

**The C:EVOLVE Project**  
**Phase II Protocol**  
**Evaluation of an online virtual environment for counselling  
young people affected by cancer.**

**Funded by Tenovus the Cancer Charity under its 2012 Innovation Grant Scheme**

**Dr Ceri Phelps**

**Carol Hughes**

**Andy Baker**

**Dr Paul Hutchings**

**Project Research Assistant: Dr Mas Minou**

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## Summary

Tenovus the Cancer Charity have recognised a need to offer an alternative form of counselling for young people in Wales who have been affected by cancer in their lives and who do not make use of traditional face-to-face counselling. In line with advances in online therapy (also known as e-therapy or e-counselling) whereby individuals can seek and receive psychological support by a trained professional over the Internet rather than face-face, avatar-based therapy is starting to be explored within the field of counselling and psychotherapy. The aim of this research project is to identify the feasibility and acceptance of a “virtual reality counselling world” amongst young people affected by cancer in Wales. The virtual counselling world will enable young people to design their own personal avatar and to engage in a therapeutic session (through text and images) via avatars. Young people affected by cancer in their lives will be involved in all stages of the project through a Young Person Project Steering Group. The pilot project will explore uptake rates and retention for online counselling, the demographic profile of those who choose to take part in online counselling, key therapeutic outcomes and overall attitudes towards the virtual reality counselling world. If shown to be successful, the virtual reality counselling world may be adopted by Tenovus for ongoing delivery of cancer support services to young people throughout Wales with huge scope for offering a wider alternative to face-to-face counselling for all age groups.

### 1. Background

The adverse psychological impact of cancer is recognised worldwide and the high prevalence of disorders such as anxiety and depression among people affected by cancer has been well-documented (Tulsky et al. 2011). Large numbers of people are now choosing to access internet counselling online which has grown significantly in the last decade (Barak et al. 2008; Chester and Glass, 2006). Interactive online counselling provides a unique opportunity for people to access counselling services without the historical constraints of time and logistics. Online counselling can offer the user a perception of a sense of privacy and anonymity that cannot be accessed by traditional counselling (Maheu and Gordon, 2000).

Young people have been shown to be drawn to this method of therapy as they have grown up with computers and may conduct many relationships through them. Research suggests that effective therapeutic relationships can be formed with young people online (King et al. 2006; Hanley, 2012) and that it is a service which is valued and used by young people (Beattie et al. 2006). We are not aware of any other cancer charity in the UK who have already developed an online counselling service in the manner intended within this project, with most charities/support groups (including those aimed specifically at younger people) offering online support groups/forums/digital stories as distinct from delivering online counselling. Whilst most forms of online counselling for people with cancer still involve simple email exchanges (David et al. 2011), the use of avatars as a mechanism through which to achieve psychological benefit is starting to be explored in other counselling settings (Beattie et al., 2006; <http://www.Kooth.com>). It is recognised that children who have suffered from cancer often miss out on schooling and may be disadvantaged in later years in employment (Larcombe et al, 1990; Pang et al., 2008). The engagement with avatars is recognised as being familiar to most young people who are used to engaging with virtual reality computer games. Younger age groups affected by cancer have been found to have higher levels of internet use (Eysenbach, 2003) and have been found to report positive experiences from engaging with online counselling (Hanley, 2012; King et al. 2006).

Although there is an increasing body of research literature supporting the development of online counselling (Barak et al., 2008), only a few of studies have investigated the online therapeutic alliance with young people. The lack of evidence in the literature indicates the 'neglect' of the alliance in youth counselling in general (Green, 2006), but also reflects the newness of such provision. Therefore there is a need to determine the potential use of Avatar-Based counselling through a "virtual counselling world" among young people affected by cancer.

