



MasterMind

Deliverable D4.5

Patient Advisory Board Final Feedback

MASTERMIND

“MANagement of mental health
diSorders Through advancEd
technology and seRvices –
telehealth for the MIND”

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This document details the final response and feedback from the Patient Advisory Board to requests for information made from within the MasterMind project.

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EXECUTIVE SUMMARY

This document provides details of the final feedback provided by the Patient Advisory Board to specific requests for information and answers to questions posed by Work Package Leaders, trial sites, or other members of the MasterMind consortium.

It also presents some potential conclusions and observations that can be made from the feedback. To place the feedback in context, the document also describes the management, operation, and membership of the board.

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1 Introduction

1.1 Purpose of this Document

Work Package 4 of the MasterMind project required the establishment of three Advisory Boards: Patient, Professional, and Committed Regions. These boards bring together individuals and organisations with expertise and experience with the aim of providing the Project Team and MasterMind consortium with:

- Feedback, advice, and support that will help increase the general applicability, acceptability, and usability of the solutions selected for the trials and the results from the project.
- Disseminate information and results from MasterMind while raising awareness of eMental health at European, national, and local levels.

This deliverable provides details and analysis of the feedback received from the Patient Advisory Board. It also provides information on the operation and management of the Board and its membership; this information is provided so that the context for the feedback can be better understood and appreciated.

1.2 Glossary

cCBT	Computerised Cognitive Behavioural Therapy
ccVC	Collaborative Care Video Conferencing
GAMIAN-Europe	Global Alliance of Mental Illness Advocacy Networks-Europe
WP	Work Package

2 Purpose of Advisory Board

2.1 Role of Advisory Board

The Patient Advisory Board's primary role was to provide advice and guidance from a patient perspective when requested by Work Package Leaders, the trial sites and other members of the consortium. The process of making a request was facilitated through a standardised request process allowing the consortium to ask specific questions on topics where they think a patient's contribution would be of value.

The secondary objective was to receive information and learning, and disseminate this within their membership and networks across local, national, and European levels.

2.2 Advisory Role

The advisory role of the Board allows for an exchange of information between MasterMind and an external, independent source of knowledge and experience. This enables specific advice and feedback to be gained from a different perspective. Feedback is provided on a range of topics and covers the many questions and issues that are discovered during the implementation and running of cCBT and ccVC services.

The advice offered is from the patient's point of view, and provides a unique insight into how patients respond and react to types of treatment, methods of communication, and the overall patient experience.

3 Management of Advisory Board

3.1 Responsibility

The Patient Advisory Board was managed and chaired by GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks-Europe).

GAMIAN-Europe represents a coalition of patient organisations, and represents the interests of persons affected by mental illness, while advocating for their rights.

3.1.1 About GAMIAN Europe

GAMIAN-Europe currently has 53 member associations spread across 25 countries.

It provides information and support through educational seminars, newsletters, and conferences across Europe, while facilitating dialogue between patient organisations and other interested bodies, to exchange information and ideas. An up-to-date, accessible website is used to share experiences and examples of good practice across professional and patient organisations.

3.2 Operation

3.2.1 Running of the Board

Members of the Board maintained contact throughout the year by email. In addition to this, the Patient Advisory Board met face-to-face a minimum of once a year around the GAMIAN annual convention held in September.

During these meetings, Board members were updated on new developments, previous activities, key learning points, and results from MasterMind. All requests for advice from MasterMind were discussed and reviewed, and feedback was provided. In addition, dissemination activities carried out in recent months were discussed and evaluated.

Throughout the year, members were informed on an on-going basis through: the research page of the organisation website; a MasterMind quarterly newsletter produced by GAMIAN; and messages posted on the GAMIAN-Europe Facebook page and Twitter.

3.2.2 Making a Request for Information

All requests were made through the Advisory Boards' Co-ordinator based in NHS 24, Scotland. This co-ordinator acted as a single point of contact to facilitate access between GAMIAN and the rest of the MasterMind consortium.

