

FOCUS GROUPS: PROCEDURE AND QUESTIONS

(Last update: 25/3/2015)

This document aims to specify both formal and substantive aspects related to the implementation of focus groups in order to take advantage of these meetings and to be able to compare the results obtained by the three different groups within the consortium: Gertner Institute/Sheba Hospital (Israel), Semmelweis University (Hungary) and Parc Sanitari Sant Joan de Déu (Spain).

In relation to the formal aspects, three profiles/roles will be required to carry out the focus groups. The first one, the moderator, will be sufficiently experienced professional in managing focus groups. The moderator will supply a psychological contract, will lead the discussion, and will be able to elicit the content. The second profile, as a coordinator, will be part of the research team (e.g. a psychologist, psychiatrist, social worker, sociologist) and will be in charge of making sure that the conditions are right for the group session to proceed (e.g. available chairs, room temperature, refreshments' supply) and also making notes about the most relevant aspects emerging from the conversation. One of these two profiles has to be an expert on the subject of this study in order to be able to give the pertinent explanations and specifications about schizophrenia symptoms and treatment. Finally, a person who takes notes about the most relevant aspects emerging from the conversation (such as silences, most mentioned items, and those issues spontaneously emerged and not predicted by the research team) will be also required, although in the case of shortage of staff, this role should be played by the coordinator.

After thanking the participants for their attendance and introducing him/herself (name, profession/position and department/work unit he/she belongs to), the moderator will summarize the study, including a short description of the m_RESIST program, with special attention paid to the need for collecting first-hand information from patients, caregivers and clinicians to design an effective and useful system. A brief description of the scheduled content of each session will be also provided, and the possibility of reducing the number of meetings, if necessary, will be mentioned, in the event of all objectives been covered in advance. Next, a short description of the focus group technique will be given, explaining the need to get an unforced speech, as freely as possible and without any constraints. The moderator will explain the possibility that talks develop among participants as long as they will not form small groups, talking at the same time. After that, the moderator will be available to answer any question that can arise related to both the objectives of the study and the focus group procedure. At the end of the presentation, the informed consent as well as the socio-demographic questionnaire will be distributed among participants, stressing guarantee on data confidentiality provided by the institution.

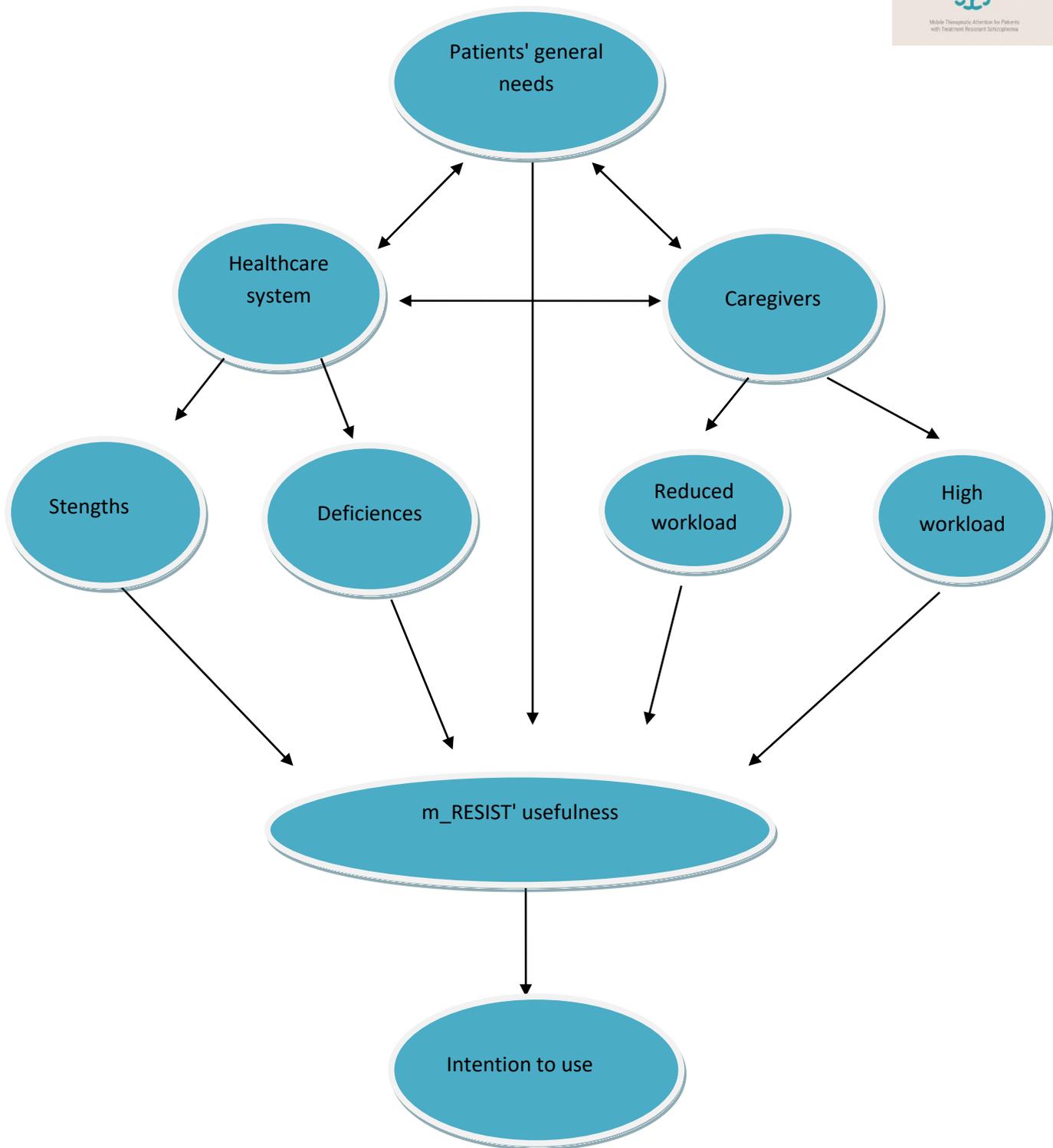
Particularly in patients and caregivers' groups, the language used by coordinator/moderator will be easily understood. Technical concepts about the treatment, the symptoms and the m_RESIST program will be avoided, using instead a more colloquial language to describe them.

