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CO-CAPTAIN

Cancer prevention among individuals with mental ill-health: CO-adapting and implementing patient navigation for primary cancer prevention

D2.2.

CO-CAPTAIN Care Model and implementation strategies

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Mental Health Europe

WP2 – Participatory co-adaptation of the Patient Navigation Model for primary cancer prevention in the European context meeting the needs of organisations, care team members, and the individuals with mental health problems

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LIST OF ACRONYMS

CFIR	Consolidated Framework for Implementation Research
EBQI	Evidence Based Quality Improvement
EU	European Union
GDPR	General data protection regulation
MD	Doctor of medicine
MSc	Master of science
MUW	Medical University of Vienna
NGO/s	Non-governmental organisation/s
PhD	Doctor of philosophy
PN	Patient navigation
PNM	Patient navigation model
POMOST	The Association of Young People with Mental Health Problems, their Families and Friends
RE-AIM	Reach, Effectiveness, Adoption, Implementation, and Maintenance

EXECUTIVE SUMMARY

Background and objectives

CO-CAPTAIN is dedicated to providing evidence-based, person-centred navigation to address cancer care disparities and facilitate primary prevention access for people experiencing mental health problems. The project will make use of the Patient Navigation (PN) model which has good potential for addressing bottlenecks and barriers in the cancer care continuum for this specific group. The features of the PN for primary cancer prevention will be co-adapted involving a broad range of stakeholders to tailor the model to the specific needs of individuals with mental ill-health and identify implementation strategies for local communities in the four pilot sites. This report presents both the findings of the cross-national co-adaptation focus group discussions and the proposed Patient navigation Model (PNM) that is to be piloted and evaluated in the next phase of the project.

Methodology

Building on an exploratory qualitative study conducted via individual stakeholder interviews, the next stage of data collection for this study comprised a series of focus group discussions conducted by a multidisciplinary team of researchers from partner organisations of the CO-CAPTAIN project in four countries - Austria, Greece, Poland and Spain. Participants included professionals from health and social care and NGOs, individuals with lived experience of mental health problems and caregivers. The aim of these focus group discussions was to explore and co-adapt the PNM to ensure that it is suitable for and meets the needs of people with mental health problems in relation to primary cancer prevention. More specifically, the focus group discussions were intended to inform decision making processes on the development and implementation of the PNM for primary cancer prevention in people with mental health problems with special consideration of 10 core components of a PNM, as defined by DeGroff et al. (2014). These components cover various stages of the intervention, including the type and mode of delivery of services provided, the profile of the navigator and the evaluation measures and will be outlined in more detail in this report.

Key findings

This section summarises the main results of the focus group discussions that were conducted in the four countries involved in the CO-CAPTAIN study. They provide focus groups' participants' perspective on the main aspects that the PNM should consider and address. Though some are not strictly applicable to the purpose of the CO-CAPTAIN project, e.g. focus on treatment, the findings reported are meant to reflect the views of participants. Whereas most findings emerge consistently across all countries, some others are country specific. As a whole, they provide a comprehensive yet flexible guide for CO-CAPTAIN partners to pilot the PNM in the next project phase according to a person-centred approach, which is clearly deemed essential by participants of all countries.

Programme goals

- Provide integrated care for people with mental health problems by connecting and facilitating access to existing health and social care services through the PNM;
- Enable the best possible provision of and access to cancer prevention measures;
- Empower people experiencing mental health problems in particular with regard to the strengthening of their sense of agency and individual responsibility for health;
- Increase health awareness in general and improve health literacy, particularly regarding cancer and cancer prevention;
- Enhance understanding of mental ill-health among service providers and decrease stigma towards people experiencing mental health problems.

Community characteristics

The programme should prioritise the following individuals:

- People with different types of mental health problems who are willing to participate and who have achieved some stability in their recovery journey;
- Those with a greater need for support due to difficulties caused by mental health problems and/or other causes of limitations (e.g., cognitive impairment, sensory impairment, aging, medication side effects, loneliness);
- Previous bad experiences with the healthcare system (e.g., due to stigmatization) or fear and avoidance of the healthcare system;

In addition, caregivers – mainly family members and relatives - should benefit from the PNM and could help to achieve the goals of the programme.

Point of intervention

- The navigation programme could begin once there is an established relationship with a mental health professional who could make the referral to the navigator;
- The opportunity to collaborate with a navigator should be part of any treatment plan and navigation should take place in both the public and private healthcare sectors;
- When people access services outside the healthcare system, an entry into the patient navigation programme could be offered. This could therefore constitute another option to initiate the programme.

Setting(s) of intervention

- Outreach mode - working in the field in various sites both within and outside healthcare settings depending on the preferences of beneficiaries (examples for such potential sites are NGOs, self-help groups, general practitioners, health insurance, crisis intervention centre, psychosocial services, mental health care units or centres, home, public places);
- On-site mode – working in a specific setting that would function as the headquarters for the navigator, at specific hours.

Range of services offered by navigator

- Facilitating access to available health and social care services;
- Accompaniment and support;
- Raising cancer awareness and education;
- Administrative/practical help.

Navigator background

- The navigator should preferably have a psychological, medical or social background (e.g., in medicine, psychiatry, psychology or social care) supplemented by additional training;
- Emphasis was placed on the following traits deemed essential for a navigator: empathic, communicative, able to listen, willing to self-develop, leading a healthy lifestyle and showing a warm and engaged approach in interacting with individuals;

Channels of communication between users and navigator(s)

- Communication should make use of a variety of means and channels to suit the specific individual circumstances and preferences;
- Communications should take place through a mix of face-to-face and online settings and could include texts, emails, phone calls, in-person meetings and home visits;
- Content of meetings and other forms of exchange should be flexible, personalised, and adapted to individual needs.

Navigator training

A modular approach to training should be adopted in order to build on and complement existing competences and skills of navigators. Training should include:

- Specific knowledge on mental ill-health and of population characteristics;
- Communication and interpersonal skills;

- Cancer-related education
- Knowledge of local services and available resources.

Navigator supervision

- Two forms of supervision are suggested: one related to the monitoring of the intervention and the second focusing on providing support to navigators in the form of guidance and counselling;
- The modalities for supervision could be designed in different ways to suit the local context, programme delivery and navigators' role: team discussions, inter-vision, supervision (e.g., single and/or group, external, expert, or multi-professional supervision, involvement of beneficiaries and their caregivers).

Evaluation measures

- Evaluation should be conducted using both qualitative and quantitative approaches although special emphasis should be put on qualitative data;
- Navigators, programme beneficiaries, caregivers and service providers should all take part in the evaluation;
- Data should be collected at different points in time on the following topics: cancer screening rates, extent off beneficiaries' engagement and participation in the programme, adoption of healthy lifestyles from beneficiaries, beneficiaries' satisfaction, quality of relationship between navigators and beneficiaries, level of cooperation between different health and social care providers.

INTRODUCTION

The CO-CAPTAIN Project

Cancer and mental health problems constitute leading public health problems in Europe. More than 84 million people in the European Union (EU) report living with on-going mental health problems. While issues concerning mental health are of great importance, they often overshadow physical problems that people with mental health problems face (Hjorthøj et al., 2017). Such is cancer, which is more prevalent in people with mental health problems and is also the second most common cause of death in this population (Cunningham et al., 2015). People with mental health problems often have difficulties in accessing quality cancer prevention services, but are also additionally overlooked in research, which makes them overall an underserved population. Available data shows that potential reasons for higher cancer morbidity and mortality rates are linked to more engagement in risky health behaviour (especially higher prevalence of smoking as well as overweight and obesity) (Bartels et al., 2015; Bellanger et al., 2019; Espina et al., 2018; Wild & Stewart, 2020) but also experiences of significant barriers when accessing the highly fragmented heath care systems (Druss, 2007; Hanlon et al., 2014; Lerbæk et al., 2019; Leucht et al., 2007; Stumbo et al., 2018). Timely and evidence-based preventive strategies including optimizing health care pathways provide a solution to the high cancer morbidity and could improve overall health outcomes in this disadvantaged population. One such mixed-skill strategy is Patient Navigation.

Therefore, the overall goal of the CO-CAPTAIN project is to co-adapt the Patient Navigation (PN) Model focusing on primary cancer prevention and investigate its utility and benefits in supporting individuals with mental health problems through health care services and reduction of cancer risk factors, and do so by increasing knowledge, health literacy and empowerment. The Patient Navigation Model is an innovative, evidence-based and patient-centred intervention, which supports patient empowerment through removal of systemic barriers, providing social support and promoting timely access to primary prevention services. Based on implementation science and utilizing the Consolidated Framework for Implementation Research (CFIR) as well as the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework, the

CO-CAPTAIN project aims to enhance equity in health for people with mental health problems by reducing cancer burden and improving overall health, which will, in turn, reduce associated costs across health and social care systems in Europe. Moreover, the CO-CAPTAIN project aims to harness the transformative potential of the integrated care pathways in cancer as well as provide health and social care policy recommendations for the adoption and implementation of the Patient Navigation Model across Europe.

Overall objectives of this report

Building on a qualitative study involving stakeholders' interviews, this report presents the results of focus group discussions conducted as part of the CO-CAPTAIN project. The focus group sessions were aimed at gathering data to inform and design the Patient Navigation Model (PNM) for Primary Cancer Prevention for Individuals with Mental Ill-health. To reach this aim, a series of co-adaptation focus group discussions were carried out focussing on the 10 core components of the PNM, as informed by the framework set out by DeGroff et al (2014). These components cover all the various stages of the model as outlined below:

- Programme goals
- Community characteristics
- Point of intervention
- Setting(s) of intervention
- Range of services offered by navigator
- Navigator background
- Channels of communication between users and navigator(s)
- Navigator training
- Navigator supervision
- Evaluation measures.

The following report's sections provide an outline of the methodological approach adopted, a summary of the key findings from each of the partner countries' focus group discussions and finally presents the main features proposed for the PNM organised according to the 10 core components that will be implemented and evaluated in the four European piloting sites in the next stages of the project.

METHODOLOGY

In order to ensure meeting the needs of the ultimate beneficiaries of the PNM, the success of the implementation as well as the sustainability of the intervention beyond the life cycle of the project, CO-CAPTAIN has placed participatory and multi-disciplinary design at the very centre of the project. A qualitative cross-national research approach was adopted involving the implementation of a series of co-adaptation focus group discussions in presence and/or online via videoconferencing in four countries - Austria, Greece, Poland and Spain.

The co-adaptation approach was guided by the Evidence Based Quality Improvement (EBQI) (Hempel et al., 2022; Swindle et al., 2023) model which is rooted in the principles of participatory research by bringing together key stakeholders to adapt evidence-based practices for local context and identify implementation strategies. Moreover, the CO-CAPTAIN consortium adopted the definition of co-creation provided by Mental Health Europe: *"A collaborative approach involving all actors in mental health working together on an equal basis to develop and implement policies, services, programmes and communication that foster positive mental health according to the psychosocial model and human rights-based approach".* The research teams that ran the focus groups were not only knowledgeable about participatory approaches, but also received training on co-creation.

Participants in the focus group discussions comprised individuals with experience of mental health problems, caregivers, representatives of mental health organisations, service managers and care team members from health and social care services. The focus groups were carried out by a multidisciplinary team of researchers from participating organisations in the CO-CAPTAIN project.

The facilitation of focus groups was conducted in line with principles of co-design and co-creation enabling all participants to voice their ideas and opinion on equal basis and in a safe space. A total of 12 focus group discussions were conducted, three in each country, with an overall sample size of 50 participants comprising 23 professionals, including managers and representatives of health and social care providers, non-governmental organisations, 15 persons with mental health problems, 5 caregivers. The 7 remaining participants were simultaneously representing more than one group (e.g., a person with mental health problems, who also functioned as a caregiver and representative of a mental health organisation).

Across all partner countries, participants were recruited through the use of existing professional networks of health and social care organisations and through expressions of interest coming from the previous phase of the study (i.e., individual interviews).

Data collection and analysis

Focus group discussions were held either in presence or online via videoconferencing, and generally lasted between two and three hours.

Prior to the sessions, participants received a project brief describing the rationale and aims of the CO-CAPTAIN project and the Patient Navigation Model and clarifications were provided at the beginning of the focus groups.

A topic guide was used to structure the focus group discussions. The guide closely followed the method proposed by DeGroff et al. (2014) and their 10 core components of navigation interventions, which were introduced to participants and discussed in turn. Alongside the topic guide, each research team made use of participatory exercises and data collection methods designed to facilitate interaction and data collection (e.g., working groups, World Café, flashcards).

Sessions were structured according to the following topics:

Session 1:

1. Introduction of participants
2. Purpose of today's session and future ones
3. Agreeing on how we will be working together (group agreement)
4. Presentation of cancer prevention programs - the aim of this item is for participants to understand the type and ways cancer prevention programmes are currently provided so that they have that in mind when they make suggestions about e.g. question 6 and question 4 of the second session
5. Presentation of the Patient Navigation Model – focus on presenting the 10 core components of the model as defined by DeGroff et al. (2014) as well as elements that resulted from the interviews of T2.1.
6. General goals of the navigation intervention

- What do we want to achieve?
- What should the priorities of the navigation intervention be?
- Which specific groups within the population of people with mental health problems would benefit most from this intervention?

7. Which features should the Patient Navigation model for primary cancer prevention for people with mental ill-health contain?

<u>Session 2</u>

1. Recap of session 1 outcomes – main focus is to present the draft PNM that resulted from the previous session
2. Which aspects of the current model should be changed or adapted or retained?
4. What are the barriers and facilitators to the Patient Navigation model for primary cancer prevention for people with mental ill-health?
5. Point of intervention and setting for navigation services
    - At what point within the existing cancer care pathways should the involvement take place?
    - Where and how can this go alongside or complement other services?
    - Where should navigation take place?
6. The navigators' role - Which tasks should the Navigators (not) be involved in?
7. Communication methods of navigation services – How should the Navigators interact and communicate with the patients?
8. Skills, supervision and training of navigators
    - What background/qualifications should the navigators have?
    - What supervision and training will they need and from whom?
    - What form should supervision and training take?

<u>Session 3</u>

1. Presentation of the draft of the Patient Navigation model based on outcomes of sessions 1 and 2, also taking into account possible barriers and contextual factors.
2. Do participants see a need for further adaptation? In what way?
3. Do the participants agree with the draft model?
4. Strategies for evaluating the navigation intervention
    - What outcomes should we measure?
    - What kind of indicators?
    - How should we measure them?

  - Who should be involve in the evaluation?
5. Further comments/suggestions on the piloting of the intervention.

While adhering to the guidelines, overall planning allowed for short-term adaptations in the scheduling of the discussion points per session on each pilot site and reacting to the dynamic of each group discussion.

Focus group discussions were audio-recorded and transcribed verbatim in their respective languages, either manually or using a software, and were then internally checked for quality. Transcripts were analysed using a combination of inductive and deductive strategies. In the first stage of analysis, researchers adopted an inductive thematic approach (Saldaña, 2021) to coding the transcripts, attaching labels of a few words in a systematic fashion in order to capture relevant information in the data. Researchers then reviewed, synthesised, and merged the most significant of these codes, and organised these into a pre-determined thematic framework, consisting of the 10 core components of navigation interventions defined by DeGroff et al. (2014). Furthermore, material (e.g., flashcards) that was gathered during the focus group sessions was also used for analysis.

