

Ethical Guidelines for Technology-Based Suicide Prevention Programmes WP 5

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Executive Summary

The **Ethical guidelines for technology-based suicide prevention (TBSP) programmes** outline which ethical guidelines should be considered when creating and maintaining a TBSP programme. They are part of **Work Package 5 'Development of an e-conceptual model'** of the **European Regions Enforcing Actions against Suicide (Euregenas) project** (Grant Agreement N°20101203).

The development of the Ethical guidelines is based on a literature review, an assessment of needs, existing ethical guidelines and feedback from suicide prevention experts.

The Ethical guidelines are divided into three sections according to the different forms of TBSP programmes, i.e. passive, active and interactive forms (see figure 1). The more active the forms of the TBSP programme are, the more ethical guidelines it should adhere to.

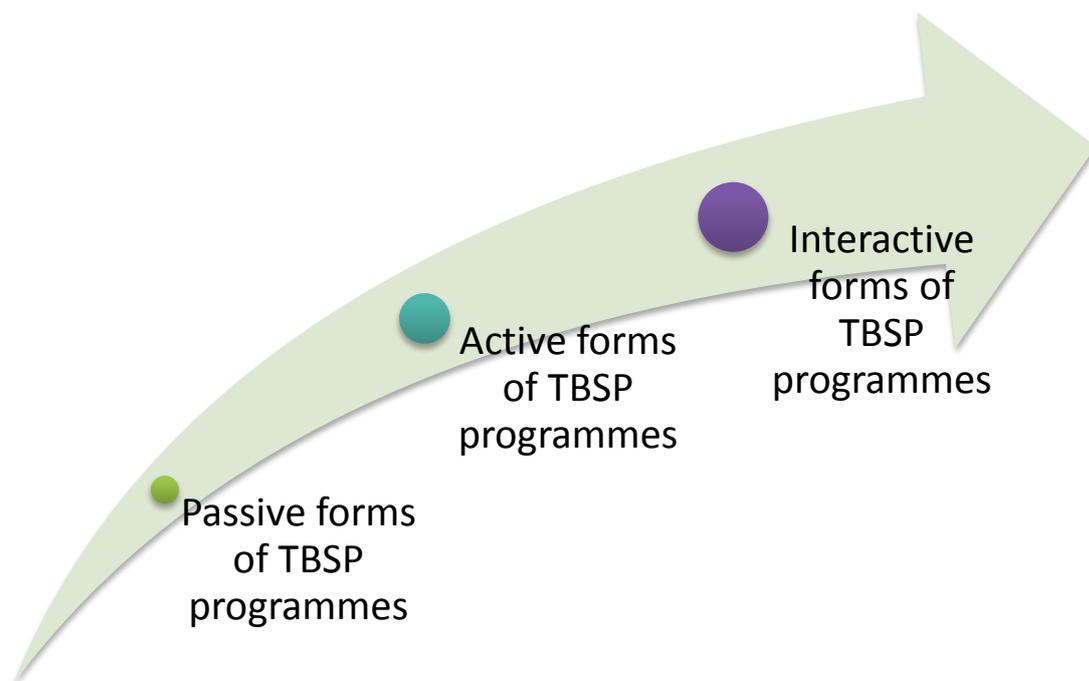


Figure 1. Different forms of TBSP programmes

WARNING:

When developing and maintaining a TBSP programme the providers should be aware that they will be dealing with suicidal persons with severe and complex problems which should not be underestimated or trivialized. Special attention is required to the vulnerable target group of a TBSP programme. The different strategies which should be used depending on the age, gender and environment of the user of a TBSP programme need to be considered.



Introduction

The Euregenas Project

Suicide is a serious public health problem worldwide. In Europe, the overall average suicide rate is 13,9 per 100.000 population [1]. The '**European Regions Enforcing Actions against Suicide' (Euregenas) project** (Grant Agreement N°20101203), financed by the Executive Agency for Health and Consumers (EAHC) of the European Commission, **aims at contributing to the prevention of suicidality** (suicidal ideation, suicide attempts and suicide) in Europe through the development and implementation of strategies for suicide prevention at regional level which can be of use to the European Community as examples of good practice (see www.euregenas.eu).

The project brings together **15 European partners**, representing 10 European Regions with diverse experiences in suicide prevention:

1. University Hospital Verona (**AOUI-VR**) - Italy
2. Flemish Agency for Care and Health (**VAZG**) - Belgium
3. Region Västra Götaland (**VGR**) - Sweden
4. Romtens Foundation (**ROMTENS**) - Romania
5. National Institute for Health and Welfare (**THL**) - Finland
6. Unit for Suicide Research, University Ghent (**UGENT**) - Belgium
7. Fundación Intras (**INTRAS**) - Spain
8. Servicio Andaluz de Salud (**SAS**) - Spain
9. Fundacion Publica Andaluza Progreso Y Salud (**FPS**) - Spain
10. Mikkeli University of Applied Sciences (**MAMK**) - Finland
11. Technische Universität Dresden (**TUD**) - Germany
12. Regional Public Health Institut Maribor (**RPHI MB**) - Slovenia
13. West Sweden (**WS**) - Sweden
14. De Leo Fund (**DeLeoFund**) - Italy
15. Cumbria County Council (**CCC**) - United Kingdom

In line with the *Second Programme of Community action in the field of public health (2008-2013)*, the project promotes the use of regional cluster management as innovative method to improve the existing services.