## **2. Phase II: Aims and Objectives**

The overall aim of this project is to gain pilot data on the acceptability and therapeutic value of a "virtual counselling world" for younger individuals affected by cancer. The final design of the virtual counselling world will be informed by the

ongoing input/feedback provided by the Young Person Project Steering Group which will include young people aged between 13 and 25.

The aim of Phase I was to develop a virtual avatar-based counselling world for young people affected by cancer, informed by the young people who are likely to make use of such a service. Following the Phase I period of developing and piloting the virtual counselling world the online counselling service will go live in Phase II for a maximum five-month period, seeking 6-8 young people affected by cancer to engage with the online service for up to a three-month period (mirroring standard practice currently offered by Tenovus for face-to-face counselling). During this phase a suitably qualified counsellor will deliver the synchronous avatar-based counselling.

The specific aims of Phase II of the study documented in this protocol are to evaluate the interaction in a live pilot trial of young people affected in some way by cancer to obtain:

1. Quantitative pilot data on the acceptability, likely usage, and therapeutic value of this virtual counselling world for young people affected by cancer
2. Qualitative data evaluating the impact of the virtual counselling world on the therapeutic alliance from the counsellor's perspective
3. Recommendations regarding the potential pitfalls and challenges in relation to the future delivery of such online interventions

### **3. Project Team (see Appendix A)**

This project is a collaboration between the Centre for Psychology & Counselling and the School of Applied Computing, Swansea Metropolitan University, and the Tenovus Counselling Service. The core academic team within the School of Psychology & Counselling at Swansea Metropolitan University (Dr Ceri Phelps – Project lead, Dr Paul Hutching and Ms Carol Hughes) offer a novel combination of experienced researchers and qualified and active counselling-practitioners and psychotherapists. This places the School in the unique position of being able to develop research programmes and interventions which are guided by strong research expertise in intervention development and service evaluation and informed by current developments in psychological counselling and psychotherapeutic

approaches. The School of Applied Computing at SMU (Andrew Baker) has significant expertise in computer games development involving avatars and will oversee the design of the avatars and technical aspects of the development of the virtual counselling world. The project is supported by one part-time research assistant (Dr Masoumeh Minou) who will co-ordinate the day-to-day running of the study and the project steering group (under the supervision of Dr Phelps) and two part-time Computer Design Research Assistants who will develop the virtual reality world (under the supervision of Andy Baker).

#### **4. Project Steering Group**

The Project Team are supported by four named collaborators (see appendix B), representing qualified counsellors with a diverse range of experience in counselling young people and/or people with cancer, or with skills and experience of engaging young people generally. This Project Steering Group has already been established and has met on several occasions to discuss the development of the project's protocol. An important consideration with this project is to recognise that the "users" of the proposed intervention are not only the young people or potential clients, but also the counsellors themselves who may be delivering the counselling through a mechanism which may be unfamiliar to them. To this end, the project team consider it important to have a number of counsellors on the project steering group, all of whom will have had direct experience of counselling young people, and who will also be consulted at all stages of the project. The project steering group will also include a representative from the Young Persons' Volunteer Panel.

#### **5. Participants and recruitment strategy**

Six to eight volunteers (both male and female) aged between 13-25 years will be recruited from the Tenovus waiting list for face-to-face counselling, advertisements placed on the Tenovus website, flyers sent out to Friends of Tenovus groups, Tenovus Sing With Us choirs and other support groups across South Wales and displayed within SMU and other collaborating organisations e.g. Cancer Genetics Service for Wales, following appropriate ethical approval (see ethical considerations section).