Each of the four partner countries then produced a summary of outcomes of the focus group discussions organised according to this framework; these summaries were then analysed and integrated to form an overall framework for the CO-CAPTAIN care model for PN which is presented as part of this report.

Ethical considerations

The Ethics Committee of the Medical University of Vienna approved the overall study, and each partner obtained additional approval from their designated ethical review board or institution before beginning the focus groups.

Prior to the start of the focus group discussions, participants received information about the CO-CAPTAIN project and the sessions and signed an informed consent form. Furthermore, participants were informed that their participation was voluntary and that they could quit the project at any time point without negative consequences. At the start of each focus group discussion, the researchers introduced a set of ‘ground rules’ in order to ensure that conversations remained respectful and confidential.

Data have been stored securely in line with GDPR (2016) regulations, and all files are encrypted and stored on computers that require password access, with unnecessary duplicates avoided. All focus group discussions were transcribed omitting identifiable details, and both transcripts and audio files have been labelled using reference codes rather than names.

RESULTS CO-ADAPTATION ACTIVITIES AUSTRIA

Overview of co-adaptation activities

In Austria, three co-adaptation focus group discussions were conducted in person at the Medical University of Vienna (MUW), each one week apart on three Fridays in January 2024. A total of 11 people participated in the focus groups, three of whom attended all three focus groups. Seven people attended the first focus group, comprising two people with mental ill-health experience, one person with mental ill-health experience who was also a caregiver, one person with mental ill-health experience who was also a representative of mental health organizations, one caregiver, one care team member, and one care team member who was also a representative of service managers. In the first session, participants received information on the project, the patient navigation model, and on results of the qualitative interviews conducted as part of T2.1 of this project. Furthermore, they discussed barriers and facilitators that should be added to those collected in T2.1 and proposed programme goals for the planned patient navigation model. Four people attended the second focus group, comprising one person with mental ill-health experience who was also a caregiver, two care team members, and one care team member who was also a representative of service managers. In the second session, participants had time to reflect on results of the previous session after receiving a summary and to add any additional points or comments if they had any. Furthermore, they discussed community characteristics, the point and setting(s) of the intervention, the range of services offered by navigator(s) and the navigator background. Six people attended the third focus group, comprising one person with mental ill-health experience who was also a caregiver, one person with mental ill-health experience who was also a caregiver and a care team member, two care team members, and two care team members who were also representatives of service managers. In the third session, participants discussed communication channels between users and navigator(s), navigator training, navigator supervision, and evaluation measures. They further received a summary of previously discussed points and had the opportunity to add their input.

Table 1. Participants' information

Age	Gender Identity	Profile	City/Region
28	Man	P01 - Care team member	Vienna, Austria
42	Woman	P02 - Caregiver	Vienna, Austria
52	Woman	P03 - Representative of mental health organizations, Person with mental ill-health experience	Vienna, Austria
49	Woman	P04 - Person with mental ill-health experience	Vienna, Austria
57	Woman	P05 - Person with mental ill-health experience, caregiver	Vienna, Austria
35	Woman	P06 - Representatives of service managers, care team member	Vienna, Austria
30	Woman	P07 - Person with mental ill-health experience	Vienna, Austria
47	Woman	P08 - Care team member	Vienna, Austria
30	Man	P09 - Care team member	Vienna, Austria
55	Woman	P10 - Representatives of service managers, care team member	Vienna, Austria
26	Non-binary	P11 - Person with mental ill-health experience, caregiver, care team member	Vienna, Austria

Programme goals

Participants identified several programme goals for the patient navigation model:

- Establishing **low threshold access** to patient navigation (e.g., easy accessibility, no barriers due to bureaucracy or health insurance) and open advertisement (e.g., leaflets or posters)
- Establishing a **relationship with the patient navigator** that is characterized by trust, humanity, sensitivity, empathy, appreciation, and a fixed contact person
- **Appreciation of patient navigators' work** should be shown (e.g., by sufficient financial compensation)

- Service users and their symptoms should be **taken seriously,** and actions should be taken accordingly
- **Empowerment** regarding one's own needs (e.g., developing the ability to ask for something that is needed in the health context) and health (e.g., by using comprehensible language and explaining medical findings)
- **Raising health awareness** by e.g., improving self-awareness regarding one's own health, acting upon it, and thereby taking care of oneself
- **Improving health literacy** by gaining a better overview and understanding, by dismantling false assumptions and by expanding knowledge on cancer, prevention measures (e.g., vaccines), early detection signs, and treatment options and thereby simplifying the handling of the topic and decreasing anxiety for anyone who is interested in educating themselves on the topic
- **Improving access to and experience with** relevant health care services; reducing stress
- **Sensitization** of healthcare providers and special consideration for people experiencing mental health problems
- **Connecting existing healthcare providers and offers**
- **Individualized health care and support** involving (self-)effective treatment/measures and the option of support if needed, also in situations of illness (e.g., with a cancer diagnosis) and exceptional situations (maintaining a common thread, reducing anxiety, make use of necessary prevention measures)
- Enable the **best possible medical care** through the use of preventive and early detection measures (e.g., via genetic screenings of risk factors paid for by health insurance) as well as optimal treatment of diseases via exchange, giving information, and accompaniment / support
- **Reducing the risk** of developing cancer.

Community characteristics

While participants agreed that the programme should be targeted at **people with mental health problems**, they also emphasized the importance of **willingness to**

participate. Further potential community characteristics comprised the wish for administration or contact, a greater need for support due to restrictions caused by mental health problems and/or chronic somatic ill-health and/or other causes of limitations (e.g., cognitive impairment, sensory impairment) or due to issues arising with aging, specific challenges due to medication side effects, an increased risk of cancer, previous bad experiences with the healthcare system (e.g., due to stigmatization experiences), fear and avoidance of the healthcare system, and persons who have little or no financial resources.

Participants further named the following **factors that should be kept in mind when implementing the programme**: sufficient time resources, sufficient and motivated personnel, one fixed contact person, appreciative communication, great variability of limitations and resources in various mental problems, fear of contact with the topic of cancer (also in caregivers), address feelings of being overwhelmed through support and friendly guidance, consider and act appropriately regarding individual problems (e.g., fear of needles when taking blood, potential re-traumatization), provide support with organizing daily living if needed by giving structure, prioritize cancer screenings in people with heightened psychological stress (e.g., sending out reminders), and address vulnerability and lowered stress resilience with providing a supporting experience in health care and preventive medical check-ups. They also stated that navigators should receive supervision for their work.

In addition, participants expressed the wish to **consider the following potential barriers** when implementing the programme: language barrier (this could be overcome by providing an interpreter), diagnostic overshadowing, two-class medicine, waiting time for appointments on site (navigators could serve as a protective factor with experiences in the healthcare system), and lack of appreciation and empathy in healthcare personnel.

Point of intervention

Participants argued that the intervention should take place **as early as possible** for the beneficiary. In particular, they named concrete situations that people with mental health problems could potentially find themselves in and that could mark appropriate timepoints for starting the programme: increased need for support, increased vulnerability, problems with activities of daily living, and lack of improvement through the use of other interventions. Participants additionally suggested offering an entry into the patient navigation programme when potential beneficiaries utilize healthcare or NGOs/self-help groups external to the healthcare system. Participants suggested different groups as potential providers of patient navigation: health insurance, NGOs, self-help groups, and general practitioners. They further suggested to involve public marketing, i.e., print, television, radio, and social media. They mentioned that people with mental health problems may be more open for prevention outside of healthcare facilities and that access should be low threshold by having navigators on site. Participants felt that the **end of the intervention** would be self-evident or marked by a sustainable decrease in cancer risk factors or by the beneficiary's choice (e.g., at an evaluation). Finally, they agreed that the focus of patient navigation as part of CO-CAPTAIN **should not be limited to cancer prevention**. Instead, participants saw the planned patient navigation model as a great concept that provides potential for general healthcare navigation for people with support needs.

Setting(s) of intervention

Participants discussed the first step of establishing contact with patient navigators as a potential barrier for people with mental health problems. They suggested that the general practitioner or caring and supporting organizations could aid in initiating contact. Furthermore, providing transport services or home visits may pose as facilitating factors. In addition, the involvement of e.g., the ambulance, or meals on wheels may be helpful. The patient navigation itself was suggested to take place within the buildings at already existing organizations (e.g., crisis intervention centre, psychosocial services, etc.) or other locations that could be confidential (e.g., at home) or public (e.g., at a café) depending on the beneficiary's wishes.

Range of services offered by navigator(s)

Services offered by navigators should encompass the following: **administrative help** (e.g., support with filling out forms, making appointments or phone calls), **accompaniment** (support on trips, on-site support), and **providing and explaining information** (debriefing after appointments, catching information between the lines, searching for and forwarding information, organizing or passing on information on talks or other opportunities to receive information). In this context, participants also suggested for navigators to receive information about health data with the patient's consent if allowed by data protection laws. On a larger scale, navigators should detect suboptimal processes and areas with need for improvement on social and political levels, function as a feedback loop in optimizing the healthcare system and **use their voice** for those having trouble speaking for themselves (i.e., advocacy). In order to carry out their tasks, navigators should have a solid background of experience, know the scope of duties, build a network of contact points (e.g., social workers), and involve relatives and trusted persons. In their work, navigators should be patient, empathic, professional (proximity-distance ratio), confident, and calm and they should build a relationship of trust, offer structure, enhance resilience, and respect wishes and boundaries (even if, e.g., someone wants to quit the programme). Furthermore, **confidentiality and discretion** should be maintained.

Navigator background

Participants wished for navigators to have **a psychological, medical or social background** (e.g., in medicine, psychiatry, or psychology), additional training (e.g., coaching, grief counselling, health buddy) or experience in these fields. They noted that a **training** would be necessary for navigators and that personal interest and language skills according to need (not limited to German) would be beneficial. They further suggested the **involvement of peers**, i.e., people with lived experience and trained peers (e.g., experienced involvement). They mentioned costs as a potential barrier. While the importance of appreciation for navigators by adequate remuneration was underlined, participants were open to the idea of navigators also working honorarily.

Communication channels between users and navigator(s)

Participants discussed providing information via websites, leaflets, and presentations. They suggested finding a **joint form of communication** for the beneficiary and the navigator and named the use of several potential communication channels including texts, emails, phone calls, in-person meetings (especially for the first meeting), and home visits. They proposed the use of communication rules and consideration of individual factors (e.g., age, dementia). Contact itself should be both continuous and flexible (e.g., regarding working times and preferences of people with mental health problems). Fixed consultation hours should be offered (e.g., in practices, insurance facilities). The possibility of involving relatives and trusted persons and communicating with them should be given. Navigators should stay connected to one another and an organizing structure for navigators should be implemented.

Navigator Training

Participants suggested a **modular training** for navigators, such that the training could be adapted depending on prior knowledge and experience of navigators. More specifically, navigators should be trained in **conversational skills** (e.g., motivational interviewing, non-violent communication, sensitizing them in communicating with the target group, using simple language). They should further gain **basic psychiatric knowledge**, **knowledge on cancer prevention** including up-to-date recommendations, and **knowledge on legal aspects**. Depending on their operation site, **specializations** should be considered for navigators (e.g., when working at pensioner homes). Navigators should further gain an **overview of relevant care services and other support offers**. In addition, trainings should include **self-care management** and **resilience training**.

Navigator Supervision

Participants suggested navigators receive options of **team discussions, inter-vision, supervision** (e.g., single and/or group, external, expert, or multi professional supervision), and **further training** (e.g., on medicine, law, etc.). These options could use various designs (e.g., involving beneficiaries) and potentially be chosen depending on the duration of working as a navigator.

Evaluation measures

Participants felt that evaluations should take place and that these could aid further development of the project. Such evaluations, however, should not be carried out by external companies. In the beginning of patient navigation with a beneficiary, the navigator and beneficiary should determine the **current status and set goals** that could later be evaluated. An overall goal that was named was to reach a status, in which there would no longer be a need for patient navigation. Evaluations should be carried out when (1) starting the programme, (2) when ending the programme, and (3) afterwards (e.g., after another 6 months) to determine sustainability. Evaluations should be conducted qualitatively and in person involving both the perspective of the beneficiary and that of the navigator. The evaluation should consider three levels: (1) the **beneficiary-navigator relationship** and interpersonal factors, (2) **effectiveness of the patient navigation** (e.g., by assessing whether previously set goals were achieved), and (3) the implementation of and the **patient navigation programme overall**.

RESULTS CO-ADAPTATION ACTIVITIES GREECE

Overview of co-adaptation activities

The initial session occurred on January 24th, followed by the second on the 26th, and the final session on the 29th. Participants were the same individuals who took part in the interviews done in the first stage of the study, chosen based on their availability for the designated session dates.

The samples for the first and second sessions included a total of 9 participants, consisting of 5 persons with mental health problems, 2 care team members, and 2 NGO representatives. The sample for the third session comprised 12 participants in total, including 4 persons with mental health problems, 3 care team members, 2 NGO representatives, 1 caregiver, and 2 service managers. Participant characteristics are outlined in Table 1.

Table 1. Participants' information

ID	Age	Gender Identity	Profile	City/ Region
CC_AG_01	36	Female	Representative of an NGO. Psychologist, Studies in psychology & MSc in public health, providing medical and psychosocial support to migrants/ refugees	Athens, Greece
CC_AG_02	47	Female	Representative of an NGO. Studies psychology (Bachelor & MSc), provides psychosocial support to refugees	Athens, Greece
CC_AG_03	55	Male	Service manager, psychiatrist, MD & PhD	Athens, Greece
CC_AG_04	67	Male	Service manager, psychiatrist, MD & PhD	Athens, Greece
CC_AG_05	41	Male	Care team member. Social worker	Athens, Greece
CC_AG_06	40	Female	Care team member. Social worker	Athens, Greece
CC_AG_07	25	Female	Care team member. Social worker	Athens, Greece

CC_AG_08	60	Male	Person with mental health problems (depression). Has a bachelor's degree, works in the public sector, married with two children.	Athens, Greece
CC_AG_09	58	Female	Person with mental health problems (depression, panic attacks and phobias). Used to work but doesn't anymore, unmarried.	Athens, Greece
CC_AG_10	62	Male	Person with mental health problems (bipolar disorder). Previously a physicist. Not working for 6 years now; on disability retirement due to mental health problems.	Athens, Greece
CC_AG_11	45	Female	Person with mental health problems (psychosis and schizoaffective disorder). She is a janitor.	Athens, Greece
CC_AG_12	46	Female	Person with mental health problems (recurrent depressive disorder and anxiety disorder). Master in management of tourism, now works part time at a social co-op.	Athens, Greece
CC_AG_13	55	Male	Person with mental health problems (schizophrenia). High school graduate, public employee as a guard at a library.	Athens, Greece
CC_AG_14	76	Female	Caregiver. A mother, who is a pensioner (previously a schoolteacher)	Athens, Greece

Programme goals

All participants have collectively established what the program's objectives should be, as outlined below:

a) Information and awareness on cancer prevention

> *"The first goal should be to inform us about what cancer is, when it occurs, what is causing cancer, and what we can do to prevent it." (CC_AG_08)*
>
> *"First of all, it's crucial to educate our children about cancer and how certain habits, such as unhealthy eating and smoking, can contribute to its development." (CC_AG_14)*
>
> *"Initially, our focus is on raising awareness about the various factors that can lead to cancer." (CC_AG_05)*

a) Actionable measures on cancer prevention: (a) undergoing preventative screenings and examinations and (b) adopting a healthy lifestyle including a healthy diet, physical exercise, and smoking cessation

> *"Following the provision of relevant information, and a subsequent discussion, you should inform us about what we can do to prevent cancer. Let's say women get a mammogram, men something else." (CC_AG_11)*

> *"Yes, first there will be information about the disease and then in detail preventative actions patients and health professionals can make. This is the logical order." (CC_AG_06)*

All participants unanimously agreed that the primary and attainable focus of the initiative is the dissemination of knowledge and awareness about cancer. In fact, they discussed that such an action would effectively motivate the beneficiaries and generate a heightened level of engagement and interest. The secondary goal, centred on taking proactive measures, either in the form of preventative screenings or changes in lifestyle behaviours, was perceived by all participants as a more challenging objective. That being said, there was consensus that achieving preventive screenings appeared to be more feasible compared to the more demanding task of instigating lifestyle changes and adopting healthy habits. Participants acknowledged that the latter requires a substantial amount of time, strong will, and extensive support from both the supportive and therapeutic frameworks to be successfully realized.