By encouraging regional interventions and campaigns dedicated to both target groups and non-health stakeholders, **the project aims to implement the Mental Health Pact** in relation to:

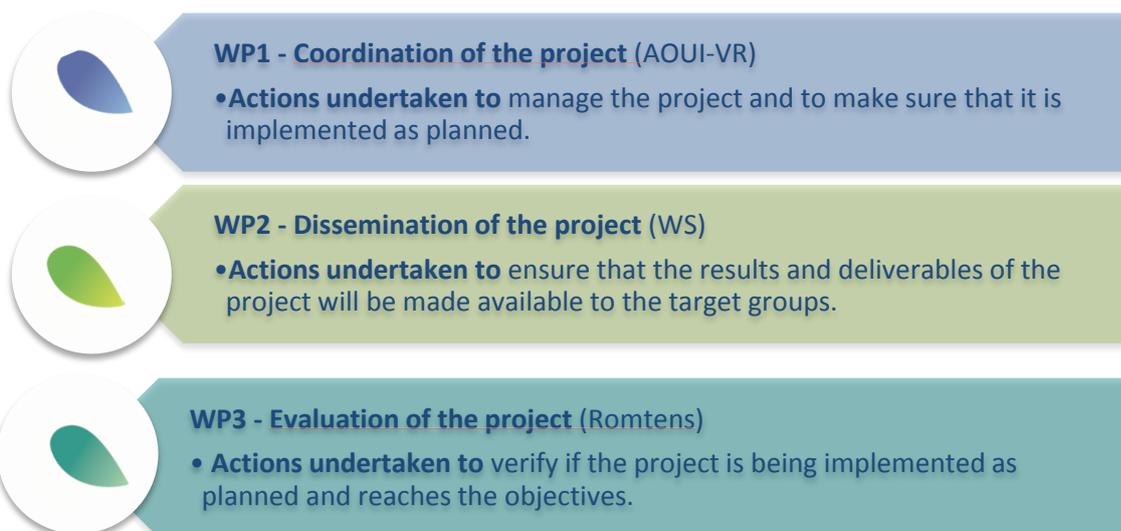
- 1) Prevention of suicide
- 2) De-stigmatisation of mental health disorders
- 3) Promoting health in youth

The **specific objectives** of Euregenas Project are the following:

1. To identify and catalogue good practices of existing actions and strategies on suicide prevention at a regional and local level;
2. To carry out a stakeholders` needs analysis;
3. To develop and disseminate guidelines and toolkits on suicide prevention and awareness raising strategies;
4. To develop the technical specifications for an integrated model for e-mental healthcare oriented at suicide prevention;
5. To improve knowledge and capabilities among local and regional professionals (i.e. psychologists, psychiatrists, GPs).

The project aims to meet its specific objectives by a **series of Work Packages (WP)**, which are structured as follows:

Three horizontal work packages:





And five vertical work packages:



WP 4 : On-Line Library and Assessment of Needs (TUD)

Aim: to develop an On-Line Library and provide an "Assessment of needs" of key stakeholders. These activities constitute the basis for WPs 5,6,7 & 8.



WP 5: Development of E-conceptual Model (VAZG)

Aim: to provide all necessary information to be able to create an integrated support and intervention mainframe for e-mental health, directed at the prevention of suicide, which can be adapted to local needs in all European regions and regional health care organisations.



WP 6: Development of Prevention Guidelines and Toolkits (UGent)

Aim: to develop general guidelines for suicide prevention strategies as well as specific prevention packages (toolkits) for the awareness raising on suicide prevention for the identified target groups.



WP 7: Development and Piloting of Training Module (AOUI-VR)

Aim: to develop a training package targeting GPs and to pilot the training package in 5 selected regions. The main goal is to provide GPs with relevant information related to the early detection and referral of suicide risk .



WP 8: Development and Piloting of evaluation tool for efficacy of support group (AOUI-VR)

Aim: to develop a toolbox for facilitators of survivors support groups. Moreover a catalogue aiming at providing information for the bereaved of suicide (including a list of groups/services available) will be compiled.



The Ethical Guidelines for Technology-Based Suicide Prevention Programmes in the Euregenas Work Package 5

Recently, technologies such as the Internet, smartphones and tablets have become available for the prevention of suicide. Technology-based suicide prevention (TBSP) programmes offer many opportunities because of the minimization of the prohibitive role of time and distance, and because of the perceived anonymity, reducing psychological barriers to seek help. Due to their high accessibility and anonymity, TBSP programmes are apparently successful in reaching out to various populations including suicidal persons. Many people may otherwise avoid conventional psychiatric or psychological services, and as such, TBSP programmes can provide much needed professional interventions [2; 3].

However, in trying to prevent suicide using various new technologies, the 'Internet paradox' [4; 5] must be taken into account. The Internet can be very helpful in preventing suicide in different ways, but it can also have a negative effect and even provoke suicidal behaviour [6]. Providers of TBSP programmes need to know which elements have to be considered when developing and offering a TBSP programme, and the users need to know which TBSP programmes are trustworthy [7]. Therefore, '**ethical guidelines for TBSP programmes**' are developed in the framework of Work Package 5 (WP 5) 'Development of an e-conceptual model' as part of the Euregenas project. The aim of WP 5 is to provide all information necessary for developing an integrated support and intervention mainframe for E-mental Health, directed at the prevention of suicide. WP 5 thus aims at developing an e-conceptual model, which can be adapted to local needs in regional health care organizations in all European regions. The 'ethical guidelines for TBSP programmes' are a part of the development of an e-conceptual model for suicide prevention. Their main aim is to guide the provider of a TBSP programme towards a trustworthy TBSP programme and to protect the user, so that s/he can use the TBSP programme with confidence and with minimum risk [8-10].



