



# the **living** project

documenting the lives and experiences of people with mental health problems

## Introductory Guide

**College Research Unit, Royal College of Psychiatrists  
and the First Step Trust 2003**



The Royal College of Psychiatrists  
Charity Registration Number: 228636



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## Summary

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The LIVING PROJECT aims to describe the everyday lives of people with mental health problems including:

- **experiences** with housing, education, employment, treatment, welfare and money
- **relationships** with partners, family, friends, carers, health professionals, neighbours, co-students, co-workers and other people
- **personal** interests (such as leisure activities), current ambitions, and future plans

Information collected during The LIVING PROJECT will be used to:

- improve help and support for people with mental health problems
- produce a book and written reports on the lives of people with experience of mental illness
- improve public understanding about peoples' lives, the types of problems encountered, and the achievements that can be made

All information collected during the LIVING PROJECT is strictly anonymous and confidential:

- **anonymous** - your name or any other personal details will not be linked to any information you provide, nor will they be mentioned to other people, or published in any form
- **confidential** - anything you tell or show the project researcher (Chris Fitch) will not be shared with anyone else without your permission

The LIVING PROJECT is a collaboration between:

- **The First Step Trust** - an organisation which provides gardening, printing, carpentry, painting and decorating services. The majority of the FST workforce are people with experience of mental health problems ([www.fst.org.uk](http://www.fst.org.uk))
- **The Royal College of Psychiatrists' Research Unit** – the RCPRU is a unit dedicated to improving services for people with mental health problems through rigorous research
- *with funding from the Community Fund (National Lottery)*

The project will run over the next three years in the Lambeth, Southwark and Lewisham area (2003-2006). The project lead is Chris Fitch (RCPRU).

# Introduction

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Fifty years ago, many people with serious mental health problems would have lived in a hospital. However, changes in government policy have meant that more people now live in the community.

Despite this increase, not enough is known about the experiences, problems, and opportunities that people with mental health problems encounter whilst living in the community. This lack of knowledge makes it difficult to improve mental health services.

The LIVING PROJECT aims to fill this gap in existing knowledge. It aims to describe the everyday lives of people with mental health problems including:

- experiences with housing, education, employment, treatment, welfare and money
- relationships with partners, family, friends, carers, health professionals, neighbours, co-students, co-workers and other people
- personal interests (such as leisure activities), current ambitions, and future plans

The LIVING PROJECT represents an important collaboration between the First Step Trust and The Royal College of Psychiatrists. The project will run over the next three years in the Lambeth, Southwark, and Lewisham areas (2003 – 2006), with the work being led by *Chris Fitch* (the project researcher).

## What does this mean for me?

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The LIVING PROJECT aims to involve people with experience of mental health problems. This includes:

- those people who have had mental health problems themselves
- those people around them (such as carers, husbands, wives, boyfriends, girlfriends, family members, friends, neighbours, co-students, or co-workers)
- health professionals involved in providing care and support

Participating in the LIVING PROJECT provides an opportunity for people with experience of mental health problems to talk about their lives. This involves speaking with the project researcher (Chris Fitch), participating in a series of interviews, and generally sharing your experience (both positive and negative) of daily living.

As well as *talking* about their life, there are also opportunities for people with experience of mental health problems to actually show the project researcher what their daily life is like. This involves spending time with Chris Fitch and showing him what your every-day life involves.

Finally, as well as participating in the LIVING PROJECT, there are also opportunities for people with mental health problems to *become part of the research team themselves*. This may involve helping with recruitment (finding people who can participate), preparing research questions (what will be asked), or undertaking interviews (asking the questions).

In summary, the LIVING PROJECT gives you an opportunity to both tell and show Chris what your life is really like. This information is extremely important as it can be used to improve mental health policy and local services. It is also valuable in improving the understanding of the wider community about living with a mental health problem.

### **"I'm a carer": what does this mean for me?**

The LIVING PROJECT realises the importance of involving the carers of people with mental health problems. If the person you care for becomes involved in the project in a significant way, then Chris Fitch will contact you to explain what this entails. Chris may also ask to speak with you about your experience of life as a carer.

### **"I'm a health or social care professional": what does this mean for me?**

The LIVING PROJECT will involve the project researcher accompanying individuals as they undertake their daily activities. This may include contact with health and social care professionals. In the event this might happen, Chris Fitch will get in touch, and will discuss with you further what this will entail.

## **Who is involved in the research? \_\_\_\_\_**

The LIVING PROJECT draws on:

- *funding from the Community Fund (National Lottery)*
- *research experience from the Royal College of Psychiatrists' Research Unit* – the RCPRU is a unit dedicated to improving services for people with mental health problems through rigorous research ([www.rcpsych.ac.uk/cru/index.htm](http://www.rcpsych.ac.uk/cru/index.htm))
- *community knowledge and printing expertise from the First Step Trust (Lambeth branch)* – the FST are an organisation which provides gardening, printing, carpentry, painting and decorating services. The majority of the FST workforce are people with experience of mental health problems ([www.fst.org.uk](http://www.fst.org.uk)).

