

Molecular Genetic Investigation of Bipolar Disorder: Recruitment and Data Collection



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Kay Redfield Jamison (Professor of Psychiatry and has bipolar disorder) 'Depression is awful beyond words...it bleeds relationships through suspicion, lack of confidence and self respect, the inability to enjoy life, or walk or talk or think normally, the exhaustion... Depression is flat, hollow, unendurable.' 'When you're high its tremendous. The ideas and feelings are fast... shyness goes... feelings of ease, intensity, power, well-being, omnipotence and euphoria...But somewhere, this changes. The fast ideas become too fast...overwhelming confusion replaces clarity.' An Unquiet Mind, A Memoir of Moods and Madness (1996)

Introduction

- Bipolar disorder (manic depressive illness) is a common (~1% lifetime risk) psychiatric disorder with episodes of extreme mood disturbance ranging from mania to depression.
- We are currently collecting clinically rich data from a large group of individuals with bipolar disorder as part of our ongoing research into the genetic and environmental causes of bipolar disorder.
- Our aim is to recruit 6000 unrelated individuals with bipolar disorder and to conduct thorough psychiatric assessments on all participants.

Systematic Recruitment Methods

• Our research programme has been adopted by the UK Mental Health Research Network (MHRN).



- We have obtained ethical approval and NHS R&D approval to recruit research participants across 30 NHS mental health trusts and health boards throughout the UK.
- MHRN-employed Clinical Studies Officers (CSOs) liaise with mental health professionals to identify potential participants.

Identifying Potential Participants

We are looking for individuals who:

- ✓ are over the age of 18.
- have had **one or more episodes** of mania or hypomania <u>at</u> <u>any time</u> that has <u>lasted longer than 4 days</u>. Participants may have, or may have had, a diagnosis of bipolar I disorder, bipolar II disorder or schizoaffective disorder.
- ✓ are able to speak English fluently due to the semi-structured nature of the interview.
- ✓ are able to provide written informed consent.
- ✓ are not known to have a blood-borne infection such as HIV.

Two of our more famous participants:





Assessing The Bipolar Phenotype

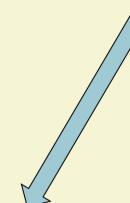
Research assistants travel all across the UK to visit research participants in their homes



A semi-structured psychiatric interview, Schedules for Clinical Assessment in Neuropsychiatry (SCAN) is administered (~1.5 hrs). Each interview is recorded and frequently reliability meetings are held to ensure high inter-rater reliability.



Participants' medical notes are accessed to supplement information provided at interview



Rich phenotype data is essential for molecular genetic studies investigating genotype-phenotype correlations

Why Participants Take Part in Our Research

To help others

Self-rated

questionnaires to

measure

psychological

aspects of illness

(endophenotypes)

 Many of our participants express concern about family members or other sufferers who may experience mental health problems in the future. They hope that their participation in our research will help lead to important advances in the diagnosis and treatment of mood disorders in the future.

Medical Research Institute.

Interest in research

 Participants are often keen to take part in our study, recognising the significant impact that research can ultimately have on mental health practice. In some cases they may have participated in other projects or have been involved in research either through their work or academic studies.

Generate awareness and reduce stigma

 Participants often state that little is known about mood disorders in the community or workplace. Taking part in a large research project may generate awareness, improve others' understanding of mental health issues and hopefully reduce the stigma faced by those with a mental health problem.

BDRN's media involvement

Small blood sample

collected (2 tubes)

DNA extracted

 Over the years our research has received extensive media coverage, featuring in a number of documentaries and radio programmes nationwide. Participants often cite this as a motivation for taking part in our research.

Recruitment to Date

• Since April 2006 the MHRN has helped us to recruit 1688 participants to the study across the UK.

Future Work

• We aim to continue to recruit to our study through our existing recruitment methods and are confident that with the help of the MHRN we will reach our 6000 participant target.

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