Ethical Guidelines for TBSP programmes

WARNING:

When developing and maintaining a TBSP programme the providers should be aware that they will be dealing with suicidal persons with severe and complex problems which should not be underestimated or trivialized. Special attention is required to the vulnerable target group of a TBSP programme. The different strategies which should be used depending on the age, gender and environment of the user of a TBSP programme need to be considered.

The coverage of ethical issues varies between countries, and depends on the culture and history of a community. Some countries tend to embed ethical issues in hard legislation. The example of legal harmonisation of ethical issues on privacy protection is the EU data protection legislation. However, dealing with ethical issues means also dealing with an assessment of common senses, and therefore ethical guidelines are an appropriate tool.

When developing a TBSP programme the provider has to adhere to existing laws and regulations of any regional, state, national or international entity, that apply to the TBSP programme (e.g. laws about whether or not to send emergency services to a user who is a threat to him- or herself) [11; 12]. Therefore, the 'ethical guidelines for TBSP programmes' need to be applied in addition to those laws and regulations and do not replace the existing legislation [10]. The 'ethical guidelines for TBSP programmes' are not intended to be mandatory or exhaustive, but may facilitate the development of trustworthy and outstanding TBSP programmes in an evolving and dynamic context.



Method

The following sources are used during the development of the 'ethical guidelines for TBSP programmes':

1. Literature review

The literature review encompasses recent literature on ethical guidelines and quality criteria for mental health applications and on suicide prevention, in particular online suicide prevention. The literature review is based on regional literature (from 2000 to 2013) from the Online library of WP 4 of the Euregenas project [13] and an international literature search using 'Web of Knowledge' which includes databases such as 'Medline', and 'Google Scholar'.

2. Assessment of needs

The Assessment of needs of the relevant stakeholders is part of WP 4 of the Eurgenas project. The results of the assessment of needs, in particular those regarding TBSP programmes, are integrated in the 'ethical guidelines for TBSP programmes' [14].

3. Existing ethical guidelines

Several existing ethical guidelines regarding e-mental health are consulted, i.e.:

- the Ethical guidelines of eEurope 2002 [10],
- the e-Health Code of Ethics [8],
- the HON Code of Conduct [15],
- the Suggested Principles for the Online Provision of Mental Health Services of the International Society for Mental Health Online (ISMHO, [12]),
- the ETHICAL Principles for eHealth of the European Health Telematics Association (ETHEL, [16]),
- the Hi-Ethics [17],
- the Guidelines for the practice of telepsychology [18] and
- the Guidelines for American Medical Association (AMA) Web Sites [19].



4. Feedback from suicide prevention experts

The revision process of the 'Ethical guidelines for TBSP programmes' is carried out in different phases. The Ethical guidelines for TBSP programmes are presented to the partners of the Euregenas project and, if possible, to regional suicide prevention experts. Their feedback is reviewed and adopted in the text. Subsequently, the revised text is submitted to the scientific board of the Euregenas project. Their feedback is also reviewed and results in the final version of the 'Ethical guidelines for TBSP programmes'.

Potential Users of the Ethical Guidelines for TBSP Programmes

The ethical guidelines for TBSP programmes aim at addressing providers of TBSP programmes. By adhering to the ethical guidelines the providers of a TBSP programme will ensure the protection of its users. Furthermore it will enable them to deliver a trustworthy TBSP programme.

Structure

The 'ethical guidelines for TBSP programmes' are organised according to three different forms, i.e. passive, active and interactive forms of TBSP programmes (see figure 2). One TBSP programme can include elements of one or more forms.

Passive forms of TBSP programmes allow a user only to read or look at the contents of the programme. Examples of passive forms include statistical information, advises, and 'Frequently Asked Questions' (FAQ's). Passive forms of TBSP programmes do not request active involvement from the user, require little effort, and since no personal information is left behind, the security risk is low. The threshold to use passive forms of TBSP programmes is therefore quite low. Passive forms are technically relatively simple, but may take some time to develop [20].

Active forms of TBSP programmes expect active involvement from the user, and therefore require more effort than passive forms. Examples of active forms include self-tests, chatbots, and serious games. When personal information of the user is stored, the security risk is higher than in passive forms. The development of most active forms is technically complex and time-consuming [20].

Interactive forms of TBSP programmes are characterized by interactions between users (and caregivers). Examples of interactive forms include forums, one-to-one chats, group chats, and online treatment. Interactive forms have the highest threshold for users since they require substantial effort from the user, and security risks may be high. They can be technically complex but generally need less time to develop than active forms [20].

In summary, the more active the forms of a TBSP programme, the higher the threshold for using it: the programme becomes more complex and the security risk increases.

