.

Who participates? How is citizen cooperation organized in *CoAct for Mental Health*? Within the framework of citizen science, the methodology proposed with citizen cooperation is based on the mutual recognition of the diversity and complementarity of the actors involved in the field of mental health and on their potential for collaborative work. The project seeks to make visible the broad community of people and institutions involved in the field of mental health (Knowledge Coalition),

and to place at the center of the research the voices and knowledge of individuals with an experience of mental health and their families (Co-Researchers). The Knowledge Coalition guides, monitors and gives support to Co-Researchers. Organized in various cooperative groups, they become co-researchers and engine of research, and at the same time co-actors in social support networks. The results of the interaction and cooperation between co-researchers and the broad community of citizens who will participate in the digital conversation (chatbot) is intended to provide the necessary evidence to legitimize the proposals of individuals with an experience of mental health and their families.

What do co-researchers create? The cooperation between individuals with an experience of mental health and their families is intended to lead to the co-creation of a digital conversation (chatbot, spring 2021) open for anyone to have a voice about social support in mental health. The digital conversation takes the form of microhistories codesigned by individuals with an experience of mental health and their families (Co-Researchers). The microhistories are meant to highlight experiences, resources, and strategies related to the establishment and strength of social support networks. Through this collective digital conversation on mobile devices, the microhistories will be shared and intended to be responded by the broader citizens community committed to mental health, in an anonymous and safe environment.

What is expected of *CoAct for Mental Health*? Research co-created through the participatory process is expected to provide new and numerous scientific data based on micro-stories. These data will serve to better understand the value of social support networks based on the experiences of people with their own experience in mental health and their family environment. It is therefore expected to publish unpublished scientific results with the co-researchers but also to share the data with the community of the Knowledge Coalition. Through a final assembly open (autumn 2022) to all organizations, institutions and stakeholders, the data will be interpreted. The results will be shared with the aim of specifying and validating those measures in terms of social support, which should be promoted in the short, medium and long term by the community itself in the field of Mental Health and the whole of society. We also hope to write a document of recommendations for weaving and strengthening social support networks.

The values of citizen social science in *CoAct for Mental Health*

Inclusion is crucial, as it seeks to improve participation of vulnerable and generally unrepresented groups in the research process.

Citizen cooperation in terms of valuing the importance of the diversity and complementarity of competences of all actors involved.

Horizontality is considered throughout the whole co-creation process to balance power relationships.

Equity is another important value as efforts and resources are expected to be evenly distributed among participants. All of these efforts are publicly acknowledged.

Trust and respect are fundamental values that are promoted at all times. Participants must be able to express themselves freely in an informal environment, without being judged by anyone else.

The principles of **open science** will govern the production of project knowledge. All materials, data sets and results will be made accessible under Creative Commons open licenses.

Co-ownership will be considered in all results obtained and will be based on the efforts of all participants involved. Co-researchers will be considered co-owners of collectively generated materials and invited to contribute as co-authors to the resulting (scientific) publications.

Empowerment is an important approach that is developed throughout all phases of research projects. Participants are empowered to act individually and collectively based on the knowledge produced.

Reflexivity accompanies us throughout the research process, both in guiding the research and in interpreting the results obtained. Our own actions and attitudes will be regularly questioned based on the hierarchies that are generated, the reproduction of discriminatory behaviors and the inclusion of all the groups involved.