KING'S College LONDON

INSTITUTE OF PSYCHIATRY,
PSYCHOLOGY & NEUROSCIENCE

Module:
Mental Health in the Community

Week 2:
Current conceptualisations of mental health

Dr Jennifer Walke

Topic 2:
'Nothing about me without me': The growth of the expert by experience
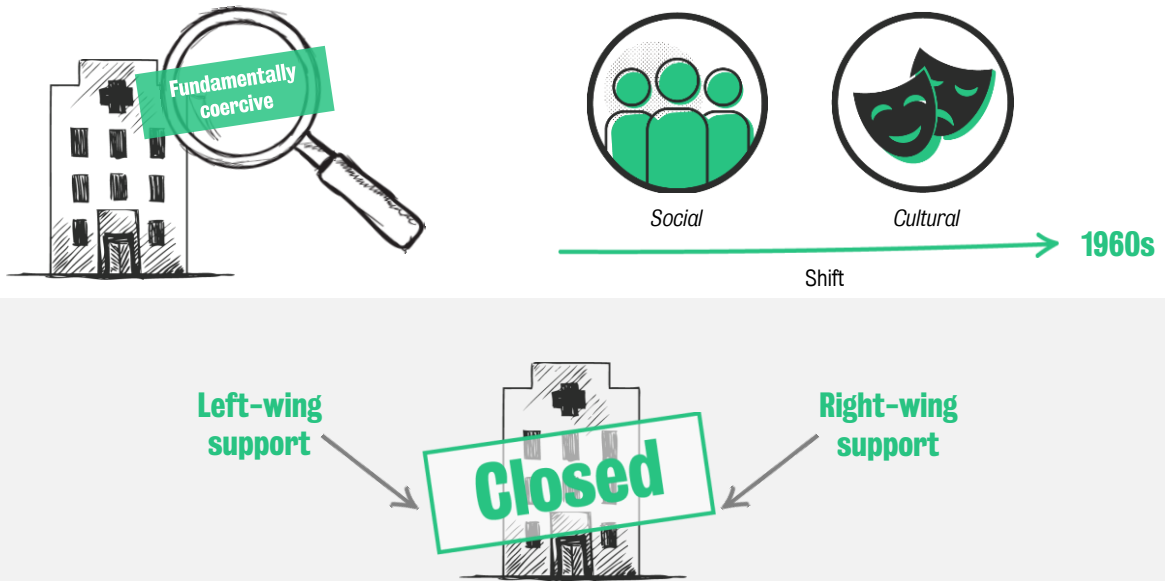

Topic list

This week, we will be looking at the following topics:

- Topic 1: Stigma and mental health
- *Topic 2: 'Nothing about me without me':*
  The growth of the expert by experience
- Topic 3: Evaluating service user involvement

Click **Next** to continue

Antipsychiatry: The beginning of dissent

Fundamentally coercive

Social

Cultural

Shift

1960s

Left-wing support

Closed

Right-wing support

Antipsychiatry: Academic interest

Erving Goffman
(1922 – 1982)

'Total institution' actually aggravated long-term difficulties

Michel Foucault
(1926 - 1984)

Mental illness was an eighteenth-century social construct

Thomas Szasz
(1920 - 2012)

Denied the very existence of mental illness

Ken Kesey
(1935 - 2001)

One Flew Over the Cuckoo's Nest Conceptualised psychiatric patients as nonconformists
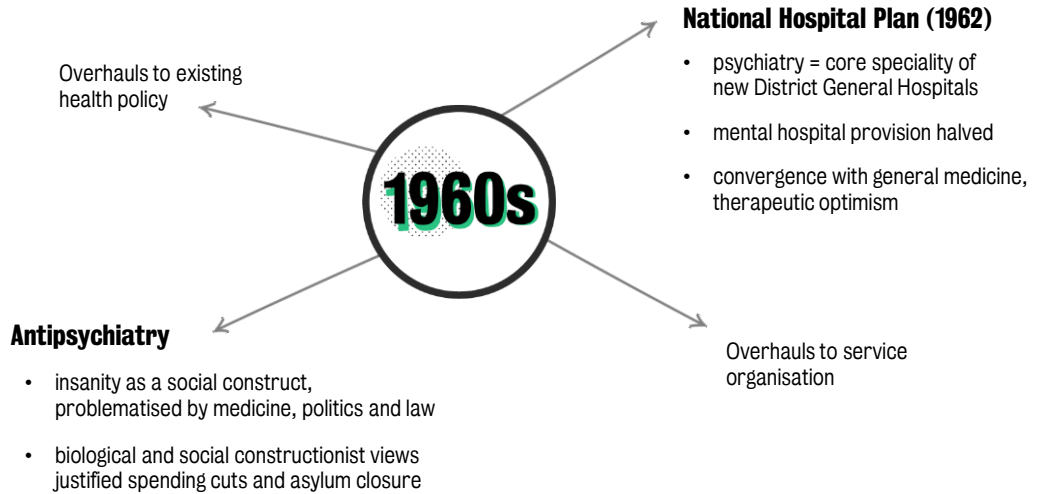
R.D. Laing
(1927 - 1989)

Rejected medical psychiatry. Encouraged greater attention to patients' lived experiences

Deinstitutionalisation: 1960 - a critical decade in British psychiatry

Overhauls to existing
health policy

1960s

National Hospital Plan (1962)

- psychiatry = core speciality of new District General Hospitals

- mental hospital provision halved

- convergence with general medicine, therapeutic optimism

Antipsychiatry

- insanity as a social construct, problematised by medicine, politics and law

- biological and social constructionist views justified spending cuts and asylum closure