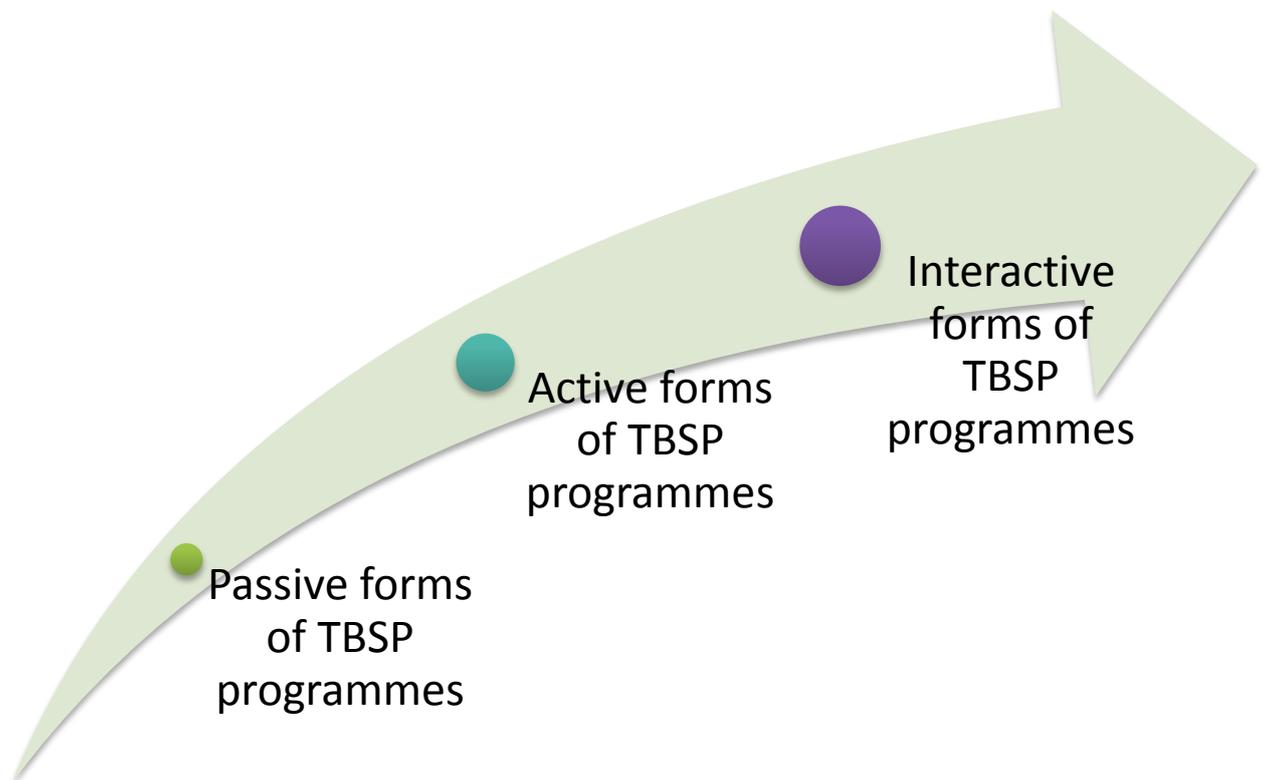


Figure 2. Different forms of TBSP programmes



Ethical Guidelines for Passive Forms of TBSP Programmes

The 'ethical guidelines for passive forms of TBSP programmes' include the following topics:

1. **Transparency**
2. **Privacy & Data Protection**
3. **Accessibility**
4. **Accountability**
5. **Quality Criteria**

1. Transparency

In order to be trustworthy, the TBSP programme should be transparent in the clearest possible way. No false information should be displayed [8-10]. Following issues contribute to transparency:

- ***Transparency of provider***

The name of the provider (i.e. organisation or person) of the TBSP programme and the physical and/or electronic address of the provider should be clearly displayed. Contact details should be available throughout the programme [8; 10; 11; 17].

- ***Transparency of objective***

The objective and purpose of the TBSP programme should be clearly stated [8; 10].



- **Transparency of information**

The information in the TBSP programme should include clear references to the authors and the source data. If possible, the TBSP programme should provide links to the source of the information [8; 15; 17].

- **Transparency of funding**

The TBSP programme should identify all contributions (i.e. funding, services, or materials) from commercial and non-commercial organisations. The user should be able to clearly distinguish advertising and other promotional material from editorial, educational or scientific content. In this way the user can decide whether or not the sponsor has a conflict of interest with the TBSP programme [8; 10; 15; 17; 19; 21; 22]. Thus, information should be provided regarding:

- *Funding*

If advertising, and sponsorships or other financial incentives are a source of funding for the TBSP programme, this should be clearly asserted, and a description of the advertising policy of the TBSP programme should be provided. This description should also include the risks and limitations of using advertising as a source of funding in the TBSP programme [8; 10; 15; 17; 19].

- *Financial arrangements*

It should be clear to the user which TBSP programme (or part of the programme) is free of charge and which is not. If the user has to pay for the TBSP programme (or part of it), fees and billing policies should be clearly explained and secure payment methods should be offered [8; 11; 12; 19]. If the use of the TBSP programme is covered in whole or partly by third-party payers, users should be informed about this as they may need to consent to releasing their protected health information [11].

- **Target population clearly specified**

Suicide prevention should be the main aim of a TBSP programme. Depending on the type of prevention (i.e. universal, selected and/or indicated [23; 24]) a target

population of the TBSP programme should be decided upon. Examples of persons who may constitute such a target population include persons at risk of suicidal behaviour (e.g., adolescents, elderly), persons with psychological or psychiatric problems, relatives or professionals dealing with someone who is suicidal, and suicide loss survivors [10]. The TBSP programme should clearly specify its target population.

2. Privacy & Data Protection

Personal data¹ gathered from a TBSP programme may be very sensitive and should be treated with great care as inappropriate disclosure of the data may have serious consequences [8]. The privacy and confidentiality of data, including personal data, should be safeguarded through complying with relevant Data Protection legislation [10].