## 6. Data collection and measures

Participants will be asked to complete an online questionnaire prior to their first online communication with the counsellor, immediately after the counselling session, and at the end of the pilot study (after six weeks or after the last online counselling exchange if sooner e.g., if the participant decides to withdraw or to take up face-to-face counselling if available). All measures will be piloted for ease of comprehension and readability by young people in the project steering group. The specific measures proposed can be found in the separate measures document but at this stage are likely to capture the following outcomes:

- o Key demographic variables (gender/age/region/whether affected or carer)
- o Key therapeutic outcomes captured through a measure such as the Young Persons' CORE (Clinical Outcomes in Routine Evaluation) assessment system. CORE is currently used by Tenovus and many other cancer charities (and other counselling services) to evaluate the outcomes of counselling along core dimensions. The Young Persons' CORE is a brief ten-item version of this scale that is easy to comprehend
- o Cancer-specific distress as measured by the Impact of Event Scale (Horowitz et al., 1979) which captures intensity of intrusive thoughts and attempts to avoid thoughts about a specific event, in this context, "thoughts about cancer".
- o Mood and emotional responses before and after each session (captured through questionnaires and digital data collection from the VR world).
- o Working Alliance/Therapeutic Relationship Evaluation.
- o Satisfaction with counselling measured through a measure such as the Session Evaluation Questionnaire (Stiles, 1980) or an in-house satisfaction questionnaire adapted from existing measures for the current context of online counselling and appropriate for young people.
- o Qualitative- Reflective diary by counsellors

## 7. Data analysis

Data from the online questionnaires will be analysed using SPSS v19 to explore changes in outcome measures over time and the demographic profile of participants. Specific analyses will be defined once the outcome measures and data collection

timepoints are agreed upon. The qualitative data from the reflective diaries will be analysed thematically.

It is recognised that the scope of this pilot project will not enable any inferential statistics or effect sizes to be calculated in regards to the quantitative data overall, but this element of data collection will instead focus on the changes within individuals over time in order to gain an understanding of potential trends and outcomes within this process.

### **8. Ethical considerations for Phase II**

The project team recognise the clear confidentiality and consent issues involved in this project, particularly with the potential age group involved (i.e., those under 18 years of age). In line with good practice and ethical guidelines a clear and thorough written contract will be needed and limits to confidentiality with minors carefully considered as part of the recruitment and consent process. NHS ethical approval has been obtained for Phase I and will also be sought for Phase II.

In all elements of the design of the intervention itself, the BACP ethical framework and other relevant guidance e.g., the Online Therapy Institute's Ethical Framework for the Use of Technology in Mental Health (Anthony and Nagel, 2009) have been consulted. The main ethical concerns of online counselling suggested will be considered carefully in finalising the Phase II protocol, VR design and recruitment and consent processes (e.g., Richards and Vigano, 2013; Lee 2010 and Sampson et al., 1997). These ethical concerns are as follows:

- 1) Confidentiality
- 2) The validity of data delivered via computer network
- 3) The adequacy of counsellor interventions
- 4) Potential misuse of computer applications
- 5) Boundary issues
- 6) A lack of awareness of location- specific factors
- 7) The effect of the digital divide
- 8) Privacy concerns
- 9) Credentialing
- 10) Issues that concerned the development of online counselling

- 11) legal implications regarding duty of care
- 12) duty to obtain informed consent

### 8.1. Ethical considerations in relation to engaging young people in an online research

During the conduct of the research in Phase II all researchers involved in this project will adhere to the ethical codes of the British Association of Counselling and Psychotherapy and the British Psychology Society's Code of Human Research Ethics (2010). Key ethical considerations at this stage are:

- **Respect for the autonomy and dignity of persons:** This will be achieved through a thorough informed consent process, which includes: 1) providing participants with the information they need in order to decide whether to take part in a study, and 2) documenting that the information was provided and that the participant volunteered to take part in the research study.
- **Valid consent:** participants must be given opportunity to provide informed consent in a free manner, with the ability to withdraw their consent/request the destruction of their data at any point during the data gathering phase. In Phase II this information will form part of the detailed written informed consent procedures prior to agreeing to take part in the pilot phase of the study. As recommended by the Ethical Framework for the Use of Technology in Mental Health, this informed consent process will address issues such as the advantages and disadvantages of online counselling, boundaries, confidentiality, technology, and emergency contact details. Written informed will clearly state that:
  - o This is a pilot online counselling service that is being evaluated,
  - o Taking part in this pilot study does not mean that they are ineligible for face-to-face counselling,
  - o They may choose to withdraw from the pilot study at any time or as soon as face-to-face counselling becomes available
  - o Taking part in the study will require them to complete a secure online questionnaire on two occasions, and that the individual data from these

questionnaires will not be seen by Tenovus staff or anyone involved in the provision of counselling through Tenovus