When a request was made, a simple "Request Form" was completed containing the topic for discussion, and the relevant questions to be answered. This was then submitted to the Patient Board via GAMIAN with any appropriate documentation, e.g. training materials. GAMIAN was then responsible for collating the feedback and ensuring that the completed request was returned to the Advisory Board Co-ordinator, and from there back to the original requester.



The central point of contact, and simplicity of the request form, enabled consistency across the potential range of topics / questions that could be asked, and ease of access for those making requests.

4 Advisory Board membership

4.1 Recruitment

Members of the Patient Advisory Board are representatives from within associate organisations of GAMIAN-Europe who have a particular focus on depression.

11 members were recruited, the first five nominees in May 2014, and the remaining by September 2014.

4.2 Membership

The members have been recruited from 11 associations in 11 countries across the EU. See the table below for details:

Name	Region Represented or Role
Erik Van der Eycken	Assistant-Research Projects (GAMIAN)
Paul Arteel	Secretary (GAMIAN)
Pedro Montellano	Portugal
Hilkka Karkkainen	Finland
Rebecca Muller	Belgium
Jacinta Hastings	Ireland
Bert Aben	Netherlands
Marthe Lokken	Norway
Urve Randmaa	Estonia
Muazzez Merve Yüksel	Turkey
Hakan Wingren	Sweden
Raluca Nica	Romania
Ausra Mikulskiene	Lithuania

5 Dissemination

5.1 Dissemination Activities

Dissemination activities occurred regularly throughout the MasterMind project. The activity has been co-ordinated and facilitated by the chairing organisation of the Patient Advisory Board, and utilised the various different media available to that organisation, including websites, social media, and attendance at conferences. Dissemination activity has occurred in 53 patients associations across 25 countries.

The key dissemination activities have included:

- Regular updates to the GAMIAN-Europe website MasterMind page throughout the duration of the project: <http://www.gamian.eu/project-category/mastermind/>.
- Posts and feedback provided through the GAMIAN-Europe Facebook page: <https://www.facebook.com/GAMIAN.Europe>.
- Newsletters were issued in May 2014, February 2015, July 2015, November 2015, February 2016, May 2016, and September 2016.
- Patient Advisory Board meetings held once a year; the last meeting was in October 2016.

6 Feedback

6.1 Requests for feedback

Through the project, a number of requests have been made by Work Package Leaders, trial site leaders, and other consortium partners in the aim of developing a greater understanding on key aspects of the use of cCBT and ccVC in the context of mental health.

The requests covered a range of topics, from specific to more generalised, and included:

- Feedback on the project's "Dissemination Plan".
- Review of "Training Material" provided by WP5 partners.
- Communication with patients.
- Barriers to treatment.
- Engaging with patients in treatment.
- Key priorities of treatment.
- Acceptability of the use of technology in mental health.
- Advantages and disadvantages of using technology.
- Accessing patient associations.

6.1.1 Acceptability of treatment

Feedback was requested to develop an understanding on what could be done to ensure that patients would consider the use of technology, for example, online computerised therapy or video conferencing, as an acceptable treatment option.

The feedback from the Advisory Board explained that a trusted healthcare professional was needed to inform and convince patients from the very start of treatment that it will make the patient's life easier.

Personal contact with an 'expert' or a therapist to explain how these services function is required. This is needed to provide a 'human' face to these kinds of services, providing reassurance, and to inform patients of the key benefits of cCBT treatment or the use of VC in the therapeutic setting.

6.1.2 Barriers to treatment

The Patient Advisory Board identified a number of barriers that would inhibit the use of eMental Health services including:

- The lack of awareness of this kind of treatment.
- Not having enough information about the services around their benefits to patients, the evidence, and the support offered when completing the treatment online.
- Lack of guidance by a professional through the course of treatment would increase the chance of drop-out and reduce patient engagement with the programme.
- Patients who prefer face-to-face treatment, and their concerns about these therapies replacing treatment with psychologists and psychiatrists.