As regards the substantive aspects of this document, we offer (below) a list of questions to be performed during the three different scheduled sessions. At the first one we will deal with the modules "general needs". The second meeting will be dedicated to talk about "the role played by the healthcare system" as well as about the "receptiveness towards m_HEALTH solutions". Finally, the last session will be focused on going deeply into these aspects intimately related to the program's usefulness, within the last module "Attitudes towards m_RESIST's services", through the scenarios.

With regard to the content of the different modules, as you can see, each question is followed by different possible answers or specifications on what we want to know (in italics), provided only by way of example since we will intend to recover spontaneous answers from each question. The moderator does not have to follow the order of this list, but he/she has to be sure all aspects are treated before the end of each session. Given the nature of this technique, as a qualitative tool used to compile information in a natural way, it is important that the first session will start with general questions about the needs perceived in order to get answers as spontaneous as possible; which will be registered as an initial research finding. Provided that sometimes the group conversation flows without the need to direct it, the moderator will only introduce those questions that had not emerged during the conversation, and in an appropriated way, i.e. just when they are related to some issue they are talking about.

The gender perspective is essential in this part of the study. We have to be able to identify the specific needs perceived by men and women in order to determine how the m-RESIST program can fit them. Moderators have to be capable to detect inhibition situations in men and women's speeches, avoiding the introduction of direct questions about items such as the menstrual cycle, sexuality and personal hygiene. These questions will be included in the in-depth interviews (for the specific case of male and female patients, a brief list of questions is already available and with regard to caregivers' interviews, we will have the same list of question used for the focus groups; in both cases the lists of questions will be completed with those relevant topics not sufficiently addressed in focus groups).

Definition of needs: Aspects, situations and circumstances related to the day-to-day life identified by patients, caregivers and clinicians as obstacles to improving patients' quality of life (i.e. to have a more satisfactory life/ feel better/ be happier).



PATIENTS

GENERAL NEEDS

1. What kind of activities do you do in your day-to-day life? Could you identify the three most important ones?

(Before introducing specific questions about the disease, it is important to know the participants' profile since differences perceived on their daily needs will be strongly related to this). Patients will be classified in two categories:

- *Highly active patients: Those who deal with housework (or a part of them) and also do any daily activity aimed at developing their professional aptitudes (e.g. a job, training courses) and/or their physical skills (e.g. doing exercise)*
- *Patients with low levels of activity: They do not do any housework. They also do not do any relevant activity to improve/increase their physical or mental skills.*

2. What do you need in your daily life in order to feel better/improve your health?
(Personal needs detected by patients concerning the illness). We will record 3 different answers, spontaneously mentioned or included in this list:

- *Needs related to health: symptoms (including self-destructive behaviour and heteroaggressivity), treatment, psychotic outbreaks, morbidity, healthy habits (diet, physical conditions), substances consumption (e.g. drugs, alcohol, tobacco), cognitive deficits: problems to stay focused, memorize, plan tasks...*
- *Problems concerning day-to-day tasks: housekeeping, personal hygiene...*
- *Deficits focus on family and social environment: lack of relationships/loneliness*
- *Lack of professional development: problems to find or maintain a job, to improve the educational level*
- *Lack of leisure activities: sports, going out, travels...*
- *Economic needs*
- *Other*

3. Who do you trust to talk about your needs?

To measure the degree of trust placed in caregivers and healthcare staff. Attention will be paid to find out the main confidant. Possible answers:

- *caregivers and family members with a daily contact*
- *Clinicians and other members of the healthcare staff: social workers, psychologists, psychiatrists, nurses...*
- *Other people suffering from schizophrenia*

4. Why do you not tell anyone about your needs?

(This question will be asked only if more than one participant state that they do not tell anyone about their needs, in order to go deeply into the reasons for this). We will record 3 different answers, spontaneously mentioned by participants. Possible answers:

- *You do not trust anyone to talk about your needs*
- *You fell that you do not have anyone to talk about them*

- *You think no one is interested in your needs (we will try to record any unpleasant experience with any member of the healthcare team, as well as with caregivers)*

5. How do you think your day-to-day needs can be met? Who make the largest contribution in order to meet your needs?

(The most relevant profiles can be included in different services/applications provided by the m_RESIST). The 3 most mentioned answers will be recorded. Attention will be paid to identify the most important person/units/services in providing assistance: caregivers, members of the healthcare team, day hospital, rehabilitation service)

6. What does your caregiver do in order to minimize or meet your needs?/What should your caregiver do to improve the assistance provided?

(Deficiencies perceived on the attention provided by caregivers will be compiled in order they will be provided by the m_RESIST system. The 3 most mentioned answers will be compiled, spontaneously mentioned. Possible answers:

- *To perform additional tasks related to your assistance: housework, personal hygiene, company...*
- *To be more involved in the treatment: drugs administration, managing the symptoms related to schizophrenia and other diseases (morbidity).*
- *To be more independent from them*

THE ROLE PLAYED BY THE HEALTHCARE SYSTEM

1. How important is the healthcare system (including psychiatrists, psychologists, nurses, social workers...this is, all those professionals involved in your treatment) to meet your needs?