- **Confidentiality:** participants have a right to expect that information they provide will be treated confidentially (in line with the Data Protection Act, 2004), and if published, will not be identifiable as theirs. Please see section below re: data protection. Any concerns raised regarding participation in the study will be passed on to Dr Ceri Phelps to ensure appropriate levels of confidentiality and further action if needed.
- **Giving Advice:** The debrief form at the end of the study will include a simple factsheet which participants can take away with them and which should answer any questions participants may have. The information sheet will include links to further information about genetics (appropriate for the lay public, e.g. the Telling Stories website) in case taking part in the study triggers any anxieties or concerns about genetic conditions in their own family. In the situation that someone reports specific distress as a result of participation then the contact name of a genetic counsellor will be provided.
- **Debriefing:** There is no deception in this study with all participants being fully informed about the nature of the study and its aims. At the end of the study participants will be provided with a written thank you letter and summary of the main findings of the study, along with a reminder that the study information sheet contains contact details for further information/advice if appropriate.
- **Maximising benefit and minimising harm:** The research team will seek to maximise the benefits of their work at all stages. Harm to participants must be avoided and where risks are unavoidable robust protocols must be in place. The research team are sensitive to the potential impact of the intervention and will conduct a robust risk assessment when completing this protocol.

- **Dissemination and feedback**

Young persons will be given sufficient space to decide if they would like to take part in dissemination activities and in what ways (e.g. seminars, presentations) rather than *'being wheeled out as walking/talking case studies to illustrate an academic point of view'*.

## **9. Delivery of Counselling**

During this period the counselling will be delivered through an appropriately trained counsellor within the Centre for Psychology & Counselling. The online counselling intervention will consist of a minimum of one online "instant" (or synchronous) Avatar-based counselling session of up to one hour a week over a six-week period (to map across the standard counselling provision within Tenovus), with additional non-instant (or asynchronous) exchanges (e.g. emails) also possible. This service will allow clients to contact a fully qualified counsellor at a time which is convenient to them and receive a reply from within an agreed time frame (to be decided by the project steering group).

### **9.1. Recruitment of Counsellor**

BACP recognises the importance of online provision for a wide range of psychological therapies and the potential for significant benefits to clients, especially those who have difficulty in accessing traditional face-to-face services or who find that they would prefer not to use them. BACP has proposed guidelines for online counselling and psychotherapy (3<sup>rd</sup> edition) under five main categories:

- Practitioner competence
- Client suitability and contracting
- Issues particular to working on line
- Issues of jurisdiction or professional codes and laws
- Confidentiality, data protection and storage issues

A competent practitioner working online will always adhere at least the following minimum standards and practices recommended by BACP in order to be considered to be working in an ethical manner. The areas of competency are as followings:

- 1) **Specialism:** requiring a level of competence at least as high as that in face-to-face work
- 2) **Experience:** help for a wide range of issues is likely to be sought and therefore it is widely recognised that online therapy is not appropriate for novice or inexperienced practitioners.
- 3) **Training:** requiring practitioners to undergo further specialist training in text-based online therapy.
- 4) **Research and development:** requiring practitioners to keep abreast of research and opinion in the field of online therapy.
- 5) **Accreditation:** Requiring practitioners to adhere to BACP's accreditation scheme
- 6) **Technological competence:** requiring practitioners to ensure that all spam blocking software, anti-virus software, encryption software, firewalls, pop-up blockers, anti-tracking/marketing devices and other technological tools remain up-to-date and do not interfere with the therapeutic process for the client.
- 7) **Supervision and support:** requiring adequate supervision arrangements to support their online work.
- 8) **Verification:** clients should be able to verify a practitioner's identity, the accuracy and adequacy of their stated credentials and whether they work in private practice or as part of an organisation.