6.1.3 Maintaining patient engagement

The MasterMind services have highlighted the continual need to maintain engagement with the patients throughout the treatment to ensure higher levels of compliance and completion. The Patient Advisory Board was asked what could be done to better support and engage with patients while they completed their treatment.

From the feedback, it became apparent that the introduction to the services is key to ensuring patients' engagement in treatment. The services being introduced by a reliable healthcare professional, such as a GP or therapist, will mean that the patient is more likely to believe that cCBT or ccVC will help.

Having a facilitator or peer advocate to encourage and support patients during treatment in conjunction with the provision of appropriate information and education about the services is important to create and maintain engagement.

The freedom when completing cCBT is also an important aspect in maintaining engagement. The knowledge prior to treatment that patients can complete it at their own pace, and that treatment is time-limited, will motivate them and increase the likelihood of completion.

Patients will remain more engaged in treatment if they can track an improvement in their symptoms and mood while monitoring their progress through the cCBT programme. Reduction of symptoms and changes to mood is inspiring to patients, and ensures engagement. Sharing the learned knowledge with close relatives will also help to encourage patients to use cCBT tools more often, and provide positive feedback and support.

6.1.4 Communication

As the feedback detailed above has shown, the provision of information and communication about services is important to ensure that patients accept and engage in both cCBT and ccVC services.

Feedback from the Patient Advisory Board around communication highlights:

- All communication should use easy, understandable language.
- It should be clear who the information is relevant for in terms of age and condition.
- Language and tone of the text used should respect the patients' experience, and an understanding of their condition, while avoiding a patronising tone.
- Acronyms such as cCBT should not be used, and if used, be given a full explanation.
- Use of clinical terms should be avoided, or if used, at least placed in a context.

The members of the Patient Advisory Board also recommend that when possible it is useful to have patients themselves provide information rather than the academic / clinical community.

To ensure that patients can access the information, it is important to use different channels of communication; not every patient has access to just one type of communication channel, and providing leaflets in GP surgeries and other health outlets, e.g. pharmacies, is helpful to create awareness of services.

Within the information, it is important that patients are provided with the relevant contact details of their local service provider and/or research co-ordinator. This allows them to follow up on information through direct contact or through project / service websites.

6.1.5 Priorities of treatment

For services utilising VC:

- Sessions should only be run when privacy is guaranteed.
- The video-conferencing technology should be flawless and easy to use.
- All software installed and running should be guaranteed by the system administrators and providers.
- Internet connection in 100% protected network.

For cCBT:

- The questions / exercises should start with some kind of 'self-scanning', so that the programme becomes 'customised' to the individual user.
- Regular access to therapist or support.
- Security of data within programme.
- Ease of access and use.

6.1.6 Impact of technology

The cCBT or VC technology used has a direct impact on the success of the services being provided, with the style, delivery, and technical specifications impacting on patient access to and engagement with treatment.

Services need to reassure patients in relation to data security, as there may be a lack of "trust" in the internet and the secure transfer of data that by its nature can be sensitive patient information. There is also a need to overcome a feeling within patients of 'big brother is watching us'; this can be achieved through the provision of the correct information before the start of treatment.

Any technical difficulties experienced by patients when completing cCBT will discourage patients and may lead to treatment drop-out. Patients perceive technical difficulties as a personal failure, and this will directly affect their levels of engagement and adherence. In addition, patients not having access to the right technology, i.e. laptops or mobile devices such as tablets, can greatly inhibit their ability to commence treatment.

Tasks or exercises completed during the course of their treatment can be demanding for patients, and may for some cause additional stress, in particular the need to find time to read and fill in the worksheets. Too much text within the presentation of the programme with not enough illustration or interactivity will also lead to disengagement from treatment.