> *"Getting informed and convincing someone to go for a colonoscopy or ultrasound is the easy part, especially if they're set up with their treatment and have a supportive framework to help them get an appointment. The hard part is the lifestyle changes. Let's say the obese should go on a diet or exercise. The smoker should quit. Those are challenging situations." (CC_AG_10)*

> *"I quit smoking after 30 years of being a heavy smoker, but now I feel great and have a lot of will power. I am an exception among those dealing with mental health issues. And it took me many years of therapy and effort to do it." (CC_AG_08)*

Health professionals emphasized additional objectives and potential advantages of the program, including: a) strengthening the socialization and social integration of beneficiaries, as this action invites them to social actions, e.g. group discussions, informational meetings, and b) expanding the range of holistic supportive services offered by mental health centres by incorporating an additional service focused on cancer prevention and the adoption of a healthy lifestyle.

> *"Secondly, the program will have a positive effect on the socialization and broader mobilization of [beneficiaries], so that they can take life into their own hands, with regards to self-care, sharing, and communicating with others." (CC_AG_03)*

> *"I should also mention that the implementation of such a program in our mental health centre will enrich and open the range of actions to support and empower [beneficiaries]." (CC_AG_07)*

Community characteristics

All participants, including healthcare professionals, persons with mental health problems and caregivers, agreed that this specific initiative should be implemented for individuals with diverse types of mental ill-health, provided they have achieved stability in their treatment and are functional in their daily lives. There was consensus across all participants concerning the challenge regarding targeting patients in the initial stages of diagnosis and treatment, as their primary focus is on regulating their treatment, with the symptoms of their illness serving as a barrier to the success of the cancer prevention initiative.

It's worth noting that the discussion predominantly revolved around individuals with a clinical diagnosis of mental ill-health, including their caregivers, care team members, and service managers of mental-health facilities, due to the composition of the participant pool. This focus, however, does not negate the potential utility of the PN model for individuals experiencing mental-ill problems without a formal diagnosis.

> *"It makes sense to go to [persons with mental health issues] who have stabilized their treatment and are now functional." (CC_AG_10)*
>
> *"I don't think this program could be done in [people] who are in the initial stage of diagnosis and finding the appropriate treatment. They are still unbalanced and trying to manage the symptoms of their mental [distress]. And their support framework is still not ready to effectively manage other health issues." (CC_AG_14)*
>
> *"I don't see how it could work in [people] who are in the first therapeutic stage of diagnosis and treatment. It would be very difficult. I imagine it for patients who have stabilized their treatment and are functional in their daily lives." (CC_AG_01)*

Furthermore, all health professionals declared that informative actions should be carried out for health professionals as well so that they may obtain applicable knowledge on cancer prevention that can be effectively carried out in persons experiencing mental health problems following an individually tailored and approachable, yet scientific approach. A manager of a psychiatric clinic in a public hospital stated that it would be effective for the doctors of a psychiatric clinic, along with the beneficiaries, to be informed about cancer prevention as a part of the treatment process.

> *"In addition to the person with mental ill-health, you should also inform health professionals. Let's say in the psychiatric clinic where I was the director, you could inform the psychiatrists who have the first therapeutic relationship with the beneficiaries about this action and how they could integrate it into their practice." (CC_AG_04)*
>
> *"At the mental health centre where you are going to carry out the activity, you should inform all health professionals about it and find ways to integrate the activity into the therapeutic context." (CC_AG_02)*

Finally, all participants reported the need for also informing caregivers, who could help to achieve the goals of the action, as they could support with cancer prevention actions such as making appointments to health clinics for preventative examinations, accompanying their close ones to health services, and providing encouragement to adopt a healthy lifestyle. Caregivers could also be involved/ present in informative sessions or could be briefed separately.

> *"And of course, let's not forget the role of caregivers. Let us also be informed because we can help the success of the action. With your help we could motivate our children to go take exams or change some bad habits." (CC_AG_14)*
>
> *"In the informative sessions about cancer, the people who support us could also come and stay there. Our families. That would be helpful. They would listen too, and we would discuss with them some issues afterwards." (CC_AG_09)*

Point of intervention

All participants stressed out the fact that the intervention would be effective if carried out at the cancer prevention stage that is before health symptoms appeared and generated anxiety to those with mental health problems. Moreover, the health professionals said that *"the intervention would be effective if it had a positive character by avoiding the use of the word 'cancer' in its title and announcement, which can create feelings of fear and 'distance' in people. You could call the action 'Information about a healthy lifestyle' or 'Health care and prevention'. (CC_AG_02)*

Participants with mental health problems emphasized that they would not want information about cancer to scare them, such as displaying them images of cancer or poor physical health and talk to them about death. They mentioned how highly ineffective to them is the strategy used on cigarette packages where scary images of people suffering from different kind of diseases due to smoking are depicted.

> *"What they are doing with cigarettes is a complete failure. They write that smoking is harmful to health and have some horrible images of diseases and patients. This is the dumbest thing. It doesn't convince anyone." (CC_AG_13)*
>
> *"Don't spread fear through the provision of information about cancer. Don't project death. This will discourage participants." (CC_AG_06)*

All participants stated that the points on which the intervention should be focused, given its preventive nature, are the following:

a) Why I choose to live healthy/ to have a healthy lifestyle;

b) What it means to live healthy, e.g. hygiene, nutrition, physical exercise, smoking, and alcohol cessation;

c) How to live healthy, simple daily healthy lifestyle tips (healthy eating tips, walking, etc.);

d) Information on tools that can help with behavioural changes for a healthy lifestyle (pedometer, etc.);

e) Types of preventive examinations by type of cancer, for each gender and at what age, e.g. (1) breast cancer for women, mammography, ultrasound, how often and from what age onwards, (2) prostate cancer for men, ultrasound, how often and from what age onwards;

f) Reference and referral to health services that can be visited free of charge in order to do clinical preventive examinations and/or receive other services such as smoking cessation advice and treatment, nutritional advice, etc.

> *"Tell us how to take care of our health so that we don't get something. That is, how to eat properly, healthy. What preventive examinations to do, where, and when." (CC_AG_10)*
>
> *"Tell us if you are a woman after 40, you need to have a mammogram and ultrasound. And tell us where to do this." (CC_AG_11)*
>
> *"Talk to us practically, not just with theory. Because then we get stressed and we don't know what to do." (CC_AG_09)*

All the above were mentioned primarily by the people with mental health issues. Therapists and caregivers agreed with them.

Setting(s) of intervention

All participants stated that this specific intervention needs to be carried out at mental health care units. In Greece such units are the mental health centres of the Municipalities. The specific mental health structures are familiar places, primarily for the beneficiaries, but also for their caregivers because their treating physician (their psychiatrist) with whom they develop a relationship of trust and security is in the same space. Also, in these structures there is a team of psychologists and social workers, which can further support health promotion and cancer prevention actions. In some cases, these teams of professionals already provide psychotherapy and social support to beneficiaries. In other words, the beneficiaries have already (hopefully) developed relationships of trust with the health professionals working at the care centre and can expand this relationship to include counselling services and further social support that may be required in an effortless way.

The implementation of the action in other organizations and spaces that would not have been previously familiar to the people with mental health issues would be an obstacle to its effectiveness, due to the lack of trust and insecurity caused by visiting them only for the purpose of the project's action.

> *"The most suitable places are the mental health centres because they provide support services for the people with mental ill-health and they could incorporate such actions." (CC_AG_02)*
>
> *"It would help me to go for this action in a place already known... I know the faces here. My doctor is here and I also have sessions with psychologists. The place and the actions don't scare me. If they had told me to go somewhere else to another organization, I might not have come." (CC_AG_11)*
>
> *"Where the psychiatrist who attends the person is. This is the best place. We feel safe there. Close to the treating physician, in the mental health centre..." (CC_AG_14)*

Range of services offered by navigator(s)

The services that will be provided by the navigators will concern the following:

a) Informing health professionals who are working at the mental health centre about the goals, content, and operation of the action within the health centre.

> *"Firstly, you should inform the workers at each centre you go to, how the action will work, what will be its aim, and how it will fit into the operating framework of that centre." (CC_AG_04)*

b) Informing beneficiaries of services at the mental health centres and their caregivers regarding the themes mentioned in the "point of intervention" section of the present report.

The participants stated that information for beneficiaries should be provided in simple language, while it is considered effective to have the information available online and in print, so that they can study it in their own space and time.

> *"You should use simple language and not medical jargon, because we are not doctors." (CC_AG_08)*
>
> *"It would be nice to give us a short form with some information on our way out, so we can work it out ourselves later, whenever we want." (CC_AG_12)*
>
> *"Even a [web]site would help some beneficiaries and some caregivers to see detailed information whenever they want." (CC_AG_02)*

It was argued that people with mental health problems need to be informed in group sessions; however, both participants representing this group and caregivers stated that they would like to have the opportunity of personal, confidential discussions with the navigator, in order to receive tailored, individualized support for their specific issues.

> *"I imagine a group session. Like today. To sit down together as a group and have someone talk to us about these issues." (CC_AG_10)*
>
> *"There should also be the possibility of personal contact when we need it." (CC_AG_12)*

Also, all the participants stressed the need for the navigator to facilitate further communication and contact with the proposed health services (book appointments and accompaniment).

> *"In some cases, there are other needs, such as making an appointment at a service or even being accompanied to the appointment. The navigator should in some cases do this as well. (CC_AG_07)*

Furthermore, participants with experience of mental health issues reported that it would motivate them to organize activities at the mental health centre, such as group walks, hiking, or gym classes, aimed at enhancing the adoption of healthy lifestyle habits.

> *"I just thought that one way to make us change our lifestyle is to organize hiking groups or fitness groups. By doing so, changing habits might come more naturally, easily." (CC_AG_12)*

Navigator background

The background of the navigator who will undertake these actions, according to health professionals, could be a health visitor[1] or a social worker with experience in the field of health promotion and mental health.

> *"I imagine a health visitor having experience with mental health but also having run prevention actions. With the proper training and cooperation with the mental health centre, it would be a successful navigator." (CC_AG_02)*

Participants with mental health problems reported that during group meetings and informational meetings, they would like to be informed by a doctor in addition to the navigator. Also, the presence of familiar health professionals, such as psychiatrists and collaborating psychologists, would strengthen their feelings of familiarity and security. Furthermore, they stated that they would like to have the opportunity to share personal experiences. Finally, they mentioned that the presentation of a lived experience by a person with mental ill-health would be very interesting where he/she would come to the educational group session precisely to tell their own story about cancer prevention.

> *“We would like a person who is both a pathologist and an oncologist and a psychiatrist and a psychologist and a social worker; however, this is not possible, so the presentation you will make could be made by a properly trained professional as well as a doctor. It would be even better for us if our psychiatrist or the psychologist we are doing sessions with was also present. We would feel more comfortable.” (CC_AG_10)*
>
> *"I want to add one more thing. I once saw a presentation that had the patient himself testifying about his experience on the subject at hand. Then we shared similar experiences. This was very helpful and generated direct communication." (CC_AG_12)*

Communication channels between users and navigator(s)

The first and main channel of communication is the treating psychiatrist with whom the person has a relationship of trust and feels safe. Even in cases where some patients receive additional psychotherapeutic or social support from the centre, so they

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[1] In Greece the Health Visitor is the health professional who is the main pillar of Primary Health Care at the level of Public, Community and Mental Health. One's goal is to promote good health and prevent illness in individuals, families and the wider community, through the provision of health services at home, at school, at work and in the community in general.

have cooperation and a relationship of trust with psychotherapists and social workers, the recommendation and encouragement to participate in the program by a treating psychiatrist is of great importance. In other words, the action recommended by the treating psychiatrist is a key element for its success, fortifying the person's interest and active participation. Moreover, the psychiatrist has the leading role in these centres.

> *“If it is recommended to me by Mr. D., who is my psychiatrist and has cured me, I will go. There's no way I'm not going.” (CC_AG_08)*
>
> *"The key person for the person to participate in the action is the psychiatrist, because a therapeutic relationship, a relationship of trust has been established so far." (CC_AG_04)*

During the project implementation action, it is necessary to establish communication and cooperation between the navigator and the psychiatrists, as well as the psychologists and social workers who support the centre/ beneficiaries. Based on the testimonies of participating health professionals:

> *"The navigator, as it is called, will have flexibility of action and will be in constant discussion and cooperation with the professionals at the mental health centre. For example, people may express some thoughts or questions to their psychiatrist, who in turn will inform the navigator and will make a referral. Also, these two will be able to discuss the best ways of addressing cancer prevention for different types of people." (CC_AG_02)*

Informing people about their participation in the intervention action could start with a telephone call from a healthcare professional the person trusts, and depending on the preference of each, further information could be provided via text, e-mail, Viber, WhatsApp, etc. Similarly, for preventive examinations, phone checks and reminders through different channels of communication based on the peculiarities of each person could be employed. In-person visits were not excluded for the people that require this including for those who do not have a supportive social circle to support this process.

> *“Look, a phone call is the first, the easiest. And then use whatever is convenient for each person. Others use emails and want to see the call to action in their emails as well. Others don't use cell phones at all. Others want an SMS reminder, others a WhatsApp text." (CC_AG_02)*

Navigator Training

Based on discussions, the person who will be responsible for the implementation of the specific action should have a very good knowledge of the following:

- Mental health: particularities and specific characteristics of those with mental ill-health depending on the various type of mental issue and the psychosocial conditions of the person;
- Cancer: extent and intensity of the phenomenon, what causes it, how it can be prevented;
- Knowledge of cancer prevention health services in the area of interest as well as knowledge of how to navigate them;
- Counselling: how to build a relationship of trust with the programme beneficiaries and ensure accompaniment when necessary;
- Communication with different stakeholders: improving/acquiring communication skills with different target audiences – people with mental health problems, carers, health professionals and ensuring multi-stakeholder collaboration.

Navigator Supervision

The supervision of the navigator is deemed necessary by health professionals, both at a) an individual level, similar to mental health professionals who are provided with personal support and supervision in order to manage the challenges of communicating with people experiencing mental distress , and b) a methodological level during the implementation, i.e. discussion with the stakeholders about the strengths and weaknesses of the action and suggestions for adaptation to improve the intervention.

