

Quick guide to the ethics submission:

Part A

- Names the two principal investigators, Dr Barbara Dooley and Dr. Robert Illback, and gives a brief description of their professional and academic qualifications. This is complimented by a list of publications produced by the investigators.
- Gives a brief description of the funders of this research, Headstrong - The National Centre for Youth Mental Health.

Part B

- Provides the detail of the research proposal, including the
 - aims
 - *to obtain information about the needs of young people in a given community*
 - *to obtain information about the resources available/required to address these needs*
 - *to assess the readiness of the community to engage in strategic planning*
 - *to ascertain service provider and recipient perspectives on service design*
 - objectives:
 - *to plan a new mental health service in collaboration with the local community*
 - scientific background
 - methodology:
 - *through the use of service provider focus groups and interviews, young person's focus groups, and anonymous community provider surveys.*
 - research design:
 - *the combination of the above sources of information with publically available data and an extensive community mapping procedure.*
 - population size and its determination
 - method of analysis:
 - *mainly qualitative methods; ethnographic interviewing and thematic analysis of information obtained by above methods*
 - the use of statistics
 - start date (*June 2007*) and duration (*until 2010 in 6 – 8 counties*)

Item 13 specifies the potential risk to participants as “*minimal*”, and any ethical dilemma to be dealt with in the following manner:

“The primary risk associated with these data-gathering approaches relates to the potential for young people to experience distress when discussing issues related to mental health. In the focus groups, participants are explicitly instructed not to discuss issues of personal concern but rather to discuss these issues in relation to young people in general. Nonetheless, such discussion could trigger the need for further intervention. For each focus group involving young people, provisions will be made to have a qualified mental health

professional immediately available to debrief any issues that may arise, as well as to link the individual to any further therapeutic intervention that may be required. Focus groups will be run by trained facilitators, who will be briefed by a trained professional.

A secondary potential risk relates to the youth-serving professionals who may express opinions or perspectives that are perceived as critical or derogatory by their supervisor or employer, or (in the context of a focus group) that may result in interagency conflict. Key informant information will be kept entirely confidential and anonymous so that no such difficulty may arise. In the instructions with respect to focus groups for professionals, emphasis will be placed on maintaining a cordial and professional dialogue, while at the same time being open to discuss one's own ideas and listening to those of others."

- It is important to note that this proposal was not intended to refer *specifically* to the Ballymun project. Rather the proposal is intended as a generic application for the type of community needs assessment process that Headstrong intends to apply, not only in Ballymun, but also to a number of similar projects around the country between now and June 2010. This may help explain small differences between the content of the application and the aims of the Ballymun Youth Wellbeing Project.

Part C

- Part C is concerned with the participants of the research, how they are selected and how they are protected. There are two categories of participant - service providers and service recipients (young people).

- Section 15 (b) explains clearly how young people and service providers will be selected for participation:

"Depending on the characteristics of the community being studied, a cross-section of young people will be selected in close consultation with programme managers and front-line workers within the primary agencies involved in the initiative. Typically these will involve the Health Service Executive, second-level schools, college/university, and specialized programmes, such as youth development centers, social and recreational programmes, youth cafes, and special programmes (e.g., for Travellers, asylum seekers, early school leavers). Within each of these settings, written permission of the administrator in charge to seek participant involvement will be obtained. Each will be selected and approached by a programme professional that has a personal relationship with the young person (prospective participant) and can assess their appropriateness for participation (e.g., verbal skills, experience level, psychological stability). If the young person is interested in volunteering and is under the age of 18, he/she will be asked to seek written consent from their parent. If desired, the researcher will discuss the research with the parent to address any concerns that may arise. For individuals age 18 and above, informed consent will be sought directly with the individual. (see consent forms accompanying this document)

With respect to individuals providing services and supports for young people, a convenience sample will be drawn to insure representativeness across the community. The project planning team of community representatives will suggest roles and individuals to participate, and a "snowballing" approach to sample selection will be employed to identify

other prospective candidates. Potential participants will be selected with reference to types and categories of services and supports, populations served, and location of services. The prospective participant will be approached individually (or through their organization, as appropriate) and asked to consider participation. They will be provided full information about the project and be asked to provide written consent (see attached consent form)."

- Section 15(c) details the inclusion and exclusion criteria. The present document refers to the young people aged between 12 and 25, but for Ballymun this bracket is restricted to an age range of 12 to 18 as agreed by the design team.

Inclusion criteria: "*Young people - Aged between 15-24, good verbal skills, knowledge of needs and desires of young people, experience in youth-serving systems. Programme professionals – Relevant role and set of responsibilities, willingness to participate"*

Exclusion criteria: "*Young People: Intellectual impairment, serious emotional difficulties (as identified by service provider), language impairment, non-English speaking."*

- Section 15(d) addresses the issue of vulnerable populations, of which two are identified; those in the 15-17 age group, and students. Issues of assent/consent to participate in relation to these populations are addressed as follows:

Individuals under the age of 18 will be required to obtain written consent through their parent/guardian, if they wish to participate and they themselves must give written assent. Older individuals will be required to provide written consent on their own behalf. In each case, the key elements of consent (as shown on the attached forms) will be discussed with the prospective participant.

- Procedures for how the details of the study will be communicated to the participants are detailed in items 17 a – l. This covers:

- objectives of the study
- date of commencement & completion
- intent to publish
- confidentiality with respect to information obtained
- data handling, storage and security
- role of the researchers
- possible risks and potential benefits for this type of research
- invitation for the participant to ask questions
- incentives for participation (*none provided*)
- participant's right to withdraw at any time without penalty

All of this information is made clearly available on the participant information sheet and consent forms.

- Item 18 specifies that written consent will be obtained from all participants.

- Item 19 specifies that no personally identifying information will be recorded during the proceedings.

- Item 20 specifies that no recording devices other than a voice recorder (complemented by written notes) will be used. You will note that both the “yes” and “no” boxes are ticked in relation to tape recording. This is the case because tape recording will be used for the interviews, but not for the community provider surveys which are also covered by this application.

- Item 21 specifies that no payment of any kind will be made to participants.

Part D

- Deals with issues of confidentiality and data protection
- No personally identifiable information will be recorded or stored.
- The principle investigators will have control over the data which will be stored in the following way:

Prior to transcription audiotapes will be stored in a locked filing cabinet (address below). Audiotapes will be destroyed once transcription is complete. Raw notes, transcriptions, and survey data will be stored in a locked filing cabinet at Headstrong, 36 Waterloo Rd, Dublin 4. Derived data will be stored on a secure password protected computer. None will include personally identifiable information. This complies with the guidelines.

- Data will be stored both electronically and in paper form for a period of 5 years.

Appendices pertaining to each section of the proposal are attached separately for your information. The appendices are as follows:

- A. Decision Process for Community Planning**
- B. Systems Framework for Youth Mental Health Systems Change**
- C. Youth Focus Group – Information Sheet, Informed Consent Procedures, and Protocol**
- D. Service Provider (Professional) Focus Group – Information Letter, Informed Consent Form, and Protocol**
- E. Service Provider (Professional) Key Informant Interview – Information Letter, Informed Consent Form, and Protocol**
- F. Service Provider (Professional) Needs Assessment Questionnaire.**

This application has been approved by the UCD Ethics Committee