The TBSP programme should provide a description of its policy regarding privacy and data protection, and clearly describe the procedure and timing of processing, storing, maintaining, disseminating and disposing data, including procedures that are invisible to users. The user should be informed about the security risks involved in using a TBSP programme [8; 11; 15; 17-19; 26].

If personal data are collected, TBSP programmes should:

- Inform the user about which data will be collected, how and by whom the data will be used and whether or not the data will be encrypted. Give the user the option to consent to the collection of personal data and to indicate whether or not the data can be used or shared. Explain why it is necessary to use and share the data and about the consequences of not consenting to it [8; 11; 12; 17].
- Prevent unauthorised use or access to personal data [8; 17].

¹ Definition of personal data as described in Directive 95/46/EC: “Personal data shall mean any information relating to an identified or identifiable natural person (“data subject”); an identifiable person is one who can be identified, directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity” [25].

- Give the user the opportunity to review, update or correct personal data and to ask the provider of the TBSP programme to delete his or her personal data from the database [8].
- Have tools available to examine how personal data is used, e.g. by using 'audit trails' that demonstrate where, when and by whom data was used [8].

3. Accessibility

The TBSP programme should have a high accessibility tailored to the target population, i.e.:

- It should be easy to search and find the TBSP programme when using the most popular search engines [10].
- International or European standards should be applied, wherever possible, to facilitate the interoperability between different national and international services [10].
- The TBSP programme should be adapted to different operating systems in order to be able to use it on different devices.
- The TBSP programme should be easy to use for the target population, e.g. the reading level should be adapted to the target population [8; 10].

4. Accountability

The TBSP programme should provide the user the opportunity to give feedback or ask questions about the TBSP programme. Contact details should be clearly indicated throughout the programme. If the contact details should not be used for help when feeling suicidal, this should be clearly marked and appropriate contact details for suicidal persons should be provided throughout the programme [8-10; 15; 17].

The provider of the TBSP programme should supervise the adherence of the TBSP programme to the 'ethical guidelines for TBSP programmes' [8].

- **Responsible partnering**

The organisations and websites or programmes to which the TBSP programme refers/links should be trustworthy. The TBSP programme should only partner with organisations and websites or programmes that comply with relevant ethical codes and legislation [8; 10; 19].

- **Editorial policy**

The TBSP programme should describe clearly how the selection of content was carried out [8; 10; 17; 19].

5. Quality Criteria

TBSP programmes may have a positive effect and prevent suicidal behaviour, but they can also have a negative effect and encourage suicidal behaviour [7]. The quality of TBSP programmes is of the utmost importance as to which effect they will have on its users. The more quality a provider of a TBSP programme wishes to offer, the more s/he should adhere to the quality criteria. The main aim of the quality criteria is to safeguard the quality of a TBSP programme [8-10].

The provider is responsible for the accuracy of the information. The source of the information should be clearly specified, e.g. scientific studies, expert consensus, or professional or personal experience or opinion [8; 10]. Especially when making use of experience-based information or opinions this must be clarified to the user.

The TBSP programme should provide the most up-to-date, correct evidence-based information that is comprehensible to the target population. This information should help potential users in making their judgement about the TBSP programme and its quality [8].

1. Information on Suicidal Behaviour

The TBSP programme should include **up-to-date and evidence-based information** on suicidal behaviour (e.g. risk and protective factors, warning signs, attitudes towards

suicidal persons) directed at the target population of the TBSP programme [27; 28]. The TBSP programme should clearly indicate when the information was created or last modified or updated. The content should regularly be verified and evaluated [8; 10; 17].

- If there is a description on the origin of suicidal behaviour, it should never focus on one causal factor but should rather highlight the **multiple factors** involved in suicidal behaviour [29-31].
- Considering that certain types of information can have a positive, protective effect (also referred to as '**Papageno effect**' [32]) on the users while other types of information can have a negative, provoking effect (also referred to as '**Werther effect**' [33]), the **type of information on suicidal behaviour** provided in the TBSP programme requires extensive consideration [32]. For example, a testimony in which suicidal ideation is described that was not followed by a suicide attempt or completed suicide, can have a 'Papageno effect'. A description of suicide methods may lead to contagion and can cause a 'Werther effect' [3; 34].

2. Links

Taking into account the target population of the TBSP programme, **appropriate links** should be provided. Links and contact information to emergency services and, if possible, local community resources, should be available at all times [11].

- When the TBSP programme may have users who are suicidal, there should always be a '**crisis/alarm button**' available in case the user is in distress and needs immediate help. The 'crisis/alarm button' should lead the user to appropriate help, e.g. a crisis helpline or contact details of emergency medical services. The 'crisis/alarm button' should be permanently visible and therefore easy to find when using a TBSP programme [27].



3. No Propaganda

TBSP programmes should not contain any propaganda such as pro-suicide, anti-life, or pro-life statements, as they can influence suicidal persons or discourage them. [3; 27].

4. Tailored TBSP Programmes

The TBSP programme, in particular the presentation, style and nature of the information in the TBSP programme, should be tailored to the target population [35]. For example, a TBSP programme aiming at adolescents should be different from one that aims at elderly. It should be clear to the users what the target population of the TBSP programme is. This can help the users in deciding whether or not the TBSP programme can be helpful [10].