The LIVING PROJECT also has the support of local, national, and international user groups, carer groups, health professionals, and policy makers or ([www.thelivingproject.info](http://www.thelivingproject.info)).

# What will happen to the information collected? \_\_\_\_\_

It's natural to have questions about participating in a research study. One of the most commonly asked questions is about what happens to the information collected during research.

Some people worry about participating in research because they are afraid what they tell researchers will be repeated to other people, or that their name or personal details will be mentioned.

However, all information collected during the LIVING PROJECT is strictly anonymous and confidential:

- **anonymous** – your name or any other personal details will *not* be linked to any information you provide, nor will they be mentioned to other people, or published in any form.
- **confidential** – anything you tell or show Chris Fitch will *not* be shared with anyone else without your permission

Therefore you can speak freely and know that this information will *not* be repeated to anyone else, nor will your name or personal details be mentioned or published.

There is one important exception to this rule: if you indicate that you are going to harm yourself, or you are going to harm another person, then an appropriate professional will be informed.

# How will the information be used? \_\_\_\_\_

Information collected during the LIVING PROJECT will be used to prepare a number of different publications. These will include a book and shorter written reports.

- **book** – this will describe what the lives of people who have experienced mental health problems are like. This will enable other people to understand what every-day life is like, the type of problems encountered, and the successes and achievements that can be made.
- **reports** – these will either concentrate on one or two specific issues such as education or housing, or will summarise the findings of the research.

If something you have shared with Chris Fitch is to be included in the book or reports, then Chris will ask your permission to include this information. Importantly, unless research participants state otherwise, the books and reports will *not* contain peoples' names or personal details.

The First Step Trust will be involved in the production, printing, and sharing of these written materials.

## Will we be paid for the research? \_\_\_\_\_

The main reward of participating in the project is the knowledge that you will be helping to improve services for people with mental health problems. Your involvement *will* help others.

However, it is acknowledged that small payments to cover expenses (such as travel or food) may need to be made to some participants.

## How will *our* views on the research be heard? \_\_\_\_\_

If you have an opinion, question, or an idea for the research, then the best person to speak to is Chris Fitch. His contact details are at the back of this booklet. He will listen to your views and discuss them with you.

Another way of getting your views heard is through the 'Project Steering Group'. This is a group of workers from First Step Trust, researchers from the Royal College of Psychiatrists, and other community representatives who will meet three times per year to review project progress. Again, contact details can be found at the back of this booklet.

## Other questions \_\_\_\_\_

If you have a question or view on the research, then speak to Chris Fitch (contact details at back of this booklet). However, some commonly asked questions include:

### **Do I have to take part in the research?**

No. Participation is totally voluntary. If you decide not to participate then any treatment or care you are receiving will not be affected. However, your participation in the project will be of enormous help and value.

### **I've been asked to sign a consent form – what is this?**

If you are interviewed by Chris Fitch, then he will ask you to sign a consent form. This form is there to protect you. The form allows you to indicate: (i) that you have been given enough information about the study by the researcher; (ii) that you've been given the opportunity to ask questions about the research (and received answers to these questions); (iii) that you agree to take part. The form also indicates that everything you say will be treated as anonymous and confidential, and also gives you the right to withdraw from the research at any time. The research study has received full ethical approval from The Institute of Psychiatry Ethics Committee.

### **I've been asked if the interview can be taped – why?**

Using a tape recorder allows the researcher to fully concentrate on what you are telling him, and avoids important details being missed. After the interview, only the research team will hear the tape, and it will be destroyed once it has been typed up.

### **Are other methods used?**

From time to time, you may see Chris Fitch making notes. These notes provide important information on what is happening in a situation. If Chris Fitch wants to observe what you are doing, and wants to make notes about this, he will ask for your permission. Occasionally, Chris Fitch may ask to take a photograph of a situation (as these can describe a situation more powerfully than words). If you are in this situation, you will be asked for your permission. If you don't want to be photographed, then you can refuse. If the research team wish to publish any photographs featuring you, your permission will be asked. You may refuse.

### **What happens to all the notes, tapes, and photographs from the study?**

All information is anonymous and confidential. All materials are kept in a locked metal cabinet. No one apart from Chris Fitch has access to this cabinet.

### **My friend might be interested in the research – can they take part?**

Yes. If your friend has experience of mental health problems and lives in the local area, then they can help with the research. The easiest way to make this happen is to make contact with Chris Fitch.

## **THANK YOU**

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The success of the research is entirely down to all those people who agree to participate in the project. If you are able to help in any way, then we are very, very grateful.

By assisting with the research, you will be helping to improve public understanding about the lives of people with mental health problems.

This will hopefully allow positive changes to be made in the way in which mental health services and help are provided.

#### **Chris Fitch**

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#### **The Living Project Steering Group**

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