(Spontaneous answers about both the most appreciated aspects of the attention received by patients with resistant schizophrenia, and those which should be improved in order to provide a better assistance). Three different answers will be recorded, regardless of whether they are positive or negative, spontaneously mentioned or included in this list:

- *Lack of information provided by professionals/ Misinformation*
- *Opinions about the treatment prescribed*
- *Suggestions about the referral system*
- *Attitudes towards the different units/services provided by the healthcare system: rehabilitation service, day hospital, labour guidance services*

2. From your own experience, what aspects might be changed/improved by the healthcare system in order to provide you better attention?

(Deficiencies related to the attention given by the healthcare system, suitable to be solved by the m_RESIST program). Three different answers will be recorded, spontaneously mentioned or included in this list:

- *To increase the information about the symptoms, psychotic outbreaks, other diseases (morbidity).*
- *The way in which this information is provided: if professionals use an incomprehensible language, or if patients perceive are receiving confusing information from several members of the healthcare staff (e.g. from psychiatrists and nurses) about the same point*

- *Poor medical/psychological monitoring: related to the number of visits and their length, the supervision beyond the hospital (at home or at the residence)*

3. Suggestions to meet these deficits/needs

(We aim to know if their answers coincide with these aspects to be covered by the m_RESIST. We will record 3 different opinions, spontaneously mentioned or included in this list:

- *To provide general information about the disease, treatment, symptoms, morbidity and habits*
- *To Increase the levels of medical supervision: regarding to drugs administration, others treatments, physiological rhythms.*
- *To improve/increase communication between different professionals belonged to the health staff (psychiatrists, psychologists, nurses, social workers...) and patients.*

4. Would you like to have greater contact (to increase the contact) with any person involved in your treatment?

(To know if they are really interested in increasing the contact. Beside this, we will identify what type of clinicians/health staff members are more required by patients and to find out the reasons for this. We have to keep in mind that references to personal characteristics could be mentioned, but we will focus on recording those opinions about professional aspects). The 3 most mentioned will be recorded:

- *Psychologists*
- *Psychiatrists*
- *Social workers*
- *Nurses*
- *Monitors/community workers*
- *Others*

RECEPTIVENESS TOWARDS m_HEALTH SOLUTIONS

1. Are you confident enough using technological devices such as mobile phones, computers, tablets or smart watches as well as internet? Do you use them regularly?

(We want to know if patients are technically challenged. If she does not have any of these devices at home, but they are confident enough using them, the moderator will explain them that these devices could be provided, so the rest of the conversation will be focused on this hypothetical situation)

2. Do you use these devices in matters relating to your disease? For example, to remind you it is time to take your pills, to search for information on the internet about schizophrenia and other healthcare issues...

(We have to take into account that it is likely these devices are already being used by patients. Those who are using these devices might be more liable to use m_RESIST apps). We will record three different answers, spontaneously mentioned by patients. Possible answers:

- *My caregiver (or any family member) remind me it is time to take my pills through a phone call/sms/whatsapp*
- *I use an alert to remember it is time to take my pills*
- *I use internet to search for information about symptoms*

3. How do you think that devices such as computers, mobile phones, tablets or smartwatches could help you manage the disease?
(We seek to generate a brainstorming among participants in order to get spontaneous answers aimed at improving m_RESIST services). General Information about the sort of needs to be met, the professionals who could meet them, and the way in which this help can be provided (devices/format), will be recorded.
4. What do you think about the chance of having a website focused on schizophrenia? Which sort of information would you like to find on it?
(Three different answers, spontaneously mentioned by participants or related to these topics will be recorded:
 - *symptoms*
 - *treatment*
 - *psychotic outbreaks*
 - *morbidity diseases*
 - *healthy habits (diet, physical condition)*
 - *substances (e.g. drugs, alcohol, tobacco))*
5. Would you like to have more contact with your psychologist, psychiatrist, or any other professional involved in your treatment?
6. How do you think internet and devices such as mobile phones, tablets, computers and smart watches can help you get in touch with them?
(We are looking for spontaneous answers concerning online visits, alerts, and data collection systems)
7. Would you like to know and stay in touch with other people suffered from schizophrenia through the internet?

ATTITUDES TOWARDS m_RESIST' SERVICES

At the beginning of this part, we will try to record opinions about the usefulness perceived towards the m_RESIST services, through a scenario.

Scenario: "Alex is 30 years old, he has had a diagnosis of schizophrenia for 5 years. He has some troubles with his anti-psychotic medications, and has already tried three different kinds. Some of them caused nasty side effects, some of them seemed dangerous to him, so he stopped taking them without consulting his doctor. Recently, he has been feeling more tired and anxious, and started to think that these feelings have to do with his neighbor, who does not like him. He suspects that the neighbor might be planning to hurt him. A week ago he had a quarrel with his mother, so he doesn't speak to her and she doesn't know that he is not well. Yesterday he missed an appointment with his psychiatrist - he was just too tired and scared to take a bus to the clinic. He thought that it would be better for him to get some rest.

The next morning, at 10 a.m. he is awakened by the ringing of his Smartphone. He is participating in a new technological intervention program, called **m-RESIST**, that includes a Smartphone and a watch that he has to wear. The system "passively" records information about him, such as his record of sleep and wakefulness hours and medication intake. This information is transferred to a computer that "learns" his individual patterns, and sends him alerts as well as alerts to his treating clinicians. This program has an option for

caregivers, and her mother is connected to this system on Smartphone and receive alerts about possible worsening of her son's condition

He checks his Smartphone and sees 3 messages, another one bugging him that he forgot to take his medication another one asking him to give information about his mood today, and a missed call from his clinic, which must be because of the appointment he missed yesterday"

1. How do you think he is feeling right now? What will he do?
2. What about you? How would you react in this situation?
3. Do you consider the 3 messages suitable?
4. Now, please, have a look at the following smartwatches, similar to Alex's watch. The first model has a similar operating to a Smartphone, i.e. a lot of information and potential commands. The second one, is an intermediate situation, with limited interaction capabilities, i.e. the possibility to "control" the smart watch but in a simple way. The third watch is a "blind" smart watch, which not provide any possibility of interaction apart from switch it on/off. According to your personality and your way of life, which watch would be more suitable for you?
(Important question related to users friendliness)





5. Do you think it could be useful for you to wear one of these smartwatches night and day?
6. Apart from sleep, wakefulness hours and medication intake, these smartwatches can record information about habits related to your shape, such as physical activity and rest time. Do you find this service useful for you?
7. Now, here you are different models of Smartphone. The m_RESIST program in which Alex is involved includes an application whereby he receives alerts when he forgets to take the medication or as a visit reminder. What do you think about this service?