Ethical Guidelines for Active Forms of TBSP Programmes

The 'ethical guidelines for active forms of TBSP programmes' include the following topics:

1. **Crisis Intervention**
2. **Transparency**
3. **Privacy & Data Protection**
4. **Accessibility**
5. **Accountability**
6. **Quality Criteria**
7. **Informed Consent**
8. **Professionalism**
9. **Appropriateness**



1. Crisis Intervention

When actively dealing with a high-risk population such as suicidal persons, crisis situations may frequently be encountered. Therefore, there should always be a **crisis intervention plan** available including information e.g. on how emergencies will be handled when they arise. The user should be informed about this plan [11; 12; 20; 21; 36; 37].

If the TBSP programme permits, safeguards in dealing with high-risk situations should be built-in in order to automatically respond in case of emergency by providing the user with links and contact information to emergency services and, if possible, local community resources. When information about the user's identity or whereabouts is available, this information can be used in dealing with an emergency [11].

2. Transparency

See 'Transparency' in Ethical guidelines for passive forms of TBSP programmes, p. 13.

3. Privacy & Data Protection

See 'Privacy & Data protection' in Ethical guidelines for passive forms of TBSP programmes, p. 15.

4. Accessibility

See 'Accessibility' in Ethical guidelines for passive forms of TBSP programmes, p. 16.



5. Accountability

See 'Accountability' in Ethical guidelines for passive forms of TBSP programmes, p.16.

6. Quality Criteria

See 'Quality criteria' in Ethical guidelines for passive forms of TBSP programmes, p.17.

1. Information on Suicidal Behaviour

See 'Information on suicidal behaviour' in Quality criteria, Ethical guidelines for passive forms of TBSP programmes, p.17.

2. Links

See 'Links' in Quality criteria, Ethical guidelines for passive forms of TBSP programmes, p.18.

3. No Propaganda

See 'No propaganda' in Quality criteria, Ethical guidelines for passive forms of TBSP programmes, p.19.

4. Tailored TBSP Programmes

See 'Tailored TBSP programmes' in Quality criteria, Ethical guidelines for passive forms of TBSP programmes, p.19.



5. Evidence-based Instruments

The TBSP programme should only include **evidence-based instruments** for suicide prevention in the target population [28]. These instruments such as self-tests, should be scientifically validated and verifiable in order to provide the user objective results or feedback [22].

6. Supervision by a Moderator

Since user-generated content on e.g. suicide methods can increase the risk of suicidal behaviour [32; 33], TBSP programme should be **moderated by a mental health professional** who is specifically trained in dealing with suicidal persons [38]. Potentially dangerous messages should be removed, and the user should be informed about the reason for removing the message [39; 40]. A TBSP programme moderated by a mental health professional may help reduce the risk of suicidal interactions and behaviours [38].

7. Suicide Alert Reporting System

The TBSP programme should have a **'suicide alert reporting system'**. This system allows a user to report alarming suicidal content in the TBSP programme to the provider. The provider can then react to the content by responding to it or, if necessary, deleting it [41].



7. Informed Consent

The TBSP programme should disclose all information that a reasonable person would need to make a decision on whether or not s/he wants to use the programme. The information should be about how it works, who will interact with the user, what its potential benefits and risks/limitations are, what safeguards are being used against those risks/limitations, and which other options than the TBSP programme are available to the user. The information should be in a format that the potential user can easily understand and should not, in any way, guide the user to make a certain choice [12; 16; 18]. The user should always be able to easily withdraw his/her consent when s/he wants to discontinue the use of the TBSP programme [26]. Issues that need to be addressed with regard to informed consent include:

- ***The procedure***

The procedure of the TBSP programme should be explained to the user, e.g. how it works, what can be offered to the user, what can be expected, what the timing is [12]. Particularly relevant topics include:

- *Possible misunderstandings*

The user should be informed that misunderstandings can happen when using the TBSP programme instead of face-to-face contact e.g. because of the lack of non-verbal cues [11; 12]. The caregiver should be alert for misunderstandings and should attempt to avoid them [11].

- *Turnaround time*

If the communication is asynchronous, the user should be aware that the turnaround time is mostly longer than in face-to-face contact. The user should be informed about how long the turnaround time may be [12; 39].

- *Privacy of the caregiver*

The caregiver has a right to his/her privacy. If the user makes copies or recordings of their communications, the caregiver can ask the user to restrict the use of those copies or recordings [12].

- ***The caregiver***

The caregiver should abide by the same ethical codes of his or her profession as in face-to-face relationships.

The user should receive sufficient information about the caregiver to decide whether or not s/he wants to make use of the caregiver's services [12].

- *Qualifications*

The caregiver should meet all the necessary legal requirements [8]. The requirements may depend on the location of the caregiver and even the location of the user [12; 42]. The user should be informed about the caregiver's basic qualifications e.g. degree, license, and certification. Information about special training or experience can be added [11; 12; 15; 17; 43].

- ***Potential benefits***

The user should receive information on the potential benefits of the TBSP programme. If possible, the potential benefits should be backed up by appropriate evidence-based information in a manner as is outlined in 'Transparency' [12; 17; 36].

- ***Potential risks and limitations***

The user should be informed about the potential risks and limitations inherent to the TBSP programme. Some potential risks and limitations may lead to breaches of confidentiality for example when emails or chats are hacked. The user should explicitly be cautioned that the TBSP programme complements face-to-face contact, it cannot replace face-to-face contact. The user should also be advised not to use the TBSP programme in certain situations or conditions and to rather make use of face-to-face contact. A list of those situations or conditions should be available to the

user. For example a situation in which a user should seek face-to-face help is when the user harmed himself or ingested an excessive amount of medication and/or drugs [8; 10; 12; 17; 36].