The Patient Advisory Board was asked to rate what aspects of the cCBT programme are important. This is detailed in the table below:

Rated As	Aspects of cCBT Programme
Very important	<ul style="list-style-type: none"> • Ability to work with the programme in the patient's home environment. • Availability in different languages. • Usability / user-friendliness of the programme. • Initial contact to discuss the programme and its benefits.

Rated As	Aspects of cCBT Programme
Important	<ul style="list-style-type: none"> • Use of case studies as examples during sessions. • Monitoring of patient progress by appropriate staff.
Less important	<ul style="list-style-type: none"> • Availability on mobile devices (smart phones, tablets). • Attractive visual look of the programme. • 'Homework' between sessions to improve use of CBT techniques.

6.1.7 Advantages and disadvantages

The key advantages of technologically enabled treatment identified by patients include:

- No need to travel to hospital / therapist appointment, thus less cost.
- Through VC it is easier to have a conversation with the therapist more often, especially at moments when the need for this is high.
- Savings in terms of time and money.
- Having the chance to speak with the therapist / doctor more often.
- During a period of depression, it might be much easier to contact the doctor this way than to force yourself to go out and travel to the hospital.
- In rural areas, it is easier to be 'incognito' as a patient in order not to be stigmatised by neighbours.

The disadvantages identified include:

- No personal contact or less contact with the therapist; therefore it is important to maximise the opportunities to see the therapist when it is urgently needed.
- Innovative and recovery-oriented therapy should help, but is often not available in the countryside.
- More difficult to establish the 'click' between therapist and patient; this 'click' often makes the difference between a successful and an unsuccessful therapy.
- Getting used to going outdoors less and staying at home too much, which is not always the best 'medicine'.

6.1.8 Engaging with Patient Associations

To better inform and raise awareness within patients, it is important to engage with Patient Associations at regional and national levels. There are a number of recommendations made by the Patient Advisory Board:

- Organise regular information session(s) by specialist for groups of patients / peers while providing detailed and accessible information by means of leaflets.
- Results of research findings showing whether or not technology is advantageous should be published in medical journals / magazines.
- Present new technology during meetings of self-support groups to make it more attractive, especially for depressed patients.



- Encourage the patients' use of the internet in general, and thus lead them to new technologies for therapies. For the younger generation, use social media to exchange information on this type of therapy.

7 Conclusions

7.1 Barriers and facilitators

When reviewing the feedback received from the Patient Advisory Board, we can identify a number of potential barriers and aspects of the service development that can help facilitate the implementation and sustainability of cCBT and ccVC services within mental health.

Barriers

- Not having a technology / programme that meets the patients' needs, or is inaccessible due to the technical requirements of the products used.
- Lack of direct support from peers or clinicians when patients are commencing and completing treatment.
- Limited information, understanding, and awareness of the benefits of eMental Health within patient populations.
- How communication is presented and written.
- Perception or preference of patients for face-to-face treatment.
- Patients' concerns of the delivery of treatment over the internet or by other technological means.

Facilitators

- Ensure treatment is introduced by a reliable, trusted clinician with the appropriate knowledge and understanding of the benefits of the programmes / services.
- Ensure that the patients are supported throughout the treatment.
- Services need to ensure privacy and security, and provide reassurance of this to patients.
- Ease of access and availability of treatment or therapists through VC when the patient needs it.
- Accessibility of treatment.

7.2 Summary

The Patient Advisory Board has provided important insights into the patient requirements of technologically enabled services within mental health. The key element of the feedback is in the need to blend the right technology with the right levels of clinical or peer support offered to patients during their treatment.

It is important to ensure that implementation of the services addresses a number of key issues that the Patient Advisory Board has identified, such as the privacy of the technology, and the style and content of any communication. From the feedback, it becomes apparent that providing the correct information that educates patients about the value and benefits of services such as cCBT or ccVC is vital to the success and continued use of technology within mental health.