8. Apart from medication and visits reminders, What would you like to receive an alert for?
(Those circumstances associated to their day-to-day life will be recorded, regardless if they have to do with the treatment, such as reminders for housework)
9. Would you accept to wear a Smartphone like this during all day?
10. Alex has decided to share these alerts with his mother, because she is the person who take care of him. Who would you like to share your alerts with?
(Relevant question aimed at guaranteeing data confidentiality and increasing the acceptance of the system). Possible answers (the 3 most mentioned will be recorded):
 - *Psychiatrists*
 - *Psychologists*
 - *Social workers*
 - *Nurses*
 - *Other health staff members*

- *Caregivers*

11. Is there any sort of information you would not like to be recorded and shared with other people?

We will records spontaneous answers in relation to these aspects that patients consider might be private:

- *Sexuality*
- *Substances*
- *Voices*
- *trembling*
- *Others*

12. Apart from alerts and data storage, short messages can be provided psychologist through his Smartphone in order to calm you down, for example, when you start to hear voices. Do you think this service could be useful for you?

13. Both Smartphone and smartwatches need to be charged. Are you available to charge them? Do you prefer to take care directly of them plugging them to the power (photo1) or prefer to have a place where they could be automatically recharged (photo 2)



14. Apart from these services provided by m_RESIST program, Alex has the chance of having regular appointment with his psychiatrist or his psychologist using a webcam, without leaving home. In your case, Would you find this service suitable?

(We will compile information with regard to the degree of acceptance)

15. In your opinion, How often these visits should take place and how long should they take be?

(Answers can vary depending on specific patient' requirements, but we will get an average answer from all opinions compiled)

16. In addition, Alex has the chance of having non-scheduled contacts (within 48 hours) with his psychologist/psychiatrist or any other member of the clinician staff, if a worsening of his conditions was observed. What do you think about this possibility? Would you use it if you had the chance?

(We will get the group overall assessment about these visits: positive or negative)

17. In which particular situations should these contacts be taken?

Three different answers will be recorded, spontaneously mentioned or related to these circumstances:

- *effects derived from substances consumption*

- *if a difficulty with routine activities is experienced: concentrating, being persistent at tasks, pacing oneself, among others*

18. How long should these specific visits take?

(In this case there is no sense of asking about how often these visits have to be carried out since their number depends on the patients' needs. As regards the length, we will try to obtain an average on the basis on participants' opinions)

19. Do you believe interacting with other patients suffering from resistant schizophrenia through a virtual forum could be helpful for you? Would you like clinicians could access?

(An overall assessment about this service will be recorded as well as opinions about the chance of including members of the healthcare staff in order to solve any question related to the disease)

20. And what do you think about the chance of having a website specialized on schizophrenia available for patients like you? Should be accessible to caregivers and clinicians as well?

21. Finally, we would like to know in which mental health services/unit do you consider the m_RESIST system would be more suitable/helpful in order to meet patients' needs and the reason for this.

(To know where the m_RESIST program could be more useful. A flowchart about the mental health services provided by each institution of the consortium will be showed participants). In Spanish case, the flowchart would include these units/services:

- *Residential care: hospital, medium and long stay, sub-acute unit, supervised flats and residential services*
- *Community mental health center*
- *Day care: day hospital, rehabilitation services, vocational guidance service*

CAREGIVERS

GENERAL NEEDS

1. How is your day-to-day life as a caregiver? What are the most important activities related to it?

We will record the 3 most important activities identified, according the time they spend on doing them and the degree of mental and/or physic effort required:

- *Activities related to patient's health: symptoms, treatment, psychotic outbreaks, morbidity, healthy habits (diet, physical condition), substances (e.g. drugs, alcohol, tobacco...)*
- *day-to-day tasks: housekeeping, patient's personal hygiene*
- *Supervision of patient's daily tasks: journey to work, shopping...*

2. Apart from these activities. What do you do in your daily life?

(Taking into account that caregivers might be assisted (maybe psychologically assisted) by the m_RESIST program, we want to know if they are focused on taking care of patients or have another

activity: job or leisure activities. We will also record if these activities are considered as an additional burden or as a way of escape). The 2 most frequent activities will be compiled. Possible answers:

- Professional development: job, training courses
- Leisure activities: sports, going out...