> *"I take it for granted that this person, from the moment he/ she will work with this population will be supervised by a psychotherapist in order to manage the burden from the communication with people with mental ill-health." (CC_AG_07)*
>
> *“And there should also be regular feedback regarding the action between the navigator and the implementing organization. To discuss with them what is going well, what is not working very well and to proceed with changes." (CC_AG_02)*

Evaluation measures

The evaluation should include questionnaires as well as personal testimonies and experiences of the participants. It will concern not only the evaluation of the effectiveness of the intervention by measuring the number of preventive medical examinations and the life-style changes of participants but also the methodological parameters of the intervention, which health professionals consider to be more or less the chapters of this report.

> *"As you said, you will use both quantitative and qualitative methods and because this action is very new you will need to evaluate how it was implemented. That is, to evaluate everything you ask us here. That way you will see which the good practices were and which were not." (CC_AG_07)*
>
> *"You will definitely measure what the beneficiaries did. Did they proceed with the examinations? Did they change anything in their lifestyle? Do they want to change something?" (CC_AG_04)*

Both participants with mental health issues and health professionals reported that the evaluation of the action effectiveness regarding the adoption of a healthy lifestyle (diet, physical exercise, cessation of smoking, etc.) should be done after a sufficiently long period of implementation, as opposed to assessing awareness and understanding of the need for preventive actions that can be realized shortly.

> *"When I hear 'evaluation', a questionnaire comes to mind that we will fill out after the action, saying if we liked it or not, if the presenter was good or not, if we understood it or not. But the bottom line is whether we are going to do anything based on what we have heard. So, you will have to do an evaluation later. You need more time, if you want to see if someone took the clinical examinations, or why they haven' t done anything so far. Or if they have changed eating habits." (CC_AG_10)*

RESULTS CO-ADAPTATION ACTIVITIES POLAND

Overview of co-adaptation activities

Three focus group sessions were held on the 15 January, 17 January and 24 January 2024. Each of them lasted 3 hours including breaks. The sessions were attended by a total of 12 people (6 women and 6 men, aged between 22 and 68 years), although the composition of participants in each session was not the same (cf. table 1 below). Meetings took place at the NGO "The Association of Young People with Mental Health Problems, their Families and Friends "POMOST" in Lodz. The choice of this location was based on the profile of the organisation, and it was done to ensure the participants a sense of safety and physical and psychological comfort.

Table 1. Participants per session

1st session	2nd session	3rd session
• 4 Individuals with mental ill-health (CC_PL_P01, CC_PL_P02, CC_PL_P07, CC_PL_P09) • 1 Caregiver (CC_PL_P03) • 2 Care team members (CC_PL_P10, CC_PL_P12) • 2 Representatives of mental health organizations (CC_PL_P06, CC_PL_P11) • 2 Service managers (CC_PL_P04, CC_PL_P05)	• 4 Individuals with mental-ill health (CC_PL_P01, CC_PL_P02, CC_PL_P07, CC_PL_P09) • 1 Caregiver (CC_PL_P03) • 2 Care team members (CC_PL_P08, CC_PL_P12) • 2 Representatives of mental health organizations (CC_PL_P06, CC_PL_P11), • 2 Service managers (CC_PL_P04, CC_PL_P05)	• 3 Individuals with mental ill-health (CC_PL_P01, CC_PL_P02, CC_PL_P09) • 1 Caregiver (CC_PL_P03) • 3 Care team members (CC_PL_P08, CC_PL_P10, CC_PL_P12) • 2 Representatives of mental health organizations (CC_PL_P06, CC_PL_P11) • 2 Service managers (CC_PL_P04, CC_PL_P05)

Session 1 The meeting aimed to brainstorm and deliver the first draft of the Patient Navigation Model (PNM). The meeting was divided into two parts. In the first, informative part, the participants learned about the cancer programs available in Poland and were informed about the general idea underlying the navigation model. The presentation of the latter was based on the 10 core components of the model as defined by DeGroff et al. (2014). In the second part, the interactive part, the participants discussed the general goals of the Patient Navigation Model and which groups could benefit from the model.

Session 2 It began with the recapitulation of session 1. As the participants had some difficulties in relating to the model, which seemed too abstract to them, we decided to focus on the person of the navigator as the central point of the model and discuss its subsequent elements through the lens of the navigator. The World Café technique was used for this. The participants were divided into 3 teams and the room was divided into 3 tables. Table 1 dealt with the discussion of the "WHO?" (characteristics of the navigator), table 2 with the "WHAT?" (service characteristics) and table 3 with the "HOW?" (description of methods of providing navigation services). Printed material was distributed on the tables to help participants memorize the areas of discussion at each table. They were also provided with colourful sticky notes, blank sheets of paper and blank posters to record their shared ideas on the topics. The time for this activity at each table was 30 minutes, after which the participants were asked to change tables. After 3 rounds there was a break, and a summary of the session was produced to present the impact of the teamwork.

Session 3 The printed summary of the second session was distributed to help the participants recall what had been worked out previously. Then the list of issues to be addressed was presented and the participants were able to discuss them step by step so that any disagreements could be resolved, and the PNM clarified. The group's synergy effect was used to work out the topics on which there were different views in the previous sessions. During this session, to summarise some of the findings, the participants were also asked to select some items from two different lists, one regarding the objectives of the PNM for the health system and the community and the other regarding the mobile application (as a tool to potentially support navigation services). During the break, these materials were analysed, and a summary was presented to the participants to illustrate their views and opinions. As a result of this session, the group agreed on the main features of the PNM and the role of the navigator.

Table 2. Participants' information

Age	Gender Identity	Profile	City/Region
22	Female	Individual with mental ill-health	Lodz, Poland
40	Male	Individual with mental ill-health	Lodz, Poland
27	Female	Care team member	Lodz, Poland
45	Female	Care team member	Lodz, Poland
42	Male	Representative of mental health organisation	Lodz, Poland
44	Female	Service manager	Lodz, Poland
47	Female	Representative of mental health organisation	Lodz, Poland
68	Male	Caregiver	Lodz, Poland
46	Male	Service manager	Lodz, Poland
49	Male	Individual with mental ill-health	Lodz, Poland
38	Female	Individual with mental ill-health	Lodz, Poland
47	Male	Care team member	Lodz, Poland

Programme goals

In Session 1, participants outlined the general objectives of the Patient Navigation Model (PNM), and the objectives' definitions were finalized during the Session 3 including all reflections and discussions that far. Participants were asked to select the 5 most important goals from a prepared list based on previous focus sessions. Almost all participants claimed that the most important goal of PNM is to reduce the risk of cancer among people experiencing mental ill-health (*n*=9). Special attention was also paid to empowerment of people experiencing mental health problems. It is reflected by responses such as “increase individual responsibility for health” (*n*=7) and “strengthen the sense of agency among people experiencing mental problems” (*n*=6).

The following goals were also indicated: to increase community awareness of the role of a healthy lifestyle (*n*=4), to stimulate oncological vigilance among people with mental health problems, their families and caregivers (*n*=4), as well as among medical staff and psychologists (*n*=4). A few people pointed to the improvement of public awareness of cancer (*n*=3) and the possibility of reducing cancer mortality (*n*=3). Less frequently, improvements in general mental health, better coordination of health care and increased access to specialists or reduced health care expenditure were indicated. Occasionally, participants also indicated improving social factors by reducing the stigmatization of people with mental health issues, their relatives or families in healthcare, and ensuring equal access to health and healthcare for all citizens. Improving the possibility of using telemedicine and e-health solutions and access to healthcare in general and reducing the number of visits were not indicated by any of the participants.

Community characteristics

In this part the following issues were considered by participants:

- Who are the people who will be using the services?
- How to tailor the service to their needs?

After Session 1, participants identified 4 potential beneficiaries of the navigation service (Figure 1).

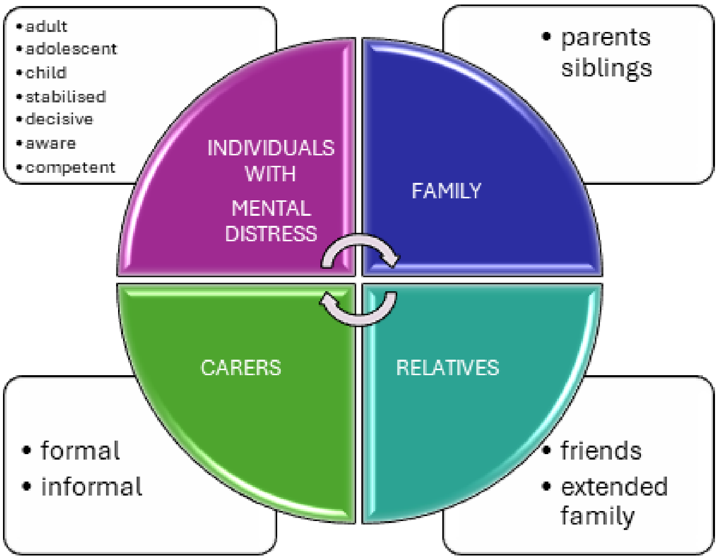

Figure 1. Potential beneficiaries of PNM (first draft)

In Session 2, when the World Café method was used, participants had the chance to refine the beneficiaries for navigation services. They answered the question "For whom?" as follows: "all those who do not embrace the health care system", "all those who want to embrace the system and see some deficits in it", "those who need", "for people in mental distress, for all people experiencing mental health problems and their families”. In one group it was stated that they were to be adults only.

During the last session, all participants sought consensus on the final definition of the beneficiaries of the navigation service. It was agreed that they would be adults who are experiencing/ have experienced mental health problems. Consideration was given to when it might be appropriate to extend the service to include carers/family members:

- when this is due to the legal situation of the person with mental health problems (incapacitated person, dependent on third parties, elderly person with daily support from the environment);
- when the navigator notices the need to involve the person's close ones, having first obtained the person's consent to do so; the navigator's ability to assess when the inclusion of carers will be justified.

Participants stressed the importance of building and maintaining the person's independence and self-determination:

> *"It would be good for the navigator to have this kind of competence to recognise whether the inclusion of such a caregiver or parent would be necessary and appropriate, because there are probably such situations". (CC_PL_P10)*
>
> *"Above all, what I am concerned about is that there should not be a situation where the navigator supports tendencies that are present in the family system, which will work in the other direction than the pursuit of independence, so that independence is built up rather than hindered". (CC_PL_P10)*

Another participant added:

> *"Well, it can be difficult, if such a navigator is not a psychotherapist at the same time, or does not have such competences, they may not recognise what the interaction is between the environment and this person, so I think that this support should always go towards the person, even if he/she has some limited possibilities; and not [the navigator] here with the parents arranges something*

> *and here sits the person, so this work should always be with the person and this family should be included as a kind of support". (CC_PL_P06)*

It was also pointed out that a form of caregiver involvement in the patient navigation process would be to educate them about primary prevention and goals of navigation:

> *"If the family works in the opposite direction, so to speak, from the goals of navigation, nothing will come of it anyway, because the environment largely shapes how a person functions, so by teaching, educating the family, we can also achieve the goals of navigation". (CC_PL_P05)*

Point of intervention

During the World Café session, all participants unanimously confirmed that the person's collaboration with the navigator should start with the early recognition of symptoms of a mental health problem. Most participants also stated that navigation should begin once a relationship with a mental health professional (either a psychologist/psychotherapist or a psychiatrist) has been established. These professionals should refer individuals, considering not only the person' needs, but also their mental health status, lifestyle risk factors and medication side effects. Each person should be referred to a navigator without delay but must be ready and willing to engage in such a collaboration. The final decision to work with a navigator is made by the person together with the doctor/therapist.

The integration of PNM into primary care practice was also discussed. However, some participants had different opinions on this idea. A representative from the group of individuals with mental ill-health claimed: *"It's a place to do other things (not for navigation)". (CC_PL_P02)*

One healthcare manager representative also stated:

> *"Primary care physicians know very little about their patients, patients say very little. Internists often treat people (with diagnosed mental problems) as 'not my' patients. The patient is in pain, it means to them that he or she is over-sensitive. A strange mindset is switched on among doctors: 'I can't handle this patient' ". (CC_PL_P04)*

The same person added at the same time:

> *“There are also primary care physicians who like to engage with this patient, they know them holistically. They don't always refer to a psychiatrist, they try to deal with the patient in a simpler way. A navigation service in primary health care would be an option, but not a priority". (CC_PL_P04)*

It is also important to note that there were statements that the implementation of the PNM should start at an early stage of education. According to one participant:

> *"Changing lifestyles by working with the navigator from an early age (education in schools) can also have an impact on improving health in adulthood". (CC_PL_P01)*

In conclusion, referral to a navigator should take the form of a recommendation and should not be mandatory. It is recommended that the opportunity to collaborate with a navigator should be part of any treatment plan. However, this collaboration should be tailored to the needs of the recipient, considering their needs and level of health literacy. Navigation should take place in both the public and private healthcare sectors.

Setting(s) of intervention

During the meetings, participants discussed where the intervention should take place. They presented a wide-ranging approach to the accessibility of navigation services, but all emphasized the flexibility of the navigator as an important element of an intervention. During the World Café, they mentioned the following places where the Navigator could be located:

- Medical facilities (outpatient services, hospitals, psychiatric clinics);
- NGOs that support people with mental health problems;
- The home of a beneficiary;
- The mental health centres.

