



Advance Directives in Mental Health Care Information Sheet

***Please read the information sheet below before completing the questionnaire**

You are invited to take part in a research study designed to explore the introduction of advance directives in Irish Mental Health Care. The purpose of this questionnaire is to understand your views as a service user towards their possible use. Before you decide, it is important for you to understand what advance directives are and what the research involves. You can keep this information sheet if you wish.

What are Advance Directives?

Advance directives allow you to sit down when you are well and work out what works best for you when you are mentally unwell. They allow you to state your mental health treatment preferences and other life choices in case you become unwell and have difficulty making decisions for yourself in the future.

Why might I be interested in an Advance Directive?

None of us go to hospital when we are well, so hospital and crisis staff often only see us when we are unwell. This tells them little about what works and what doesn't work for our mental health, who we are and our home life. If you become unwell and it is difficult for you to make decisions, the people making decisions about your care and treatment can look at your advance directive and think about **what you want**.

How does an Advance Directive work?

You may not want to be treated with a particular medication because you reacted badly to it in the past. **Example: For my medication, care and treatment I have found the following helpful and unhelpful.....**

You can also include other life management issues such as who you want to look after your children, your household or pets while you are unwell. You can change your advance directive at any time when you are well.

Why should I complete this questionnaire?

While there is no law stopping you from expressing your mental health treatment wishes in Ireland, these may or may not be respected under the current framework. It is important that you

have an input into whether advance directives become available under Irish law and what you would like to see included. Advance directives for mental health care are already available in Scotland, England, the United States, Canada, Germany and other countries. This study will help inform mental health law and policy in Ireland. Advance directives for mental health care will be referred to as ‘advance directives’ in the questionnaire.

Who is the study being undertaken by?

The study is being undertaken by Fiona Morrissey as part of doctoral research on the advance directives in Irish mental health care under the supervision of Dr. Mary Keys at the School of Law, NUI Galway. The study is partially funded by the Mental Health Commission.

Do I have to take part?

Participation in this study is entirely voluntary. It is up to you to decide whether or not to take part. You are free to withdraw at any time without giving a reason.

Who can take part in this study?

Anyone aged 18 years or over who has experienced mental unwellness and is a user or has been a user of mental health services in Ireland can participate.

What will happen to me if I take part?

If you agree to take part, we will ask you to fill out a questionnaire and sign a consent form which will take approximately 30 minutes. The forms may be returned by post in a SAE or collected by a service user representative or the researcher. The questionnaire has been pilot-tested among a smaller number of service users. You do not have to give your name or contact details in the questionnaire unless you are interested in participating in a follow up interview which will be conducted with a small number of participants.

What are the possible benefits of taking part?

By participating you can help people with mental health problems have more say in the management of their treatment and their lives. Your input will also help policy makers make decisions relating to mental health treatment and potentially change how people perceive mental health conditions and how they are treated in Ireland.

What are the possible disadvantages and risks of taking part?

While participation in this study does not carry any obvious or serious risks, the study includes a questionnaire which asks about your past experience of mental health treatment. You might find,

while you are answering it, that you would like to talk to someone about some of the issues it raises. We will be happy to recommend someone to you.

What happens at the end of the study?

At the end of the study, the results of the postal questionnaire will be analysed and discussed as part of a doctoral thesis and published in relevant Irish publications. It will also be sent to the Irish Mental Health Commission to inform future mental health policy and practice. A similar study will also be carried on consultant psychiatrists' views of advance directives.

What happens if I change my mind during the study?

You can change your mind about participating at any time during the course of the study.

Permission to carry out the study

Full ethical approval has been granted by the Research Ethics Committee at NUI Galway.

Where can I get further information?

If you need any further information or you do not understand anything in this leaflet, please contact me and I will be happy to discuss or explain any of the details.

Fiona Morrissey	Postal address:	Rinville East
School of Law		Oranmore
NUI Galway, Galway		Galway
Email: f.morrissey1@nuigalway.ie Tel: 087 9955582		

If you have any concerns about the study and wish to contact someone independently and in confidence, you may contact 'the Chairperson of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for Research, NUI Galway.

Confidentiality

You don't need to include your name in the questionnaire and all information is confidential and anonymous. Information will not be disclosed to anyone except the principal researcher. The answers to the questionnaire will be stored securely in a locked cabinet in the School of Law at NUI Galway. The information collected in this study will be stored in a way that protects your identity. Results from the study will not identify you in any way. **Thank you for participating in this study!**