3. What are the main needs perceived in your day-to-day life as a caregiver? Your main needs are related to...

(To identify those situations in which they need to be helped). We will record 3 different answers, spontaneously provided by caregivers or included in this list:

- Patient's health: symptoms (including self-destructive behaviour and heteroagressivity), treatment, psychotic outbreaks, morbidity diseases...
- Problems to deal with housework
- The effects of patient's substances consumption (e.g. drugs, alcohol, tobacco...)
- Patient's cognitive deficits: problems to stay focused, memorize, plan tasks
- Patient's personal hygiene
- The lack of time for your professional development: to find or maintain a job, to improve your education
- Lack of time for leisure activities: sports, going out, travels...
- Economical needs derived from the attention to patient

4. In your opinion, which are the most important patient's needs/deficits in order to improve their quality of life?

(We want to know if needs perceived by patients coincides with those identified by caregivers). We will record 3 different answers, spontaneously provided or included in this list:

- Health: symptoms (including self-destructive behavior and heteroagressivity), treatment, psychotic outbreaks, morbidity diseases, healthy habits (diets, physical state), substances (e.g. drugs, alcohol, tobacco...), cognitive deficits: problems to stay focused, memorize, plan tasks...
- Problems to deal with routine tasks: housekeeping, personal hygiene
- Family and social environment: lack of relationships/loneliness
- The need to escort patients' work/leisure activities/ shopping...
- The lack of professional development: problems to find or maintain a job, in order to improve your education
- The lack of leisure activities
- Economic needs
- Lack of information about the disease: treatment and symptoms

5. What sort of needs or problems do you identify in yourself as a result of your activities as a caregiver? *(Essential information to increase the m_RESIST effectiveness). We will record 3 different needs/problems, spontaneously mentioned or included in this list:*

- Mental problems (depression, anxiety)
- Physical problems (muscle pain, muscular diseases...)
- Lack of time to do a gainful activity/economic needs
- The lack of time for leisure activities
- Loneliness/lack of relationship

THE ROLE PLAYED BY THE HEALTHCARE SYSTEM

1. From your point of view as a caregiver, How important is the healthcare system (including psychiatrists, psychologists, nurses, social workers...this is, all those professionals involved in patients' treatment) to meet patients' needs? *Strengths and deficiencies will be recorded (Spontaneous answers about both the most appreciated aspects as regard the attention received by patients with resistant schizophrenia, and those which should be improved in order to provide them a better assistance). Three different answers will be recorded, regardless of whether they are positive or negative, spontaneously mentioned or included in this list:*
 - *Lack of information provided by professionals/ Misinformation*
 - *Opinions about the treatment prescribed*
 - *Suggestions about the referral system*
 - *Attitudes towards the different units/services provided by the healthcare system: Rehabilitation services, day hospital, labour guidance services...*

2. In your opinion, what aspects might be changed in order to improve patients' attention? *(To know in which ones the m_RESIST program might be focused). We will record 3 different needs/problems, spontaneously mentioned or included in this list*
 - *Lack of information in order to deal with the symptoms, psychotic outbreaks, other diseases.*
 - *The way in which this information is provided: using an incomprehensible language, or receiving confusing information from several clinicians/ assistance staff about the same point*
 - *Poor medical/psychological monitoring: related to the number of visits and their length, the supervision beyond the hospital (at home or at the residence)*
 - *Inadequate attention from the assistance staff: Stressing those opinions about services provided by nurses, social workers, monitors, volunteers...*

3. And related to the attention given to caregivers, what should healthcare system do in order to provide you a better assistance?
We will record 3 different suggestions, spontaneously mentioned. Possible answers:
 - *Increases in assistance staff: specifying units/areas in which is required and the reason for this*
 - *Changes aimed at improving care-givers' knowledge/skills about symptoms, treatment...*

4. Would you like the patient had a more regular contact with any person involved in her/his treatment?
(The objective is to know what type of clinicians/health staff members are more required by caregivers and to find out the reasons for this. We have to keep in mind that references to personal characteristics could be mentioned. We will focus on recording those opinions about professional aspects).The 3 most mentioned will be recorded:
 - *Psychologists*
 - *Psychiatrists*
 - *Social workers*
 - *Nurses*

- *Monitors/community workers*
- *Others*

RECEPTIVENESS TOWARDS m_HEALTH SOLUTIONS

1. Are you confident enough using technological devices such as mobile phones, computers, tablets or smart watches as well as internet? Do you use them regularly?
(We want to know if caregivers are technically challenged. If they do not have any of these devices at home, but they are technically challenged using them, the moderator will explain that these devices could be provided, so the rest of the conversation will be focused on this hypothetical situation)
2. Do you use these devices in matters relating to the disease? *For example, do you use an alert to remember it is time to give patient the pills, or the internet to search for information about schizophrenia, among others*
(We have to take into account that it is likely these devices are already being used by caregivers. Those who are using these devices might be more liable to use m_RESIST apps). We will record three different answers)
3. Would you like to have more contact with the psychologist, psychiatrist, or any other professional involved in patient's treatment?
4. How do you think internet and devices such as mobile phones, tablets, computers and smartwatches can help you get in touch with them?
(We are looking for spontaneous answers concerning online visits, alerts, and data collection systems)
5. Do you search information about schizophrenia on websites? What specific information do you search for?
(We intent to know caregivers' familiarity with ICTs when it comes to seeking information about the disease since it is likely that those caregivers who are used to seeking information online will be more receptive to use the services provided by m_RESIST). Three different answers will be recorded, spontaneously mentioned or included in this list of topics:
 - *symptoms*
 - *treatment*
 - *psychotic outbreaks*
 - *morbidity diseases*
 - *healthy habits (diets, physical state)*
 - *Substances (drugs, alcohol, tobacco...)*
6. Do you search information about any specific aspect related to your role as a caregiver? What sort of information do you search for?
 - *Diseases (physic and mental) derived from that role*
 - *Social problems: lack of time for leisure activities*

- *The impact of substances consumptions in family and social environment/how to manage the abuse*
- *Others*

7. What do you think about the chance of having a website focused on schizophrenia? Which sort of information would you like to find on it?

(Three different answers, spontaneously mentioned by caregivers or related to these topics will be recorded:

- *symptoms*
- *treatment*
- *psychotic outbreaks*
- *morbidity diseases*
- *healthy habits (diet, physical condition)*
- *the impact of substances consumptions in family and social environment*
- *substances (e.g. drugs, alcohol, tobacco))*

ATTITUDES TOWARDS m_RESIST' SERVICES

At the beginning of this part, we will try to record opinions about the usefulness perceived towards the m_RESIST services, through a scenario.