Some of the participants also claimed that medical environment is the most convenient setting for implementation PNM. Mental Health Centres (Centra Zdrowia Psychicznego), providing regional psychiatric services were recommended. This is the current solution in psychiatric health care in Poland. People living in a certain area are under the care of a regional coordinator (nurse) who, after filling in questionnaires, decides which psychiatrist or psychotherapist the person should go to. According to a person who has practice working in this institution, the coordinator has many responsibilities, and the additional task of navigator is not possible for such a person. According to this participant:

> *"The coordinator from the Mental Health Centre can refer you to a navigator. There should be a navigator at these centres". (CC_PL_P04)*

Another person indicated that other sites were also proposed:

> *“[Navigator] could be placed in the primary care centres, pharmacies, can be in other clinics, e.g. at an at the orthopaedic, but the most important thing is that the person is able to identify that he or she needs it". (CC_PL_P05)*

The idea of introducing a navigator to NGOs was discussed. However, there is concern about the lack of medical care/control for the patient. According to a person with medical background:

> *“The medical context is possible through access to documentation, information about the patient, foundations will not necessarily have the opportunity to view such data”. (CC_PL_P12)*

Two thirds of the participants suggested that the navigator's way of working should be like the role of a community worker who goes into the environment of the potential beneficiaries. In the final session, this topic was revisited to make it clearer and more precise. The group explained that they were not thinking of typical street working, but rather an office work. According to the participants, the navigator should work in two modes. The first can be called “field mode” – the navigator goes to the places where people who are potentially interested in this type of service can be found. The role of fieldwork would be to provide information about such services, their goals, locations and the like. They could also analyse the needs and build trust in the model itself:

> *“The navigator could come to an organization, an association, to say something there, to organize an event and in this way build a relationship, he/she can be a known person”. (CC_PL_P10)*
>
> *“The navigator should go into the environment, build trust, he/she does not have to dazzle, like “I am the navigator, come to me”, but he/she can talk to the staff, study the needs, recognize who is eligible for such support and approach these people to build such relationships”. (CC_PL_06)*
>
> *“Working in the community could make it possible to “catch” people who are not coping with the formal healthcare system”. (CC_PL_01)*

The second mode would be “desk mode” – the navigator works in the office, which can be in many different facilities (as mentioned above), but with the ability to be flexible and adapt to the person's needs:

> *“I think about inpatient services with flexibility. For some people it may be more reasonable – if the context is safe and no boundaries are crossed – that one (the navigator) can visit the service user at home”. (CC_PL_P10)*

When mentioning the positive aspects of the inpatient service, participants spoke of service users who were described as 'elite' and who prefer to go to the office because they are anonymous there. Participants agreed that there should be a network of navigators and a database where people interested in the service can search and find such a place and person. Participants were divided on an official referral to the navigator. There were also doubts about who should be responsible for the referral – should it be a psychiatrist, a psychologist or a general practitioner? Some acknowledged that the referral could be a signal to the service user: “This is really important”, so it could serve as a motivation. However, all agreed that extrinsic motivation is not as effective as intrinsic motivation:

> *“If someone does not have the intrinsic motivation, the navigator can do nothing, he will hit a wall”. (CC_PL_P08)*

Participants agreed with the idea that no one can force someone to contact the navigator. It should be the person`s decision. In this context, participants emphasized that people should be ready for such an intervention. They should be in a stable mental state to be able to make an autonomous and unbiased decision about visiting the navigator. As mentioned earlier, participants agreed that the navigator should be flexible in terms of where the service is provided. They emphasized that it should not be very strict and should allow the navigator to adapt to the needs of their beneficiaries. If the service user cannot come to the office, the navigator could visit the person at home (after getting consent). Some of the participants emphasized that sometimes a person`s mental state can deteriorate, and such a home visit would be a great opportunity to provide effective assistance:

> *“Navigation should be limited to people who want this kind of intervention, who are aware of it, who are actively seeking it". (CC_PL_P07)*
>
> *“Maybe someone feels uncomfortable, and it is better if the first visit takes place at home. In such an environment the navigator can perceive more. Home visits initially, and then the person may want to go out on their own”. (CC_PL_P02)*
>
> *“The navigator could also make home visits. Be able to approach the person at home”. (CC_PL_P08)*

To summarize, the group agreed on a mixed operating mode for the navigator:

1. On-site mode - working in the field – to reach out to groups, institutions, organizations and facilities where potential beneficiaries can be found; its role would be to educate, inform and promote navigation;

2. Desk mode – working in the office – to determine an intervention for specific service users based on their specific needs. This requires flexibility on the part of the navigator – they should adapt to the user`s expectations and current condition. Home visits should be allowed and be an element of the intervention if needed.

Range of services offered by navigator(s)

Participants drew up a list of services that the navigator should provide. They emphasized that the services should be considered broadly and flexibly depending on the needs of the users. The needs that should be met by the navigation services include information, support, advice, motivation, a sense of agency. In this context, during the interaction, participants mentioned the following services that should be provided as part of the patient navigation model:

- Improving health literacy at the level of cancer primary prevention and health promotion by paying particular attention to the awareness of early symptoms of mental health problems. It should be adapted to the mental and intellectual state of a service user:

“Recognizing a service user's readiness, how much you can tell them without raising their anxiety”. (CC_PL_P05):

- Motivating the service user to adopt healthy behaviours;
- Extending support to the person when a service user has been diagnosed with cancer:

“The navigator should be the caregiver of such a person, they should work one-on-one, they could guide such a person by the hand. When it comes to oncological diagnosis, such a person should be offered the individual support of the navigator. The navigator should not only be present during the education phase but should also accompany the person later on”. (CC_PL_P08)

- Counselling, advise – depending on individual needs;
- Identifying the service user's needs and addressing them appropriately – this should be based on a high-quality relationship characterized by trust, well-being and respect on both sides;
- Develop a pathway for the service user based on the small steps approach that leads to big success and respects the service user`s dignity, autonomy and

agency. The pathway should support and promote their own resources and thus strengthen their sense of agency:

> *“Small steps in thinking, small steps in action lead to a big goal”. (CC_PL_P05)*

- Guarding – participants pointed out that the navigator should provide reminders of scheduled visits when needed and could – to some extent – monitor progress towards the goal;
- Provision of services in different locations (at the office, at the organization/institution, at the service user`s home).

Navigator background

Participants defined the competencies of a navigator in detail during Session 2. It was felt that the specific age and gender of the navigator would not be of primary importance. Although it was pointed out that it would be good for the service user to be able to choose a person in this regard according to their own preferences. It was suggested that the navigator should be characterised by certain traits, the most frequently mentioned being: communicative, able to listen, analytical, self-motivated, willing to self-develop and participate in training, mature, leading a hygienic/healthy lifestyle - *"to inspire the [person], to be authentic, to be able to sell the idea"*. (CC_PL_P08)

> *“It should be both an observer and a good listener, applying active listening, insightful, but also gentle [...] it is not about the navigator pouring a bucket of cold water on the person, because such a strategy towards a person in crisis will be ineffective”. (CC_PL_P08)*

The navigator should also have specific interests. Participants most frequently mentioned the following areas: medical topics, healthy lifestyle, prevention. The one person suggested that knowledge of the subject of herbal medicine and natural methods of supporting health would be useful.

When the education level of navigators was discussed, participants agreed that it should be a minimum of secondary education (at least a bachelor's degree). It is important that it be specialized (among the professions mentioned: psychologist, psychotherapist, doctor, nurse), supplemented by courses/training. Recommended areas of knowledge and skills would be interpersonal communication, mental health, the health care system in Poland, hard skills (medical, biological expertise), knowledge of risk factors for somatic diseases, nutrition, the impact of psychoactive substance use on the body, the role of physical activity for maintaining health.

Representatives of mental health organizations and a health care manager reported on a new profession in Poland called a ‘recovery assistant’. It is at an early stage of implementation in the Polish mental health system. A person who has experienced mental health problems and has completed specialized training can become one. A recovery assistant is a bridge between the person and his/her family and the therapeutic staff (doctors, psychologists, psychotherapists, social workers, etc.). Having experienced mental health problems themselves helps the staff better understand the person, his or her limitations, capabilities and needs throughout the treatment process. This person is also able to look at various issues from the perspective of the user of mental health support and care.

> *"I would like such a person to have experienced mental health problems, to give proof that you can cope if you want to," she adds, "Of course, not every navigator has to have such experience, but for me it would be great if there were such people". (CC_PL_P09)*

The introduction of this topic inspired participants to further discuss how much a recovery assistant could be incorporated into the PNM. It was suggested that since this professional is already being introduced into the health care system, it should be considered an important resource when building a navigation model for people with mental health issues. It was suggested that such a person could receive additional training in navigation skills and services, specifically tailored towards cancer prevention and patient support. However, there was no shortage of voices pointing out the risks of involving people with their own experience of mental ill-health.

Those familiar with the subject reported that it is not uncommon for a supportive recovery assistant, due to the burden of dealing with another person experiencing mental health problems, to begin experiencing a relapse. The discussion did not result in the formulation of a definitive position on the issue, but it should be regarded as an important voice in the discussion, set in the local, Polish health care context.

Communication channels between users and navigator(s)

Participants discussed and suggested different communication channels. They argued that contact between the navigator and the service user could be facilitated by digital solutions such as an information platform. These solutions should be dedicated especially to young people but also to the elderly who want to develop their digital competences. The use of such solutions should not be mandatory. The possibility to have access to an electronic platform should allow keeping up-to-date information and health news (e.g. about access to specialists). The possibility of online consultation was particularly important for young participants of the focus sessions. However, it was felt that online help should be possible, but only as an alternative method to support face-to-face meetings.

According to the participants, the topics of the meetings conducted by navigators should be flexible, personalised, and not one-size-fits-all. The regularity of meetings should be tailored to the person's needs, considering their lifestyle and cancer-related family history (genetic factors). The cooperation with the navigator should continue until sustainable results are achieved (healthy habits, hygienic lifestyle). However, it is up to the person to decide when to start or stop working with the navigator.

Before implementing the PNM, a broad public awareness campaign about the navigator's role should be done. It is also recommended to distribute educational material in medical facilities in the form of leaflets. Information material in the form of a business card of a small size will allow everyone to hide the material on their personal mobile phone. Posters and brochures that attract attention and motivate service users to ask questions of medical staff were also recommended.

The final session attempted to clarify the characteristics of the app that is planned for monitoring health behaviour in this project. Participants could comment on the usefulness and types of health monitoring functionalities anonymously in paper form (for this reason this is not possible to include codes of participants in this section).

There were several negative statements about the use of health monitoring apps. One participant indicated:

> *"I am put off by using yet another app and receiving notifications. I lack the desire to enter data, e.g. about meals taken, etc. The app should not be used*

to control the patient but include things that help the patient to be independent in the recovery process".

It was surprising that the majority of those present (*n*=9) felt that the app should not be used to measure parameters such as weight, number of hours of sleep, composition and number of meals, amount of water drunk, number of cigarettes smoked per day, extent of physical activity, social activity time. On the other hand, participants found functionalities such as the ability to remind them to take their medication, assess their hydration status or their wellbeing valuable.

One participant stated that the app should support people in their plans to maintain a healthy lifestyle and self-development, i.e. remind them of tasks to maintain a healthy lifestyle and help them to plan these tasks. In addition, it should support preventive activities, i.e. the development of health literacy by helping to remember information on cancer prevention. One person also highlighted the social dimension of the app and the role of gamification in supporting health behaviour.

Navigator Training

Participants had different ideas about the additional skills and training of the navigator’s knowledge and abilities. Several areas can be mentioned:

- **Soft skills and competencies** – building the relationship between the navigator and the service user based on effective communication, trust, confidence, a sense of security and comfort. Some participants pointed out that this is even a question of the navigator`s personality and not just a question of additional training. Nevertheless, everyone agreed that the most important area of training is effective communication, which includes the ability to actively listen, give constructive feedback, set boundaries in the relationship, recognize body language (non-verbal communication) and be assertive. In addition, participants mentioned a holistic approach to beneficiaries, which also includes other types of soft skills such as empathy, but also expertise on certain aspects related to health, lifestyle, prevention and health promotion;
- **Prevention and health promotion** – participants emphasized that this is the essential area in which navigators should be regularly and systematically trained

so that they are able to provide up-to-date information and recommendations to service users and design the most effective intervention pathways. Prevention and health promotion is a general category that includes areas such as nutrition, physical activity, psychoactive substance use and the like. Such training and courses should be tailored to the specific needs of the navigator.

- **Cancer education** – more specific knowledge about cancer and oncology prevention, which should be an extension of basic prevention knowledge, is another area emphasized by participants;
- **Mental health training** – it should cover both mental health and physical health issues. Knowing that navigators could design the most effective interventions tailored to the individual user's needs and limitations;
- **Additional supervision for navigators** – in the form of individual and/or group sessions with the supervisor (e.g. a psychotherapist). The role of navigator` as such can be psychologically stressful, so they need such sessions where they can review their work and ask for advice.

The participants pointed out that any additional training for navigators should be carried out cyclically and systematically so that they are always up to date with the latest knowledge and skills. They also emphasized that training and courses should be adapted to the individual needs of each navigator:

> *"If the navigator was to be, for example, a psychologist and he/she is undergoing 4-year training to obtain a psychotherapist certificate, training him/her in communication does not make sense". (CC_PL_P04)*

When asked about the people who could train the navigators, participants indicated that these should be professionals/specialists in specific areas – for example, if the training is on diet and nutrition, it should be delivered by a dietitian.

Navigator Supervision

There was an intense debate about the nature of administration over the service provided by the navigators. Participants distinguished between two forms – one, more related to control, which could be called surveillance/monitoring, and one, more related to support, which was called supervision. Formal control of the navigator's work sounded negative and unpleasant to some participants:

> *"Surveillance/inspection – that sounds terrible. Supervision sounds good. Peer supervision". (CC_PL_P01)*

Nevertheless, most participants agreed that there should be both forms of control – surveillance as a form of formal reporting that monitors the documentation and progress of the intervention based on the authority of a controller, and supervision as a form of guidance and counselling based on the experience of a supervisor:

> *"There should also be such formal control for which this person (the navigator) should be accountable to someone". (CC_PL_P08)*
>
> *"Formal control accompanied by regular support and participation in supervision, is necessary". (CC_PL_P05)*

Participants linked the type of control to the navigator's area of competence, stating that formal control is not necessary if the navigator`s tasks and responsibilities are not very demanding (e.g. if there is no strict medical/oncological knowledge involved). According to the participants, formal control should be provided by an expert/authority with a theoretical background (participants suggested a psycho-oncologist for this role), while guidance and counselling could be provided by a psychotherapist.

There were also different ideas about what should be the subject of such a control. The participants had some difficulty in specifying this aspect. They suggested that the control should concern the navigator's documentation and/or the impact of the intervention (i.e. the goals achieved by the service user). In either case, participants see possible limitations. In relation to documentation, the concern related to the legal status of the navigator and therefore the status of the documentation itself. In the second case, the problem relates to the technical way of monitoring/reporting the effects and goals achieved by the service user. It was quite difficult to find a common opinion on this point. To summarize, it can be stated that all participants agreed with the need for supervision, and some of them also insisted on formal control – surveillance among navigators.

Evaluation measures

At the end of Session 3, the issue of evaluation of the navigation service was addressed. Attempts were made to answer questions about what could be measured, with what tools, what indicators would be helpful and appropriate in the evaluation process. Finally - what, who and by whom would be evaluated.

This started by considering what could be evaluated. The conversation moved towards evaluating the effectiveness of the navigation:

> *“If the area for change is smoking, then we monitor the number of cigarettes smoked. If it is body weight, well we monitor body weight. And who should do this? The person always monitors first. And he/she relates to the navigator what he/she has achieved. And here this relationship based on trust and truth, yes. It is only then that there can be effective navigation”. (CC_PL_P05)*

The topic of the purpose of the evaluation was then introduced. Participants started to consider what this evaluation would serve.

> *"Let's consider what this evaluation would serve, because if someone were to, for example, lose their job after this evaluation then there is a conversation about something else. There could be situations where someone is skewing the system, depending on what this evaluation is supposed to serve". (CC_PL_P01)*

One participant (CC_PL_P06) pointed out that it is important whether we evaluate quantitatively ('I have recruited many patients and there is a “wow effect”) or qualitatively (“I have 2-3 patients but there has been a real change in them”). It was also suggested that it is important to keep in mind that if there are some metrics out there that become a target in the navigation process, it will completely lose the point:

> *"Because people will try to distort the evaluation system to achieve what needs to be demonstrated”. (CC_PL_P10)*

The focus then turned to what data can be used to evaluate the effectiveness of the navigation process. In some cases, the very fact of using the service, contacting and reporting to the navigator will be a measurable effect. One wondered how to evaluate a situation in which a person cooperates with the navigator for a very long time, and the effects, for example, in the form of lifestyle changes, are not visible. Should navigation be considered ineffective in such situations? Participants had serious doubts about this. Not all effects of the work will be equally measurable, and in this participants saw a considerable challenge for the evaluation process of the navigation service. One participant added:

> *"Sometimes change in general is just awareness, for example. Well, I work with young people, I am trying to convince them to drink water during class and not something sweet. And just building that awareness through repetition, education about what is healthy and what is not, can be effective. Sometimes*

> *awareness alone, the realization that it's better not to eat this and eat that, already works. And when it bears fruit, it can be long after the fact of this work with this navigator. For me, the very changes in thinking about certain things is a seed that will germinate at some point, and it doesn't have to be while working with the navigator. Maybe it's just when it's gone, because the user will know that they have to deal with it on their own?" (CC_PL_P01).*

Participants agreed that a form of evaluation would be the beneficiary's own conversation with the navigator, in which he/she expresses satisfaction (or lack thereof) with the cooperation. In some situations, questionnaires, evaluation surveys - including anonymous ones - may be useful. Obtaining feedback from the navigator on the quality of his/her services can be helpful in pinpointing areas for possible change and self-improvement. There may be situations in which, based on the results of the questionnaire, a change of navigator will occur, as the cooperation is not judged fruitful by the beneficiary.