#### 9.1.1. Technological competence

Technology basics are required for practitioners who choose to deliver therapeutic services via technology. Practitioners will possess a basic understanding of technology as the technology relates to delivery of services.

**Encryption:** Practitioners understand how to access encrypted services to store records and deliver communication. Records storage can be hosted on a secure server with a third-party, stored on the practitioner's hard drive utilizing encrypted folders or stored on an external drive that is safely stored.

**Backup Systems:** Records and data that are stored on the practitioner's hard drive are backed up either to an external drive or remotely via the Internet.

**Password Protection:** Practitioners take further steps to ensure confidentiality of therapeutic communication and other materials by password protecting the computer, drives and stored files or communication websites.

**Firewalls:** Practitioners utilize firewall protection externally or through web-based programs.

**Virus Protection:** Practitioners protect work computers from viruses that can be received from or transmitted to others, including clients.

**Hardware:** Practitioners understand the basic running platform of the work computer and know whether or not a client's hardware/platform is compatible with any communication programs the practitioner uses.

**Software:** Practitioners know how to download and operate software and assist clients with the same when necessary to the delivery of services.

**Third-party services:** Practitioners utilize third-party services that offer an address and phone number so that contact is possible via means other than email. This offers a modicum of trust in the third-party utilized for such services as backup, storage, virus protection and communication.

## **10. Outcomes and dissemination**

Ultimately, the results of this pilot study will be used to guide the future development or implementation of an appropriate online counselling service for younger people affected by cancer, with huge potential for rolling out to a more widely available service for those reluctant to undergo face-to-face-counselling/facing geographical barriers, other client groups such as those undergoing cancer genetic risk assessment or testing, and the inclusion of additional elements such as e-mentoring and online self-help coping interventions.

Finally, the nature of the community within which SMU is based within a “Communities First” and Objective One area means that many of those volunteering to become part of the project steering group will be local to this area and will help ensure that the final intervention will be sensitive to any potential issues of accessibility, computer literacy and literacy levels as a whole.

It is intended that the results of this study will inform the final development of an appropriate online counselling service for young people affected by cancer in Wales, with huge potential for rolling out to a more widely available service for those reluctant to undergo face-to-face-counselling/facing geographical barriers, other client groups such as those undergoing cancer genetic risk assessment or testing, and the inclusion of additional elements such as online self-help coping interventions. Importantly, in addition to the ongoing delivery of the online virtual reality counselling world, this project will produce recommendations regarding the potential pitfalls and challenges (practical and ethical) in relation to the future delivery of such online interventions for both clients and counsellors.

## Appendices

### References

Carrier JR, Greenberg LS (2010). Optimal levels of emotional arousal in experiential therapy of depression. *Journal of Consulting and Clinical Psychology*; 78:190–199.

Emmelkamp PM (2011). Effectiveness of cybertherapy in mental health: a critical appraisal. *Studies in Health and Technology Informative*;167:3-8.

Pagliari C, Burton C, McKinstry B, Szentatotai A, David D, Serrano Blanco A, Ferrini L, Albertini S, Castro JC, Estevez S, Wolters M. (2012). Psychosocial implications of avatar use in supporting therapy for depression. *Studies in Health Technology and health Informative*;181:329-33.

Reynolds DJ Jr, Stiles WB, Bailer AJ, Hughes MR (2013). Impact of exchanges and client-therapist alliance in online-text psychotherapy. *Cyberpsychology Behaviour and Social Networking* ;16(5):370-7.