Scenario: "Susan is 50 years old; he has a 25 year old son, Leonard, who had his first psychotic episode at the age of 18.

Leonard lives in a separate apartment, with a roommate. It's very important for him to lead an independent life and he refuses to receive help from the government and be defined a "mentally disabled" person. Unfortunately, his symptoms are not completely under control and every once in a while he starts thinking that the daily news host is trying to insert dangerous thoughts into his mind. These thoughts are terrifying and devastating for him, and when they come, he usually takes a small bag with few things, and leaves his apartment for a couple of days, trying to calm himself down in a less stressful environment. He does not bother to notify his employers, or ask for several days off, and has lost three jobs as a result of this behavior. He is ambivalent towards his antipsychotic medication, and takes them reluctantly. Only if his mother calls him twice a day to remind, sometimes convince him to take them.

Susan is constantly worried about his son and has to support him financially. Leonard's attitude towards mental health professionals in general is suspicious and hostile. He is willing to talk to a psychologist, but does not want to go to the clinic. He has very minimal face-to-face social contacts and most of his free time is dedicated to computer games, internet chats and social networks.

Susan has heard about a new technological intervention program, called m-RESIST, that includes a Smartphone and a watch for patients to wear, and enables psychotherapeutic and case management interventions using web-camera. The system also allows enables non-scheduled contacts with professional case managers (psychiatrist/psychologist) that are available during business hours (in Spanish case: from 9 a.m. to 5 p.m.) through a mobile message to providing support and focused interventions. There is also an option for Susan, as his mother' caregiver, to be connected to this system on Smartphone and receive alerts about possible worsening of his son's condition. He thinks that there is a chance that Leonard might

cooperate with this kind of service, because of his love for technology. On the other hand, she is worried that this kind of device, that has to be with him all the time, and is passively transmitting personal information, is a considerable invasion of his son's privacy"

1. What do you think Leonard will do? What would you do if you were Susan?
2. Now, please, have a look to the following smartwatches, similar to Leonard's watch. As it appears in this story, these devices can collect some information to help patients maintain in good health (such as sleeping patterns, wakefulness hours, medical intake, and others). The first watch has a similar operating to a Smartphone i.e. a lot of information and potential commands. The second one, is an intermediate situation, with limited interaction capabilities, i.e. the possibility to "control" the smart watch but in a simple way. The third watch is a "blind" smart watch, which not provides patients any possibility of interaction apart from switch it on/off. According to your experience as a caregiver, which one might be more suitable for patients? Which one would your patient accept to use?
(Important question related to users friendliness)



3. Apart from information related to sleeping patterns, wakefulness hours and medical intake, these smartwatches can record data about habits related to patient's shape, such as physical activity and rest time. Do you think this service can be useful for the person you care of?
4. In order to benefit from the service provided by smartwatches, Do you think the person you care of would accept to wear one of them night and day?

5. Now, here you are different models of Smartphone, similar to Leonard's one. As you have seen in his story, the m_RESIST program includes an application whereby patients are able to receive alerts in the event of they forget to take their pills or as a medical visit reminder. Do you find this service useful for the person you care of?



6. Apart from medication and visits reminders, is there any other situation in patients' day-to-day life in which an alert might be relevant?
7. As Leonard's mother, would you like to receive an alert as well? In which specific situation?
8. Apart from you, would you like any other person would access to these alerts, for example, a member of the clinician staff?
9. Apart from alerts and data storage, short messages can be provided by Leonard's psychologist through his Smartphone in order to calm him down, for example, when he starts to hear voices. Do you think it could be useful for your patient?
10. In order to provide him/her these services, Do you think the person you care of would accept to wear a Smartphone with him/her during all day?
11. As you can see in the story, to better support Leonard it is important his psychotherapeutic could access to some information related to his disease (such as blood pressure, physical activity, sleeping patterns). recorded through Smartphone or smartwatches' applications. According to your experience as a caregiver, what sort of information should be shared with clinicians and which one shouldn't be shared with them?
12. And what do you think about Leonard' chance of having a meeting with their psychiatrist or psychologist through a webcam, without leaving home, do you think it could be useful for the person you care of?
13. From your own experience, How often these visits should take place and how long should they take be?
(Answers can vary depending on specific patient' requirements perceived by caregivers, but we will try to calculate an average from all opinions compiled)
14. And, what do you think about the Leonard's chance of having non-scheduled contacts (within 48 hours) with their psychologist, psychiatrist, or any other member of the clinician staff who can provide them support?

(We will get the group overall assessment about these visits)

15. In which particular situations should these visits be taken?
(To avoid abuses, we have to specify participants these visits are designed to deal with specific situations). Three different answers will be recorded
16. How long should these specific visits take?
(In this case there is no sense of asking about how often these visits have to be carried out since their number depends on the patients' needs. As regards the length, we will try to calculate an average on the basis on participants' opinions)
17. Do you believe interacting with other people suffering from schizophrenia through a virtual forum would be useful for Leonard? Do you consider it could be useful for the person you care of?
18. And what do you think about the chance of having a website specialized on schizophrenia available for patients and caregivers? Should be accessible to clinicians as well?
19. Finally, we would like to know in which mental health services unit do you consider the m_RESIST system would be more suitable/helpful in order to meet patients' needs and why?
(To know where the m_RESIST program could be more useful. We will record 3 different answers. To get information as clearly as possible, a flowchart about the mental health services provided by each institution should be showed). In Spanish case, the flowchart will include these units/services:
 - *Residential care: hospital, medium and long stay, sub-acute unit, supervised flats and residential services*
 - *Community mental health center*
 - *Day care: day hospital, rehabilitation services, vocational guidance service*

PROFESSIONALS

GENERAL NEEDS

At the beginning of the group we will inform professionals about the concept of "resistant schizophrenia" defined by the consortium members.