An important form of a kind of self-evaluation for the navigator, according to participants, will be systematic record-keeping:

> *"By writing down that such and such a meeting was held, it went on so and so, the beneficiary is achieving the steps and goals set, we are just able to.... don't know.... after a year of working together, pull out such documentation and see... that with this navigator, beneficiaries are working this way, how the navigation goals are being met.... so, I think it's simply a matter of medical records, keeping them meticulously, so that you know more or less what was going on in general, whether the beneficiary comes regularly or was there once and dropped off". (CC_PL_P12)*

RESULTS CO-ADAPTATION ACTIVITIES SPAIN

Overview of co-adaptation activities

For the co-adaptation of the Patient Navigator model in Madrid, 3 focus group sessions were held with the participation of 13 people with the following profiles. 13 participants took part in the first and second session and 11 participants assisted to the third session (P_02 and P_05 didn't participate).

Table 1. Participants' information

ID	Age	Gender Identity	Profile	City/Region
P_01	G3 (40-50)	Female	Individual with mental ill-health, Receptionist	Madrid
P_02	G2 (29-39)	Male	Individual with mental ill-health, Teleoperator	Madrid
P_03	G2 (29-39)	Female	Individual with mental ill-health, Administrative Assistant	Madrid
P_04	G4 (51-61)	Male	Caregiver, Administrative Assistant	Madrid
P_05	G4 (>62)	Female	Service Manager	Madrid
P_06	G3 (40-50)	Female	Rep Mental Health organisation / Individual with mental ill-health, Chemist	Madrid
P_07	G3 (40-50)	Male	Rep Mental Health organisation, IT specialist	Madrid
P_08	G3 (40-50)	Female	Care Team Member, Occupational Therapist	Madrid
P_09	G3 (40-50)	Female	Care Team Member, Psychologist	Madrid
P_10	G3 (40-50)	Female	Individual with mental ill-health, Biologist	Madrid
P_11	G4 (51-61)	Female	Service Manager, Social Center Director	Madrid
P_12	G3 (40-50)	Female	Individual with mental ill-health	Madrid

P_13	G4 (>62)	Female	Caregiver, Administrative Assistant	Madrid

The sessions were facilitated by two social intervention providers over two days: on January 26, 2024 two face-to-face sessions were held; and on January 31, 2024 a hybrid session was held. Seven people participated in person at the "Nueva Vida" Labor Rehabilitation Center, which is part of the Social Care Network for people with severe and long-lasting mental ill-health in the Community of Madrid. The remaining 4 participants joined via Zoom and a wall display was used to see the online participants.

During these sessions, a two-way communication methodology involving both the moderator and the participants of the focus groups was employed to discuss, gather views and reach agreement to the extent possible on each of the main components of the PNM.

Programme goals

The work resulting from the working sessions made it possible to distinguish a general objective of the project, which can be accompanied by other objectives of a specific type. According to the opinion of the participants, the Patient Navigation Model **should reduce the barriers and difficulties faced by people with mental health problems in their access to health and social services for cancer prevention and treatment, while improving the knowledge of this group on the health and social programs and services offered in the field of cancer in Madrid.**

Moreover, specific issues were identified that gave rise to the following specific objectives:

a) To contribute to improving the information received in relation to cancer prevention. It was proposed to achieve greater uniformity in the reception of information (that everyone receives the screening letters, that the information is standardized and transmitted by all professionals in the same way), suggesting the existence of a dispersion and irregularity in the access to information (it does not reach everyone in the same way, and at the same time), and that the quality of the information received depends mainly on the attitude and individual commitment of each professional.

> *“I, personally, in our health centre, I am now 47 years old. My health centre has not yet informed me that from 45 onwards, between 45 and 50, you can have prostate check-ups for cancer prevention. Because of a social improvement that we have had in the laboratory where I work, we have a private company. And it was because of them that I was informed and I had my first check-ups”. P_07*
>
> *“I am older than you and I have not been informed either”. P_04*
>
> *“In the end we don't... Of course, we don't get that information. There is a lack of information. And, well, excuse me, but I do remember that previously, in the health centre where we live, there used to be a truck, like the one to donate blood for mammograms, and it was done annually. I know that this changed and after the pandemic it seems to me that it has been lost”. P_07*
>
> *“At 50 years old, I can tell you that the letters do arrive, eh. Yes, the revisions arrive too”. P_11*
>
> *“Yes, I also wanted to say that the truth is that I have no complaints about mammograms because as soon as I turned 40, I am now 41, I have had two mammograms every year. Yes, and this year it will be my turn again. Yes, yes”. P_01*

To help mitigating this problem, the possibility of having an appointment card for prevention (similar to a vaccination booklet) was proposed, as well as the possibility of improving visibility and access to information through the incorporation of more informative material (posters, etc.) in health and social centres, and improving the information available on public institutions’ websites.

b) To provide integrated care for people with mental health problems. The model could help streamlining specific problems in Madrid's health and social system by collaborating in requesting and changing appointments, providing a human resource (Patient Navigator) to alleviate the lack of professionals in primary care and mental health services, and, very importantly, ensuring access for people with mental health problems to the system's "health itineraries". With respect to this objective, citizen associations were identified as key actors in this process, given that citizen associations are currently generating "prevention spaces" (informing and raising health awareness). It is understood that the Patient Navigators should be aware of and sensitive to this work, which has been going on for some time. The Patient Navigation Model could also somehow ensure (or establish) the communication channels that ensure that new information reaches the users.

During the sessions, coordination issues were also identified that, if addressed properly could help to improve the implementation of the PNM. In this sense, problems were mentioned in coordinating the implementation of cancer prevention actions with the information provided by the Family Physician.

> *“From my point of view as a user, it is as if there is no correspondence between family physicians and the programs. That is to say, you go and tell the family physicians "I have received a letter", and they say, "but that is not our issue, that is a program issue". So it is true that there is a lack of prior information, that they say, "you are going to receive a letter after a certain age". Or if you say, "Well, it seems, doctor, that I have never received a letter”. In other words, I think there is a lack of coordination. From my point of view”. P_05*

c) To contribute to reducing deficiencies in personal treatment. In this regard, reference was made to the existence of stigma in the care of patients with mental health problems, giving priority to their condition of being mentally ill over other pathologies they may present, and relating any symptom of illness to their mental health problem.

> *“Also, because if you go to the doctor and with the stigma attached to mental health, if you tell the doctor that you have a mental health problem, you have nothing else”. P_06*

Likewise, the Patient Navigation Model should be sensitive to the diversity of mental health issues, which is why it has been recommended that all professionals who participate in it should have knowledge of mental health, given that "not all people with mental ill-health have the same needs and problems".

> *"I was saying, that within the group of the mental ill-health collective there is a lot of variety, each person, of course, is not the same, neither is one problem the same as another. For example, obsessive disorder or bipolar disorder, of course". P_03*

d) To promote awareness on cancer among people with mental ill-health: It has been reported that this population as a low level of health literacy, and especially of information on cancer prevention. **Specifically, there is a lack of knowledge to correctly self-identify possible cancer-related symptoms**. It was proposed that the navigators should advocate to increase the levels of health literacy through different activities.

> *"I agree very much with what P_07 said and I think that in general we lack a lot of health education, yes, many times when we go to the doctor we do not know how to describe well the symptoms that are relevant, to separate ourselves from the symptoms that are not relevant, to ask for information and that, to know, to have that information so that we all know when we have to pay attention or to what things we have to pay attention". P_11*

Likewise, this objective would include actions to follow-up on appointments. Although according to the information available to the participating associations, people with mental health problems attend medical appointments as regularly as other people, there are some percentages of people who are frequently missing them, mainly because of their health situation, e.g. because they suffer from episodes of depression. Improving compliance with medical appointments usually requires a great deal of effort and involvement on the part of caregivers and family members, but also with the NGOs that provide support to this population.

Community characteristics

According to the opinions of the participants in the co-adaptation group, it can be established that the cancer prevention needs of people with mental health problems in Madrid do not differ greatly from those of the rest of the population. During the discussion groups, the participants indicated that they had needs that could be extended to the rest of the population, such as obtaining more uniform, protocolized and assimilable (easier to understand) and accessible (adapted to different needs) information on cancer prevention and treatment. At the same time, recommendations and proposals for improving the health and social system in Madrid have been put forward, which are recurrent in other population groups:

- A reduction in waiting time for appointments in the healthcare systems.
- Adopting a person-centred care approach in relation to the health and social needs of the population
- Increasing the number of healthcare professionals.

This similarity between the target group of the CO-CAPTAIN project and the rest of the population of Madrid does not preclude the possibility of pointing out **specific characteristics of people with mental problems that would have a direct effect on the care that would be provided to them**. In this way, the following circumstances raised during the work sessions can be indicated, which would have a greater effect on the care of people with mental health problems:

a) **This group is more prone to social stigmatization than other population groups.** These stigmas are usually generated through behaviours and attitudes that emphasize stereotypes about people with mental health problems. As indicated above, there is a tendency to consider that any symptom expressed during a visit to the doctor is related only to mental ill-health, regardless of any other pathology or personal characteristic of the person. There would then be a reductionist approach in the care of this population group, which would be affecting the diagnosis of diseases and their treatment. On the other hand, it was also pointed out that this problem is far from being generalizable to all health professionals caring for people with mental health problems in Madrid, although there are cases of success and quality in the provision of the service. Therefore, it could be interpreted that the problem of stigma stems from personal behaviours and attitudes displayed by some professionals, rather than a systemic problem or one that can be generalized to a group of professionals. In this regard, the importance of all personnel involved in the Patient Navigator Model having basic training on mental health in order not to arrive at preconceived and/or automated ideas, was reiterated in the discussion groups.

b) **There are particularly vulnerable groups among the target population of the CO-CAPTAIN project.** The following have been indicated:

- **People experiencing mental health problems may encounter difficulties in recognizing symptoms of cancer.** It was also indicated that this population group endures the pain more and waits longer for the pain to subside before going to the doctor. For the care of this particularly vulnerable group, the importance of more frequent check-ups was proposed: continuous contacts and check-ups.

> *"I know of a case, for example, of a person who, because of her psychopathological situation, did not identify signs that made her go to the doctor. And it was a family member who, in a circumstance, realized it and accompanied her. And the cancer has already been diagnosed with a grade 4". P_08*
>
> *"Well, that's why I said before that people with [psychosocial] disabilities who are not able to identify those things, you have to be absolutely careful. How to do it? That is the issue". P_04*

- **There are groups of people with mental health problems who are more likely to suffer the effects of unwanted loneliness**. Representatives of civil organisations participating in the sessions also identified groups of people who experience loneliness. Due to a lack of significant social support, this sub-group of the population is negatively affected during the cancer prevention, diagnosis and treatment phases.

> *"And there are many people who are alone. These groups, what we are doing is to unite them so that they can participate in that support network, that trust between them. Because even if you don't take care of yourself because you don't really need it (they are not dependant), being alone you don't know how to detect when you have to go to the doctor". P_06*

c) Ultimately, individuals with mental health problems were suggested to be more prone to other cancer risk factors (such as smoking habits), thereby emphasizing the relevance of access to cancer prevention and screening programmes), yet they are not undergoing formal prevention and screening processes.

Point of intervention

During the sessions, it was established that health education and prevention are a fundamental measure to fight against cancer risks. According to the participants, it cannot be interpreted that the point of intervention of the project should differ with respect to the rest of the population, nor that there are different risk factors in people with mental problems. Specifically, the importance of informing all participants of the risk factors associated with cancer and prevention measures was expressed. They pointed out the following measures: eating healthy, avoiding the consumption of alcohol and tobacco, exercising daily, and encouraging participation in cancer screenings.

At the same time, the higher incidence of smoking among people with mental health problems was discussed, but it was concluded that this habit affects the population as a whole to the same extent and, that people with mental problems in Madrid also have a tendency in recent years to give up tobacco consumption. This measure is due both to the awareness of potential negative health effects of smoking, and to the progressive participation of this population group in therapies to quit the habit.

> *"Well, overweight has the entire population, and smoking. is a trend that in recent years has changed a lot, at least from what we see, specific services to*

> *quit smoking has been offered to the population. Smoking is not justified anymore, it used to happen a lot, in the past. I think that now the general population is also shrinking a lot and the issue of obesity is the same". P_11*

Another point of intervention in the primary prevention of cancer is the need to influence lifestyle habits typical of today's life, sometimes characterized by precarious working conditions, stress, and poor eating habits. This is a warning about the importance of intervening in a general way in the urban lifestyle (Madrid) which implies that it is characterized by haste, long journeys, jobs with long working hours, lack of leisure, etc.

> *"Stress can also trigger cancer. Stress is not good for anything. I don't know if that's the case, but I think so, it does seem to me that stress is always an enhancer of things. It's cortisol that causes stress, and cortisol can lead to cancer. That's what I read. Which in large quantities can cause cancer". P_04*
>
> *"Job has a great influence, who works twelve hours or who is very anxious about job or who eats badly or the distance. And they have a lifestyle that is more prone to having low defences and suffering from diseases". P_03*

According to the participants, the lifestyle which one develops in a city like Madrid would also affect the management of emotions, and the psychosomatic aspect that can lead to the appearance of cancer:

> *"When family members come from the village we go to dinner and two hours before you start getting ready. And they say that in the village in five minutes you get ready. Then you see the bus coming and you run off in a big hurry. And of course, lifestyle and mind can also make the body sick". P_06*
>
> *"Yes, I think we have an emotional management problem and that influences everything a lot. we have not been educated in the management of our emotions and that influences any disease, nowadays everyone has depression, why didn't that happen in the past"? P_07*

Setting(s) of intervention

The following priority intervention points have been identified for the figure of the Patient Navigator: Primary Health Care Centres, Mental Health Centres and any type of Social Center providing care for people with mental health problems. Additionally, it was proposed that it may be useful to focus the intervention on areas of Madrid where there is a higher incidence of people with mental health problems or where more cases of cancer have been diagnosed:

> *"Well, I thought it was a good idea to start in the areas where it is believed that there are more cases of cancer and mental ill-health, just as my colleagues have said, but the ideal would be in all of them, but it is difficult, but of course the ideal would be in all of them". P_13*

Moreover, it was indicated that the quality of the service would not be dependent on the location of the professional, but rather on the capacity of the navigator to do referrals for the people with mental health problems to the health and social services and to resources adapted to their needs:

> *“The important thing is not that there is a person, whether in a social services centre, hospital, primary care. For me, it makes more sense for them to be in a mental health centre, but the important thing is that they are referred directly, that they are informed of the resources”. P_06*

In this sense, it can be interpreted that there would not be a specific point of intervention of the Navigator but a network of services and resources in which the Navigator's work would be deployed. All the participants agreed that the aim of the intervention would be to promote networking among the different mental health stakeholders in Madrid, seeking to broaden the impact of the intervention of the navigators:

> *“On the subject of preventive talks, the Navigator could count on the different mental health and cancer associations in the different towns, so that they could lend a hand and manage the talks where they had to give them and thus at least help him to manage these types of resources”. Q_07*

When assessing the intervention, the participants consider that the application of this Model is an objective that should be carried out long term, progressively integrating it little by little into the social and health care structure of Madrid.