- **Safeguards**

Some potential risks can be lowered or even eliminated if the caregiver or the user takes certain safeguards. The user should be informed about such safeguards. Examples of safeguards are: using a password to access the TBSP programme, using encryption to encode messages, and requesting a 'return receipt' when an email is sent [12].

- **Alternatives to the TBSP programme**

The user should receive information about the alternatives to the TBSP programme, on- and offline. If possible, the user should be informed about local services [8; 12].

8. Professionalism

The laws, regulations and fundamental ethical obligations of one's profession should be respected as one would in face-to-face contact [8; 12; 36].

- **Requirements to practice**

The providers and caregivers of the TBSP programme should have the appropriate knowledge, skills and training to create, manage, and execute the programme [11; 12]. They should be aware of the hazards and potential benefits of TBSP programmes [7].

- **Boundaries of competence**

If the caregiver would not treat a certain problem face-to-face, s/he should absolutely not treat it online [12; 26; 36].



9. Appropriateness

Suicidal persons are vulnerable and therefore require special protection. When targeted at a certain population or age group, the TBSP programme may not be appropriate for all users [21]. Therefore, an adequate screening and/or intake procedure prior to the start of the TBSP programme is important in order to make sure that the TBSP programme is suitable for the user [43; 44]. This will help in evaluating if the user's needs will be met through using the TBSP programme [11; 12; 45]. If the TBSP programme proves to be unsuitable for the user, s/he should be referred to other appropriate help, e.g. a crisis helpline, another TBSP programme or contact details of emergency medical services.

The screening and/or intake should be recommended but should not be mandatory since it may stop potential users from using the TBSP programme.



Ethical Guidelines for Interactive Forms of TBSP Programmes

The 'ethical guidelines for active and interactive forms of TBSP programmes' include the following topics:

- 1. Crisis Intervention**
- 2. Transparency**
- 3. Privacy & Data Protection**
- 4. Accessibility**
- 5. Accountability**
- 6. Quality Criteria**
- 7. Informed Consent**
- 8. Professionalism**
- 9. Appropriateness**



1. Crisis Intervention Plan

When interactively dealing with a high-risk population such as suicidal persons, crisis situations may frequently be encountered. Therefore, there should always be a **crisis intervention plan** available e.g. on how emergencies will be handled when they arise. The user should be informed about this plan before the onset of the interactive TBSP programme and, if necessary, the plan should be discussed with the user [11; 12; 20; 21; 36; 37].

If the TBSP programme permits, safeguards in dealing with high-risk situations should be built-in in order to either automatically respond in case of emergency by providing the user with links and contact information to emergency services and, if possible, local community resources or to alert the caregiver in case of emergency and allowing an appropriate response. When information about the user's identity or whereabouts is available, this information can be used in dealing with an emergency [11].

2. Transparency

See 'Transparency' in Ethical guidelines for passive forms of TBSP programmes, p.13.

3. Privacy & Data Protection

See 'Privacy & Data protection' in Ethical guidelines for passive forms of TBSP programmes, p.15.



4. Accessibility

See 'Accessibility' in Ethical guidelines for passive forms of TBSP programmes, p.16.

5. Accountability

See 'Accountability' in Ethical guidelines for passive forms of TBSP programmes, p.16.

6. Quality Criteria

See 'Quality criteria' in Ethical guidelines for passive forms of TBSP programmes, p.17.

1. Information on Suicidal Behaviour

See 'Information on suicidal behaviour' in Quality criteria, Ethical guidelines for passive forms of TBSP programmes, p.17.

2. Links

See 'Links' in Quality criteria, Ethical guidelines for passive forms of TBSP programmes, p.18.

3. No Propaganda

See 'No propaganda' in Quality criteria, Ethical guidelines for passive forms of TBSP programmes, p.19.



4. Tailored TBSP Programmes

See 'Tailored TBSP programmes' in Quality criteria, Ethical guidelines for passive forms of TBSP programmes, p.19.

5. Evidence-based Instruments

See 'Evidence-based instruments' in Quality, Ethical guidelines for active forms of TBSP programmes, p.23.

6. Supervision by a Moderator

See 'Supervision by a moderator' in Quality, Ethical guidelines for active forms of TBSP programmes, p.23.

7. Suicide Alert Reporting System

See 'Suicide alert reporting system' in Quality, Ethical guidelines for active forms of TBSP programmes, p.23.

8. Qualified Caregivers

Only caregivers qualified through training should interact with persons who have mental health problems. The level of required training of a caregiver depends on the goal of the TBSP programme:

- When the TBSP programme aims at primary care, e.g. by helping a suicidal person through a crisis situation, a caregiver should be adequately trained in dealing with suicidal persons and in handling the technologies in which s/he delivers the care [11].
- When the purpose of the TBSP programme is to give therapy, the caregiver should have a university degree in Clinical Psychology or Psychiatry, preferably with a

psychotherapy training, and should be trained in dealing with suicidal persons and in handling the technologies by means of which s/he delivers the care [11].