1. What do you think about this definition?

(Since our concept of "resistant schizophrenia" can be subject to clarifications and critical observations)

2. Which are the main patients' needs detected by you?

(Attention will be paid to those specific needs/aspects/situations detected by each professional profile: social workers, psychiatrists, psychologists and nurses). We will record 4 different answers (one from each profile), spontaneously mentioned or included in this list:

- *health: symptoms (including self-destructive behaviour and heteroagressivity), treatment, psychotic outbreaks, morbidity, healthy habits (diet, physical state), substances consumption (e.g. drugs, alcohol, tobacco)*
- *cognitive deficits: problems to stay focused, memorize, plan tasks*
- *day-to-day tasks: housekeeping, personal hygiene*
- *Family and social environment: lack of relationships/loneliness*
- *Supervision of daily tasks: journey to work and leisure activities, shopping...*
- *professional development: to find or maintain a job, to improve the educational level*
- *Leisure activities: sports, going out, travels...*
- *Economic needs*
- *Lack of information about the disease: treatment and symptoms*

3. And with regard to caregivers, What sort of needs do you identify in them?

(Relevant information to know those aspects in which caregivers should be monitored by m_ RESIST program. We will focus on identifying personal caregivers' needs arising from the development of their role). We will record 3 different needs/problems, spontaneously mentioned by professionals or related to:

- *Patient's health: symptoms (including self-destructive behavior and heteroagressivity), treatment, psychotic outbreaks, morbidity diseases...*
- *Problems to deal with housework*
- *Inability to manage the patients' substances abuse: both the consumption and their affects*
- *Problems to deal with patient's personal hygiene*
- *The lack of time for their professional development: to find or maintain a job, to improve their education*
- *Lack of time for their leisure activities: sports, going out, travels...*
- *Economical needs derived from the attention to patients*

THE ROLE PLAYED BY THE HEALTHCARE SYSTEM

1. From your professional point of view, which are the main healthcare system's deficits related to the attention provided to patients suffered from resistant schizophrenia?

(This information is essential in order to adjust the m_RESIST applications to these needs. Three different problems will be recorded). These deficits could be related to these issues or others spontaneously provided by participants:

- *Shortage of staff: including these units/areas in which the shortage is higher*
- *Deficits related to the lack of time for routine visits*
- *Problems on the referral system: opinions focused on the need to alter it.*
- *Deficiencies related to the kind of attention and care provided by the different members of the health staff (social workers, psychiatrists, psychologists and nurses). We will try to compile as much information as possible about deficiencies perceived (e.g. deficits mentioned by nurses related to the attention given by psychiatrists)*

2. What do you suggest to meet these deficiencies?

(General and specific proposals can be compiled from this question. Three different answers will be recorded). Possible answers:

- *Increases in staff: specifying units/areas in which is required*
- *Suggestions about a new referral system*
- *Opinions about the sort of attention and the way in which is provided by the different members of the health staff (social workers, psychiatrists, psychologists and nurses), with the attention paid to both self-improvement suggestion and those related to the attention given by the others professionals (e.g. suggestions from social workers about the attention provided by psychiatrists)*
- *Increases/improvements in the information given to patients about treatment, symptoms and health recommendations (e.g. food, physical exercise, substances consumption)*

3. And as regards the attention provided to caregivers, What should healthcare system should do in order to offer them a more effective assistance aimed at improving patients' quality of life?

- *Suggestions about a new referral system: with the attention paid in those changes aimed at improving caregivers' knowledge/skills.*
- *Increases/improvements in the information provided: about treatment, symptoms and health recommendations (e.g. food, physical exercises, substances consumption)*

RECEPTIVENESS TOWARDS m_HEALTH SOLUTIONS

1. Are you confident enough using technological devices such as mobile phones, computers, tablets or smart watches as well as internet in your day-to-day life?

(We want to know if professionals are technically challenged. If they do not have any of these devices at home, but they are confident enough using them, the moderator will explain that these devices could be provided, so the rest of the conversation will be focused on this hypothetical situation)

2. Do you use these devices in the course of your work?

(Through this question we will get information about the use of ICTs with patients, this is, the type of services used and the usefulness given: to remind them a visit, to ask them about their progress with the

treatment... Those professionals who are using these devices might be more liable to use m_RESIST apps. We will record three different answers)

3. Would you need to have more contact with patients suffered from resistant schizophrenia?
4. How do you think internet and devices such as mobile phones, tablets, computers and smartwatches can help you get in touch with them?
5. Do you know if patients search for information about schizophrenia on websites? What specific information do they search for?
(We intend to know if the use of the internet is widespread). Three different answers will be recorded, spontaneously mentioned or included in this list of topics:
 - *symptoms*
 - *treatment*
 - *psychotic outbreaks*
 - *morbidity diseases*
 - *healthy habits (diets, physical state)*
 - *Substances (drugs, alcohol, tobacco...)*
6. Which sort of information do you think should be on a website focused on resistant schizophrenia?
Three different answers will be recorded, spontaneously mentioned by participants or related to these topics:
 - *symptoms*
 - *treatment*
 - *psychotic outbreaks*
 - *morbidity diseases*
 - *healthy habits (diets, physical state)*
 - *substances (e.g. drugs, alcohol, tobacco)*
 - *sexual dysfunctions*
 - *Others)*
7. Would you deem necessary to include specific information/advises for caregivers in the website? What sort of information would you include?
(We want to know how important caregivers' role is from professionals' point of view in order to include specific information for them. We will record 3 different answers, spontaneously mentioned by participants or related to these topics:
 - *About symptoms*
 - *treatment*
 - *psychotic outbreaks*
 - *morbidity diseases*
 - *healthy habits (diets, physical state)*
 - *substances (e.g. drugs, alcohol, tobacco)*

ACTTITUDES TOWARDS m_RESIST's SERVICES

At the beginning of this part, we will try to record professional's opinions about the usefulness perceived towards the m_RESIST services, through a scenario.