> *“Well, I see this (Model) as something very long term, that is, just as when our network was formed it started with a resource, a Psychosocial Rehabilitation Center and then with a Labor Rehabilitation Center, and now I have lost count of how many resources are included”. P_09*

Range of services offered by navigator(s)

Four categories of services have been delineated for potential provision by the Navigators, encompassing the following domains:

a) Facilitating access to available health and social care services: Within the framework of the intervention, facilitating service users' connection with Madrid's network of public and private resources for cancer prevention is essential. Throughout the sessions, emphasis was placed on the Navigator's need for comprehensive knowledge of available resources, marking it as the primary service the Navigator could offer. Among these services, the following were most frequently cited: Mental Health Centres, Primary Care Centres, Rehabilitation Facilities, Oncology Services, and Social Services.

b) Accompaniment and support: During the sessions it was suggested that the Navigator's role should encompass accompanying individuals from their initial exposure to information regarding cancer prevention through their engagement in cancer prevention programs. Addressing a specific need within this group, it has been highlighted that the Navigator should facilitate service users' access to civil society associations offering support during screenings and consultations. This entails ensuring they have ongoing assistance throughout the screening process and any necessary treatment. It was emphasized that in Madrid, associations such as the Spanish Association against Cancer are available to provide comprehensive support throughout all stages of disease treatment.

c) Raising Cancer Awareness and Education: Within this service, the Navigator should adeptly inform individuals with mental health problems about the primary symptoms associated with cancer and impart knowledge regarding healthy lifestyle habits and preventive measures. This educational outreach should extend beyond a singular location where the Navigator is stationed; rather, it should be conducted in a mobile manner, encompassing visits to various centres within the network of care for individuals with mental health problems: Day Centres, Vocational Rehabilitation Centres, and Psychosocial Rehabilitation Centres. The Model's proximity to the service user's areas of activity would be particularly valued in delivering this service.

> *"But prevention is before you are diagnosed, so I think that yes, it should be included as a function of the navigator to go to the different resources, to go*

> *to the base centres, to go to rehabilitation resources to our CRLs, CRPS, day centres to inform about the diagnostic tests that are usually done in prevention and when it is convenient to do them, that is, to provide that training, so to speak, or to transfer that information so that it is provided in the resources".* P_08

Given the complexity and variety of services and functions that the Health Navigator can perform, it was considered important that the definition of the scope of its work be coordinated with actors in the healthcare system. Therefore, the deployment of the Navigator's functions should include **coordination with healthcare services and social services.** It is necessary for the navigator to be coordinated with all the relevant stakeholders in the network of care in healthcare and social services systems. In pursuit of this objective, an initial phase of coordination with the mental health centres, primary care centres and social services where the intervention will be implemented needs to be put in place. Within the framework of this coordination phase, the navigator will establish the referral pathways and the scope of their actions for accountability, also clearly defining the services involved in the intervention and adapting the type of collaboration established with key professionals in cancer prevention such as nurses, and social workers.

> *"From the coordination meetings it can be decided where support is most needed, how everything can be organized, but not only from the work done by the Navigator, but from a very close coordination with nursing, social work, etc." P_11*

According to the opinion of all the participants, the conclusion was reached that, together with the public resources mentioned above such as Mental Healthcare Centres, Primary Care Centres and Social Services Centres, it would be necessary to include grass roots associations to effectively address the needs of the people with mental ill-health.

> *“From the associative sector, from the prevention part, associations can get involved because you don't need to be a doctor to inform, so I think that is where associations can help. Besides, there are also the resources of subsidies that you can ask for from the city councils as an association”. P_06*

Throughout the co-design sessions, the importance of networking was reiterated by the participants, emphasizing the need for coordinated navigation within a network comprised of both public and private resources. Additionally, the model should aid in disseminating awareness of these resources and harmonizing them to prevent duplications.

> *"I think that all these resources should be mandatory knowledge, that there should be a resource guide and that an association or anyone who wants a Labor Rehabilitation Center or a Socio-labour Rehabilitation Center that wants to do this activity, where to look, where to go, because jobs are being duplicated. These do one thing, the others do the same, all for not communicating". P_06*

Navigator background

During the sessions, greater emphasis was placed on the Navigator's personal and professional competencies and skills rather than the possession of a specific academic degree. While it is deemed advantageous for the Navigator to hold a degree in the health or social-health field, the following professional skills were deemed essential: empathy, active listening, and a warm and engaged approach in interacting with individuals. Specifically, the Navigator should possess knowledge and information about various types of mental health issues prevalent among the target population to enhance cancer prevention for individuals with mental health problems.

> *"It is true that we are talking about a very specific group, people with mental ill-health. So the professional would have to have knowledge about the group, that is important, because it is very important apart from personal empathy skills, but of course [the navigator] should know the group he is working with". P_09*

> *"I have even been told, for example, with my compulsive nervous disorder...you know, there are things you can't do. Also when I told the person who was going to do an ultrasound, "Now I'll take off my bra, but slowly". This person answered me: "Well, hurry up," she said and "she went to me to take off my bra". I understand that they are not psychologists. And they don't need to know that. But, jeez. I have a lack of serotonin in my brain. But I can think. And they don't talk to you like you're dumb." P_06*

Regarding the professional profile of the Navigator, two primary aspects concerning the aforementioned services were defined in some detail. The aspect of facilitating access to available health and social care services would predominantly align with the profile of a social worker equipped with knowledge of available resources and capable of providing informative guidance. On the other hand, the accompaniment, education, and information service would be more closely associated with a professional who possesses competencies and attributes such as empathy, active listening, warmth in interactions with users, and a strong sense of engagement with them.

> *"In the part that has to do with knowledge of resources and coordination between resources, it seems to me that a social worker profile, although there are other professional profiles that would fit, but I think that this part is very specific to social work, coordination of management resources. And then the part of the accompaniment of the person would fit more what we were talking about, something more linked to the skills that the person may have, the capacity of empathy that we were commenting on the need to have". P_08*

This approach led to agreements proposing to have two professionals involved in Patient Navigation.

> *"There should be two professionals, one dedicated to coordination and the other to human treatment (accompaniment and training)". P_04*

During the sessions, participants reached a consensus that the description of services and the characteristics outlined in the Navigator's profile might exceed the capabilities of a single individual, suggesting that the proposed professional profile would require the involvement of multiple professionals. Additionally, during the co-adaptation sessions, participants acknowledged that the proposal was presented at its maximum potential and that its implementation would ultimately depend on the available budget.

Communication channels between users and navigator(s)

During the sessions, great importance was attached to ensuring that physicians and other health professionals, mainly from the mental health centres, were adequately informed of the existence of the role of the Navigator, so that this professional resource could be activated as soon as possible. At the same time, it was suggested that contact could be direct between individuals with mental health problems and the Navigators, through a contact telephone number or through virtual appointments.

> *"For an emergency, a phone that is for this is a good idea, once you contact by phone the Navigator will already give you the appointment, they already tell you the information or they already refer you wherever they have to attend you". P_13*

For the activation of this intervention by the general practitioner or mental health professional, it appears that priority should be given to the most vulnerable groups of the population with mental health problems, and which are indicated in point 3 of this document.

Navigator Training

During the sessions, it was emphasized that preliminary training is essential for all aspects of the three identified services: resource management and coordination, accompaniment, and education. Simultaneously, specific topics were highlighted and mutually agreed upon by the participants. The Navigator's pre-training should focus on enhancing knowledge in the following areas:

- Psychosocial and community rehabilitation.
- Detailed understanding of cancer screening and prevention programs in Madrid.
- Bereavement support skills training.
- Education on healthy lifestyle habits.
- Keeping up to date with regional and municipal resources regarding cancer prevention and healthcare.

> *“The previous training in psychosocial rehabilitation and in the group [of people with mental ill-health] seems important to me, because it may be a person that comes from working with other groups”. P_11*

Navigator Supervision

For the supervision of the navigator, the possibility of creating a commission was proposed, not directly dedicated to the control of their work, but to the detection of needs and difficulties that the navigator might have during their daily work. The commission should help navigators, guide them in the execution of their work, and could be made up of a multidisciplinary team of service users, general practitioners, oncologists, members of mental health associations, and other professionals.

> *"Yes, there should be a commission to review what is being done, which could be represented by people from oncology, mental health, social services and associations, to follow up and also to see the difficulties, to see how we can work together to improve rather than to think about supervision”. P_11*

Evaluation measures

Among the evaluation measures, the importance of applying standardized programme follow-up forms to be applied periodically was expressed. In relation to the indicators, it was proposed to measure the variation in the number of cancer diagnoses among people with mental health problems before and after the implementation of the intervention as well as to make comparisons with the total population:

> *“Because of the objectives of the navigation service, it might be possible to see data on cancer diagnoses of people with mental health before the start of the project and afterwards”. P_08*

At the same time, the use of forms and the possible creation of satisfaction reports was considered to be a very heavy workload on the part of the Navigator.

> *“We are talking about all the functions of the navigator, but if you also have to do all the bureaucratic part of the registration, we should not forget it, because it takes a lot of work.... For example, every year we are asked to fill in the satisfaction questionnaire to be evaluated, it is a lot of work to register all the data that you have to enter...”. P_09*

It was proposed to evaluate the possibility of creating monitoring committees formed by the multidisciplinary team to supervise/facilitate the Navigator's work, through periodic meetings, in which, in addition to coordination tasks, evaluation tasks would also be carried out, assessing qualitative aspects of the programme execution.

Finally, the experience of the organisations which take part in the CO-CAPTAIN consortium recommend looking for indicators that could be extracted automatically from Madrid's registry systems. If the reports are person-dependent (i.e., we depend on the voluntariness and accuracy of the records), they will not always be made and we will not be sure that the reported data is reliable as there may be omissions.

DISCUSSION - CO-CAPTAIN PATIENT NAVIGATION MODEL AND IMPLEMENTATION STRATEGIES

This section outlines the main results of the focus groups' participants' perspective on each of the core elements that CO-CAPTAIN should consider when developing and implementing the PNM in the four pilot sites. Whereas several findings emerge consistently across all countries, some are more country specific.

There is significant cross-national agreement on the fact that the PNM has to be set and delivered according to a person-centred approach that takes into account to personal and contextual situation of the navigation's beneficiaries. Consequently, this demands an important level of flexibility in relation to the navigators' role, profile and type of navigation services provided.

The navigator will be a professional with a health or social care background with knowledge on mental ill-health as well as cancer prevention. Moreover, all countries put emphasis on the need for the navigator to have strong communication and interpersonal skills leading to the establishment of a trustful and empowering relation with the programme beneficiaries. The navigation model will encompass cancer prevention and will facilitate access to integrated health and social care services. It should range from improving health literacy to promoting adoption of healthy lifestyles and providing very practical support in accessing care. The involvement of caregivers in the PN along service providers is considered important to support the beneficiaries' participation in the programme.

The expectations on the range of services the PN should provide and also on the competencies the navigator should have are broad. This can be addressed by building a network of service providers around the navigator and the beneficiary and providing a comprehensive training package to navigators. Building on professional profiles already existing in certain countries (e.g. Greece and Poland) could be a means to facilitate PN and could inspire other countries, too.

In this section the overall findings are summarised according to the 10 core components of the PNM; they provide a comprehensive yet flexible guide for CO-CAPTAIN partners to pilot the PNM in the next project phase.

Programme goals

The overall outcome of the co-adaptation focus group sessions confirm and support the goal that the CO-CAPTAIN project has set for the Patient Navigation Model, that is the PNM should aim **to reduce the barriers and difficulties faced by people with mental health problems in their access to information, health care and social services for primary cancer prevention** and **to improve their experience with relevant health care services**.

In order to achieve the above, the following set of related objectives should be pursued:

Provide integrated care for people with mental health problems. The PNM could help streamlining services in health and social systems by connecting existing health and social care providers and offers and establishing communication channels and supporting the coordination of access for people with mental health problems to the system's health itineraries. Additionally, this network could include relevant actors (e.g., civil society associations).

Enable the **best possible access to primary cancer prevention measures** and accompaniment for the adoption of a healthy lifestyle. Navigation services should be designed according to a person-centred approach based on the specific needs of the beneficiaries.

Empower people experiencing mental health problems by strengthening their sense of agency and individual competence for health, and the ability to express their health-related needs and by lowering the threshold to accessible information.

Further objectives of the PNM that are conducive to empowerment should be:

Increase awareness on health in general by e.g., improving self-awareness regarding one’s own health, acting upon it, and thereby taking care of oneself.

Improve health literacy about cancer and cancer prevention by providing clear information, avoid misinformation and expanding knowledge on prevention measures, early detection signs, and treatment options. Increased health literacy could possibly enhance motivation, interest and engagement regarding one's own health. Moreover, to address the problem of dispersion and irregularity in the access to information (information does not reach everyone in the same way and with the same quality), the PNM should strive to achieving greater uniformity in the dissemination of information.

Enhance understanding of mental health problems and decrease stigma towards people experiencing mental health problems – awareness should be promoted among all actors involved in the programme so as to prevent diagnostic overshadowing and provide optimal prevention services that meet the needs of beneficiaries and are respectful of their individual circumstances and preferences.

Community characteristics

From the co-adaptation activities it emerges that the programme should be targeted at **people with mental health problems who are willing to participate** and **provided they have achieved some stability in their recovery journey** so they can benefit from participating in the navigation model. Involving participants who are in the very initial stages of recovery may be challenging as their primary focus will likely be on taking care of their mental health problem.

Further potential characteristics among people experiencing mental health problems to be considered as priorities are:

- a greater need for support due to difficulties caused by mental health problems and/or other causes of limitations (e.g., cognitive impairment, sensory impairment) or due to issues arising with aging;
- the lack of significant social support and loneliness as hindering factors to access the cancer prevention, diagnosis and treatment;
- specific challenges due to medication side effects;
- increased risk of cancer due to family history,
- previous bad experiences with the healthcare system (e.g., due to stigmatization);
- fear and avoidance of the healthcare system;

- little or no financial resources.

There is a second group that should benefit from the PNM, that is **caregivers – mainly family members and relatives** - who could help to achieve the goals of the programme, as they could support with cancer prevention actions such as making appointments for preventative examinations, accompanying their close ones to health services, and providing encouragement to adopt a healthy lifestyle. Caregivers could also be involved/ present in informative sessions or could be briefed separately.

Consideration was given to the questions of if and when it might be appropriate to extend the service to caregivers because of the importance of building and maintaining the independence and self-determination of the person with mental ill-health:

- when this is due to the legal situation of the person with mental health problems (incapacitated person, dependent on third parties, elderly person with daily support from the environment);
- when the navigator notices the need to involve the person's close ones, having first obtained the person's consent to do so.