In training on how to deal with suicidal persons the following items should be highlighted [46]:

1. Take all thoughts of suicide seriously
2. Ask the user directly for suicidal thoughts if you think s/he might be having them
3. Asking a user about suicide will not trigger thoughts about suicide or increase suicidal ideation.
4. When facing with a suicidal crisis, appear confident
5. State clearly that suicidal thoughts might be linked to a treatable mental health problem such as depression, bipolar disorder, and substance abuse.
6. Bear in mind the warning signs or risk factors for suicidal behaviour
7. Ask the user directly if:
 - S/he has any suicide plans
 - S/he knows how s/he would do it
 - S/he has taken steps to carry out his/her plan by securing the means to end his/her life
 - S/he chose a date or time when to end his/her life
8. Try to determine if the user used alcohol, drugs and/or medications
9. Ask the user if s/he has ever tried to kill him/herself in the past
10. Make the user feel cared about by e.g. expressing empathy
11. Let the user talk about why s/he wants to die, about his/her reasons
12. Keep reminding the user that suicide is not the only solution and that s/he does not need to act upon his/her suicidal thoughts or carry out his/her plans
13. Ask the user about his or her reasons for living as this can decrease his or her feelings of hopelessness [47; 48]
14. Try to find out what helped the user in the past to get over the suicidal thoughts and if s/he can still use this help
15. Stimulate the user to talk about his/her thoughts and feelings
16. Do not use threats or guilt to prevent the user from killing him/herself
17. Provide safety contacts when needed

18. Encourage the user to get professional, face-to-face help
19. If possible, contact emergency instances when the user seems to be a threat to himself or others
20. Do not consent to keeping the user's suicidal plans a secret
21. Always involve the suicidal user if you are planning to alert someone about his/her suicidal crisis.

7. Informed Consent

See 'Informed consent' in Ethical guidelines for active forms of TBSP programmes, p.24.

8. Professionalism

See 'Professionalism' in Ethical guidelines for active forms of TBSP programmes, p.26.

9. Appropriateness

See 'Appropriateness' in Ethical guidelines for active forms of TBSP programmes, p.27.

Conclusion

The 'ethical guidelines for TBSP programmes' are outlined according to the three different forms of TBSP programmes, i.e. passive, active and interactive. In figure 3, the topics of the different guidelines are summarized for passive, active and interactive forms of TBSP programmes.



Figure 3. Ethical guidelines for the different forms of TBSP programmes

As can be seen in figure 3, all forms of TBSP programmes have an ethical guideline about quality criteria. They differ however in the number of quality criteria they should adhere to. The more active the forms of the TBSP programme are, the more quality criteria it should adhere to. Figure 4 summarizes the different topics of the quality criteria.

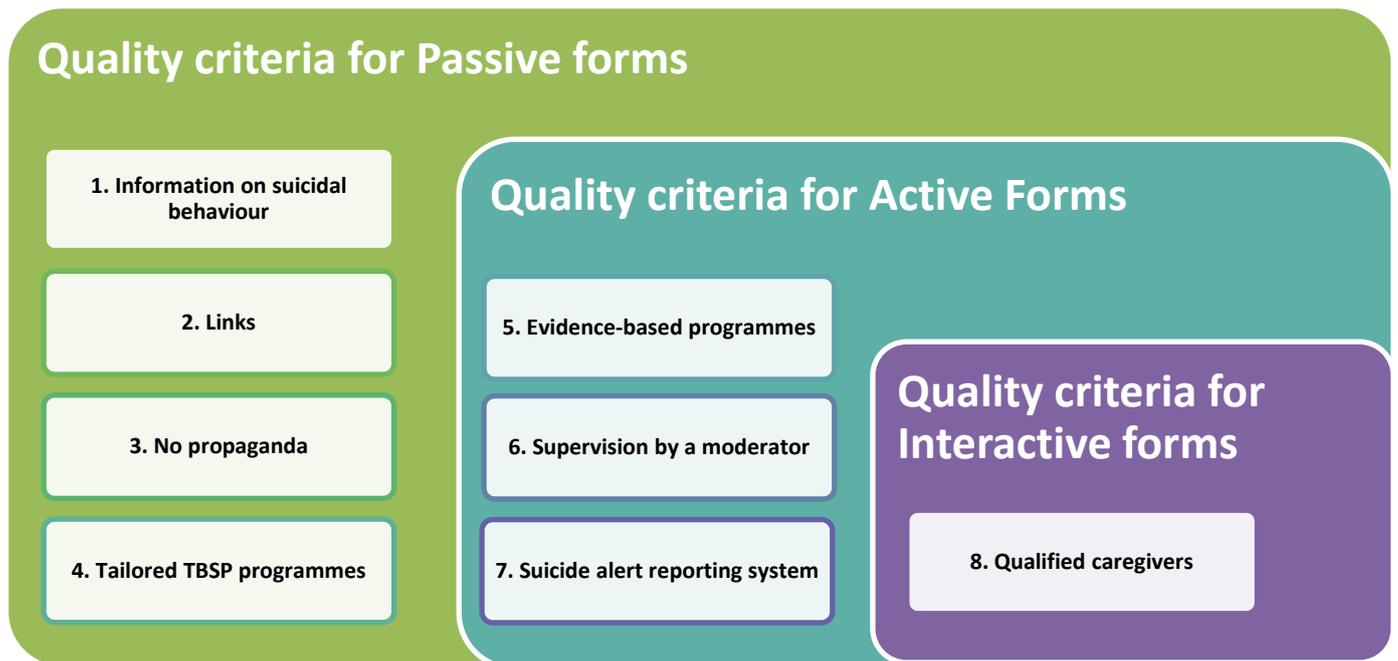


Figure 4. Quality criteria for the different forms of TBSP programmes

The 'ethical guidelines for TBSP programmes' should be used as a non-exhaustive tool towards trustworthy and high level TBSP programmes in an evolving and dynamic context.

Appendix

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