Scenario: "The patient is a 21-year old male who had started the use of various substances at the age of 12. At the beginning of his substance use career he used alcohol, but since the age of 15 years also cannabis several times a month. The patient was hospitalized for the first time at the age of 19 due to fears and aggressive symptoms related to a recent use of amphetamines. The psychotic symptoms lasted for two weeks and were accompanied by considerable deterioration of functioning. The patient had paranoid ideations at discharge and met the diagnostic criteria of DSM-IV schizophrenia.

The patient loves to use modern mobile technology, so when he heard about the new experimental project in his clinic, called m-RESIST, that includes a Smartphone and a watch for patients to wear, and enables psychotherapeutic and case management interventions using a web-camera, he asked for participation. The system also allows enables non-scheduled contacts with professional (psychiatrist/psychologist) that are available during business hours (Spain: from 9 a.m. to 5 p.m.) through a mobile message app. to providing support and focused interventions. There is also an option his caregiver to be connected to this system on Smartphone and receive alerts about possible worsening of his condition.

He decided to join it, and got a Smartphone and a watch, that enabled him to contact clinicians between appointments, when he felt a need to do so. In addition, this program sends him a message two times a day with reminders to take his medications, and sometimes asks him to fill in some personal information.

One week before the encounter with his psychiatrist/psychologist the patient got a message on reception and consulting hours. The patient accepted the meeting. He could also send text messages to them. Patient-patient interaction was also possible via the program.

Next month because of the escalation of the reported hallucination his psychiatrist prompted an online visit on skype/or equivalent electronic devices. After this intervention the level of stress and the frequency of hallucinations were reduced.

In another occasion he was extremely bothered by voices and he rated the voices powerful and the voices were giving orders. A personalized thought-challenging message was sent about the power of voices: "Maybe voices do not have power over you". Then he received a behavioral coping or behavioral experiment suggestion, for example "do not follow the orders of voices! Try doing what you find reasonable despite the voices!"

In his social network ratings all of his alters were rated untruthful. His social activity reduced to zero. Then he stopped to use his mobile devices. His family members were alerted and an appointment was scheduled with his psychotherapist/psychiatrist"

En aquest cas la tecnologia s'adapta a les necessitats del pacient. No obstant això, els últims missatges enviats al pacient potser podrien haver emfatitzat la necessitat de contactar amb el psiquiatre / psicòleg, en lloc de tractar de minimitzar l'impacta de les veus

1. If you were this patient's treating clinician, what would be your thoughts about this program?

2. What do you think about the chance of managing interventions using a web-cam? How often these visits should take place and how long should they take be?
3. And about the chance of having non-scheduled contacts (within 48 hours) with professionals if a worsening in patient's conditions is observed?
4. How long should these specific visits take?
5. The watch used by the patient is able to collect information such as sleeping patterns, wakefulness hours, medication intake, blood pressure, and others. There are three different watches available for patients. The first watch has a similar operating to a Smartphone i.e. a lot of information and potential commands. The second one, is an intermediate situation, with limited interaction capabilities, i.e. the possibility to "control" the smart watch but in a simple way. The third watch is a "blind" smart watch, which not provides patients any possibility of interaction apart from switch it on/off. Which one might be more suitable for patients? Do you think patients would accept to use them? Do you think patients would accept to wear one of these night and day?
(Important question related to users friendliness)



6. Apart from sleep patterns, wakefulness hours and medication intake, these smartwatches can record information about habits related to patient's shape, such as physical activity and rest time. What do you think about this possibility?
7. Now, here you are different models of Smartphone. The m_RESIST program in which the patient is involved includes an application whereby they receive alerts when they forget to take the medication or as a visit reminder. Do you think about this service?



8. Apart from medication intake and visits reminders, In which situations could be useful an alert?
(Those circumstances associated to their day-to-day life will be recorded, regardless if they have to do with the treatment, such as reminders for housework)
9. Do you think patients would accept to wear a Smartphone with them during all day?
10. The m_RESIST program includes the possibility to share the alerts with other people. Do you think alerts ought to be shared? Who with?
(Relevant question aimed at guaranteeing data confidentiality and increasing the acceptance of the system). Possible answers (the 3 most mentioned will be recorded):
 - *Psychiatrists*
 - *Psychologists*
 - *Social workers*
 - *Nurses*
 - *Other health staff members*
 - *Caregivers*
11. How many alerts do you think patients should receive a day?
12. Apart from alerts and data storage, short messages can be provided by the psychologist/psychiatrist through a Smartphone in order to calm patients down, for example, when they starts to hear voices. Do you think it could be useful for your patients?
13. Both Smartphone and smartwatches need to be charged. Are you available to charge them? Do you prefer to take care directly of them plugging them to the power (photo1) or prefer to have a place where they could be automatically recharged (photo 2)



14. Do you believe interacting with other patients suffering from resistant schizophrenia through a virtual forum could be helpful for patients? Would you like to access?
(An overall assessment about this service will be recorded as well as opinions about the chance of including members of the healthcare staff in order to solve any question related to the disease)
15. And what do you think about the chance of having a website specialized on schizophrenia available for patients? Should be accessible to caregivers and clinicians as well?
16. Finally, we would like to know in which mental health services/unit do you consider the m_RESIST system would be more suitable/helpful in order to meet patients' needs and why?
(To know where the m_RESIST program could be more useful. A flowchart about the mental health services provided by each institution of the consortium will be showed participants). In Spanish case, the flowchart would include these units/services:
- *Residential care: hospital, medium and long stay, sub-acute unit, supervised flats and residential services*
 - *Community mental health center*
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