Point of intervention

There were different suggestions on potential good starting points for participating in the PNM. The navigation programme could begin once a relationship with a mental health professional (e.g., a psychologist, psychotherapist or psychiatrist) has been established. These professionals may refer individuals to the PNM, taking into account the person' needs, their mental health status, lifestyle risk factors and, if applicable medication side effects. Each person should be referred if ready and willing to engage in such a collaboration and could decide to work with a navigator in consultation with the doctor/therapist. The intervention should ideally take place as early as possible for the beneficiary in situations when people with mental health problems could potentially find themselves in and that could mark appropriate timepoints for starting the programme: increased need for support, increased vulnerability, problems with activities of daily living.

It was also recommended that the opportunity to collaborate with a navigator should be part of any treatment plan and navigation should take place in both the public and private healthcare sectors. This would fit with the idea that the focus of patient navigation should not be limited to cancer prevention, as it being indicated as one of the objectives of the programme. Instead, participants in co-adaptation activities saw the planned patient navigation model as a great concept that provides potential for general healthcare navigation for people with need for support.

Offering an entry into the patient navigation programme could also happen when potential beneficiaries utilize healthcare or NGOs/self-help groups external to the healthcare system because people with mental health problems may be more open for prevention outside of healthcare facilities and that access should be low threshold by having navigators on site.

To enhance engagement the intervention should be presented in a positive manner by carefully use or avoid the word 'cancer' in its title and announcement, as well as images of poor physical health which can create feelings of fear and rejection in people. The main focus should be the adoption of a healthy lifestyle.

Setting(s) of intervention

The first step of establishing contact with patient navigators may be a potential barrier for people with mental health problems. Therefore, a trusted health professional or an organisation already providing support and care could aid in initiating contact.

Different entities and sites were indicated as potential providers of patient navigation: NGOs, self-help groups, general practitioners, health insurance, crisis intervention centres, psychosocial services, mental health care units or centres. The latter would be advantageous, given these structures are familiar places, primarily for the beneficiaries, but also for their caregivers because there are professionals with whom they might have a relationship of trust and security. Also, in these structures there is a team of psychologists and social workers, which can further support health promotion and cancer prevention actions. The expansion of this trustful professional relationship could include counselling services and further social support that may be required with little additional effort.

Furthermore, providing transport services, or home visits or other location familiar and comfortable for the beneficiary (e.g., at a café) may pose as facilitating factors. What comes up clearly is emphasis on the flexibility of the navigator as an important element of the intervention. To summarize, there could be a mixed operating mode for the navigator:

3. Outreach mode - working in the field in various sites both within and outside healthcare settings according to the preferences of beneficiaries;
4. On-site mode – working in a specific setting that would function as the headquarters for the navigator, at specific hours.

Moreover, it was indicated that the quality of the service would not be dependent on the location of the navigators, but rather on their capacity to do referrals for the people with mental health problems to the health and social services and to resources adapted to their needs. In this sense, rather than having a specific setting of intervention of the navigator there could be a network of services and resources in which the navigator's work would be deployed.

With regard to elements to consider for the PNM implementation that could be hindering or facilitating factors, some participants highlighted: sufficient time resources, sufficient and motivated personnel, empowering communication, specific issues linked to the beneficiary mental health problem, fear of topic of cancer, diverse experiences in using health services, language barriers, diagnostic overshadowing, two-class medicine, waiting time for appointments on site.

Range of services offered by navigator(s)

The services should be considered broadly and flexibly depending on the needs of the users. Four areas of services have been delineated for potential provision by the navigators, encompassing the following domains:

a) Facilitating access to available health and social care services: Within the framework of the intervention, facilitating the programme beneficiaries’ connection with and access to the network of public and private resources for cancer prevention and other relevant services is considered to be essential. Emphasis is placed on the navigator's need for comprehensive knowledge of available resources. Among these services, the following were most frequently cited: mental health centres, primary care centres, rehabilitation facilities, oncology services, and social services.

b) Accompaniment and support: it is suggested that the navigator's role should encompass accompanying individuals from their initial exposure to information regarding cancer prevention through their engagement in cancer prevention programs. This could include presence at medical consultations, debriefing after appointments, counselling and advising, searching for and forwarding information, organizing or passing on information on groups sessions or other opportunities to provide information. In this context, participants also suggested for navigators to receive information about health data with the patient's consent if allowed by data protection laws. Furthermore, confidentiality and discretion should be maintained.

The navigators should develop a pathway adapted to the beneficiary in respect of the dignity, autonomy and agency of the beneficiary. The pathway should support and promote the resources of the beneficiaries and thus strengthen their sense of agency.

Depending on the beneficiaries' circumstances, the navigator should also facilitate access to civil society associations offering support during screenings and consultations. This entails ensuring the beneficiaries have ongoing assistance throughout the screening process and any necessary treatment.

c) Raising Cancer Awareness and Education: Within this service, the navigator should inform individuals with mental health problems about the primary symptoms associated with cancer and educate them regarding healthy lifestyle habits and preventive measures. Information for beneficiaries should be provided in accessible language and format and to fit individual preferences regarding space and time. This educational outreach should extend beyond a singular location where the navigator is stationed; rather, it should be conducted in a mobile manner, encompassing visits to various centres within the network of care for individuals with mental health problems. The programme's proximity to the service user's areas of activity would be particularly valued in delivering this service.

d) Administrative help: This is related to support with filling out forms, making appointments or phone calls, providing reminders of scheduled visits.

Given the complexity and variety of services and functions that the navigator could perform, it is considered to be important that the scope of their work is coordinated with actors of the health care system and social care system. Therefore, the deployment of the navigator's actions should include coordination with these services as well as with grassroot associations.

Within this framework, the navigator and other involved actors will establish the referral pathways and the scope of their actions for accountability, also clearly defining the services involved in the intervention and adapting the type of collaboration established with key professionals in cancer prevention such as nurses, and social workers.

On a larger scale, navigators should detect suboptimal processes and areas with need for improvement on societal and political levels, function as a feedback loop in optimizing the healthcare system and **use their voice** for those having trouble speaking for themselves (i.e., advocacy).

Navigator background

Participants wished for navigators to have **a psychological, medical or social background** (e.g., in medicine, psychiatry, psychology or social care) supplemented by additional training or experience on for example coaching, grief counselling, and health buddy. Specifically, the navigator should possess knowledge and information about various types of mental health issues prevalent among the target population to enhance cancer prevention for individuals with mental health problems.

Great emphasis was placed on the navigator's personal and professional competencies and skills. In addition to formal education in the health or social-health field, the navigators should be empathic, communicative, have active listening skills, willingness to self-develop, leading a healthy lifestyle and showing a warm and engaged approach in interacting with individuals.

According to some participants, it appears that the navigation could be also delivered by a team rather than a single individual only. For instance, the aspect of facilitating access to available health and social care services would predominantly align with the profile of a social worker equipped with knowledge of available resources and capable of providing informative guidance. On the other hand, the accompaniment, education, and information service would be more closely associated with a professional who possesses competencies and soft skills as described earlier. Some participants with mental health problems reported that during group meetings and informational meetings, they would like to be informed by a doctor in addition to the navigator. Other participants mentioned that the presence of familiar health professionals, such as psychiatrists and collaborating psychologists, would strengthen their feelings of familiarity and security.

Moreover, the **involvement of peers**, i.e., people with lived experience and trained peers (e.g., experienced involvement) was strongly recommended. Having experienced mental health problems helps better understand the beneficiaries and look at various issues from the perspective of the user of mental health support and care. Furthermore, participants with mental health problems stated that they would like to have the opportunity to share personal experiences and the presentation of a lived experience by a person with mental ill-health would be very interesting where he/she would come to the educational group session precisely to tell their own story about cancer prevention.

Quite interestingly in Poland and Greece there currently already are professional profiles that could fit or easily develop into the navigator’s role. In Greece the Health Visitor is the health professional who is the main pillar of primary health care at the level of public, community and mental health services. The Health Visitor’s goal is to promote good health and prevent illness in individuals, families and the wider community, through the provision of health services at home, at school, at work and in the community in general.

In Poland there is a new profession called a ‘recovery assistant’. It is at an early stage of implementation in the Polish mental health system. A person who has experienced mental health problems and has completed specialized training can become one. A recovery assistant is a bridge between the person and his/her family and the therapeutic staff (doctors, psychologists, psychotherapists, social workers, etc.). Since this professional is already being introduced into the health care system, it should be considered an important resource when building a navigation model for people with mental health issues. It was suggested that such a person could receive additional training in navigation skills and services, specifically tailored towards cancer prevention. However, there was no shortage of voices pointing out the risks of involving people with their own experience of mental distress since it is not uncommon for a supportive recovery assistant, due to the burden of dealing with another person experiencing mental health problems, to begin experiencing a relapse.

Communication channels between users and navigator(s)

A clear finding from the co-adaptation stage across all countries is that the communication between the navigator and the programme beneficiaries should make use of a variety of means and channels to suit the specific individual circumstances and preferences.

There should be communication rules set and also consideration for factors like age or difficulties due to the nature of the mental health problem of the beneficiary or forms of impairment. Even the content of meetings and other forms of exchange should be flexible, personalised, and not one-size-fits-all.

Contact itself should be both continuous and flexible (e.g., regarding working times and preferences of people with mental health problems). Fixed consultation hours should be offered in specific sites. The regularity of meetings should be tailored to the person's needs, considering their lifestyle and cancer-related family history (genetic factors). The possibility of involving relatives and trusted persons and communicating with them should be given. Contacting people about their participation in the intervention action could start with a telephone call from a healthcare professional the person trusts.

Communications could include texts, emails, phone calls, in-person meetings and home visits. The last two are important especially for the first meeting and for those beneficiaries who do not have a supportive social circle to help with this process. Contact could be facilitated by digital solutions particularly when it comes to interacting with young beneficiaries. The possibility to have access to an electronic platform could facilitate sharing and keeping up-to-date information and health news (e.g. about access to specialists and appointments). The possibility of online consultation was particularly important for young participants of some of the focus groups in Poland. However, it was felt that online help should be possible, but only as an alternative method to support face-to-face meetings.

Although the use of health monitoring apps was discussed only in Poland the majority of participants felt that the app should not be used to measure parameters such as weight, number of hours of sleep, composition and number of meals, amount of water drunk, number of cigarettes smoked per day, extent of physical activity, social activity time. On the other hand, participants felt the app should support people in their plans to maintain a healthy lifestyle and self-development, i.e., remind them of tasks to maintain a healthy lifestyle and help them to plan these tasks. In addition, it should support preventive activities, i.e., the development of health literacy by helping to remember information on cancer prevention.

Navigator Training

Training for navigators should be adapted to the individual needs of each navigator; therefore, it could be organised as a **modular training** so as to be adapted depending on prior knowledge and experience of navigators. There were three main areas of training recommended:

Soft skills and competencies. The relationship between the navigator and the beneficiary has to be built based on trust, confidence, a sense of security and comfort. It is essential that navigators are trained in empowering and non-violent communication approaches which could include empathy, active listening, constructive feedback, self-confidence, setting boundaries in the relationship, recognising non-verbal communication, motivational interviewing, and use of accessible language.

Cancer prevention and health promotion. Within this area the topics addressed should be knowledge on cancer, for example causes, preventive measures, symptoms, types of cancers and treatment options. Moreover, navigators should have an understanding of cancer screening and prevention programmes and knowledge of cancer prevention services available in the area of interest and of how to navigate them. Navigators should also be able to educate beneficiaries on **healthy lifestyle habits** in relation to e.g., nutrition, physical activity, and substance use.

Mental health. To deliver the most effective interventions tailored to the beneficiary's needs it is important navigators have a good understanding of mental health in general as well as of specifics of the type of mental issue or psychosocial disability of the beneficiaries they will interact with. In addition, training should include **self-care management** and **resilience training** for the navigators themselves as the navigation programme may be challenging and thus impact their wellbeing.

Other beneficial training areas to consider are:

- **Overview of relevant health and social care services and other support offers and** improving/acquiring communication skills with different audiences involved in the intervention, e.g., caregivers, health professionals, and social workers. This would be needed for the navigators to foster multi-stakeholder collaboration and delivery of holistic integrated prevention, promotion and care.
- Depending on their intervention site, **specializations** should be considered for navigators (e.g., geriatrics when working at elderly care homes).

Training should be carried out cyclically and systematically so that navigators are always up to date with the latest knowledge. This is deemed particularly important in relation to cancer prevention programmes so that they are able to provide up-to-date information and recommendations to service users and guide them towards most effective intervention pathways. Training should be provided by professionals/specialists in the specific area of competence/skills (e.g., a nutritionist for training on nutrition).

Navigator Supervision

Findings from the co-adaptation activities indicate that there should be two forms of supervision:

1. The first is related to the monitoring of the intervention's implementation and progress in regard to set goals. This should be based on ongoing reporting from the navigators and other tools that will also feed into the evaluation of the programme. This form of supervision should be based on and take into account the navigator's area of competence and the nature of services provided by the navigators.
2. The second should focus on providing support to navigators in the form of guidance and counselling.

The modalities for supervision could be designed in different ways to suite the local context, programme delivery and navigators' role: team discussions, inter-vision, supervision (e.g., single and/or group, external, expert, or multi professional supervision, involvement of beneficiaries), and further training.

The possibility of creating a commission was suggested In Spain. This entity could assess the needs and difficulties that the navigator might have during their daily work. It could help navigators, guide them in the execution of their work, and could be made up of a multidisciplinary team of service users, general practitioners, oncologists, members of mental health associations, and other professionals.

Evaluation measures

Participants felt that evaluations should take place and that these could aid further development and improvement of the PNM programme. The evaluation would benefit by defining both common comparable indicators as well as personalised ones. For the latter, at the beginning of the navigation process the navigator and beneficiary should determine the **current status and set objectives** that are **relevant and specific to the beneficiary**.

The evaluation should assess three areas:

(1) the **beneficiary-navigator relationship** and interaction;

(2) the implementation of and the **patient navigation programme overall** looking at its key components, namely points and settings of the intervention, services offered, communication about the intervention, role of navigators and level of engagement of beneficiaries.

(3) the **effectiveness of the patient navigation** measuring for instance the number of preventive medical examinations and the adoption of life-style changes of participants (diet, physical exercise, cessation of smoking, etc.) and variation in the number of cancer diagnoses among people with mental health problems before and after the implementation of the intervention;

Evaluations should be conducted involving both the perspective of the beneficiary and that of the navigator through e.g., questionnaires (even anonymous), satisfaction surveys, reports and as well as personal testimonies and experiences of the participants and self-evaluation by the navigators. Moreover, in Spain it was considered it may be helpful looking for data already available that could be extracted automatically from health registry systems.

Both quantitative and qualitative focused data should be used and evaluations should be carried out when starting the programme to get a baseline, when ending the programme, and a certain time afterwards to determine sustainability. The evaluation of the programme’s effectiveness should be done after a sufficiently long period of implementation, as opposed to assessing awareness and understanding of the need for preventive actions that can be realized shortly.

In Spain it was proposed to consider the possibility of creating monitoring committees formed by representatives of the multidisciplinary team involved in the delivery of the programme to supervise/facilitate the navigator’s work, through periodic meetings, in which, in addition to coordination and supervision tasks, evaluation tasks would also be carried out, assessing qualitative aspects of the programme execution.

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