Overhauls to service
organisation

Deinstitutionalisation: Asylums
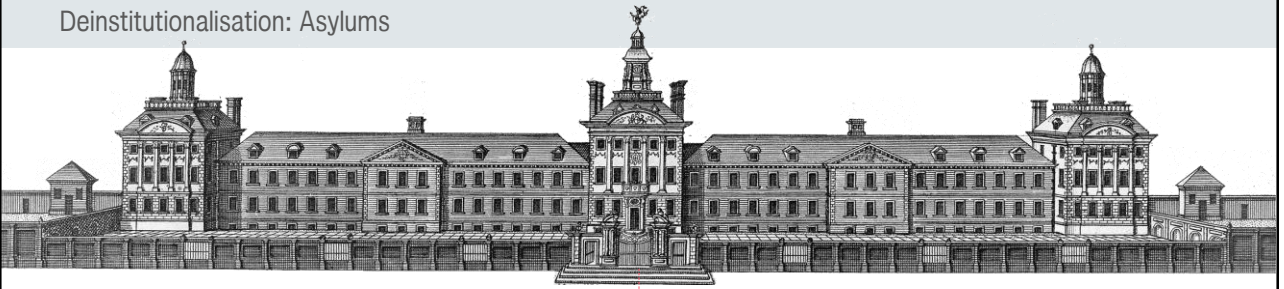
Colney Hatch Lunatic Asylum

Original location: North London

Mid-1950s: Accommodated over 2,000 people

20th century: Renamed Friern Hospital

Bethlem Royal Hospital

1247: Founded as a priory

Today: Part of South London and Maudsley (SLaM) NHS Foundation Trust

Alleged disorder and neglect sustained public and academic interest.

Recent project: 'Mansions in the Orchard' involved service users, staff and local residents to create a 'public history' of the hospital.

Chaney and Walke (2015)

Deinstitutionalisation: Realities of hospital closure

1975 White Paper
Better Services for the Mentally ill
Presented by Barbara Castle

- shortcomings of the Hospital Plan
- limited scope for progress
- concerns over closure before community-based alternatives were available

Closing…

Closure was a gradual process

Peter Barham

- inability of community care to deal with the vicissitudes of mental illness
- failures increased the stigma and isolation experienced by recently-discharged patients

Barham (1997)

The growth of the service user movement

Late twentieth-century
decarceration

→ Community-based studies
→ Patient-authored accounts
→ Activism

1 | **Camden Mental Health Consortium (CMHC)** | **Good Practices in Mental Health**

Service user views of the new inpatient provision in a District General Hospital

Two user controlled research projects – 1990s

1. Strategies for Living

Modus operandi:	People's own strategies for dealing with mental distress
Coordinator:	Service User
Interviewers:	Service User
Published:	2000

2. User-Focused Monitoring

Modus operandi:	Peer evaluation of community and hospital services
Coordinator:	Service User – provided research skills training
Published:	1998

Peer-review later spread to other locations and services assisted by INVOLVE

Criticisms: Openly political which some understood as biased

Rose et al. (1998)

The growth of the service user movement: Service User Research Enterprise (SURE)

2001 | Service User Research Enterprise (SURE)

User-led research ➡ Academia

Professor Dame Til Wykes
Championed service user involvement in all aspects of research.

SURE Research (at the IoPPN)

Tests the effectiveness of services/treatments from the perspective of those with mental health problems and their carers.

Service user researchers have insider knowledge about:

- mental distress
- services
- treatments

In addition to conventional training and qualification.

SURE is the largest academic department of its kind in the world.

The growth of the service user movement: Prominent research groups

Suresearch
- members include users and survivors of mental health services

Shaping Our Lives National User Network
- independent user-controlled group, think-tank and network
- works with a wide and diverse range of service users

GROUPS PROMINENT IN THE RESEARCH COMMUNITY

The McPin Foundation
- a dedicated, user-focused mental health research organisation

Internationally
- many individuals working as service user researchers

St. George's, University of London
- work alongside 'peer' researchers with experience of mental health problems
- critique and strengthen knowledge about mental health

The Survivors' History Group
- celebrate the historical contributions of mental health service users
- maintains a detailed online mental health timeline

1990s onwards edited collections have appeared offering:

Sociological critiques of conventional mental health research

Drawing on epistemologies derived from feminism and post-colonial studies

Reframing the 'double identity' of researcher/mental health service user…into…

A specialist knowledge broker.

Self-definitions and language (1)

> "
>
> "Service user" (Europe) or "consumer" (Australia, New Zealand and USA), on the one hand, and "survivor of psychiatry," on the other, are expressions of two different perspectives on psychiatry: the first one focuses on reforming the existing system, while the second puts the entire psychiatric system in question, including the very premise of mental illness.
>
> "
>
> Russo (2012)

Critical to distinguish between

User involvement in research

Service user researcher

Peer researcher

Expert by experience

Our focus

Patient participation in clinical care-planning

Patient

Client

Russo (2012)

Self-definitions and language (2)

ser•vice user
noun

Widely used

Criticised by various groups;

- value laden
- restrictive
- implies passivity
- disregards aspects of an individual's identity

It also fails to capture those who qualify for, but are unable/unwilling to access support.

These considerations are of increasing importance amid widespread cutbacks.

Hugh McLaughlin described...

Three types of service users

Direct	Recent or current experience
Indirect	Involved in studies focused on related services outside their geographical area
Alternative	Experience of using services in one specific domain (e.g., breast cancer)

McLaughlin (2009)

Slide 1

Aims and objectives

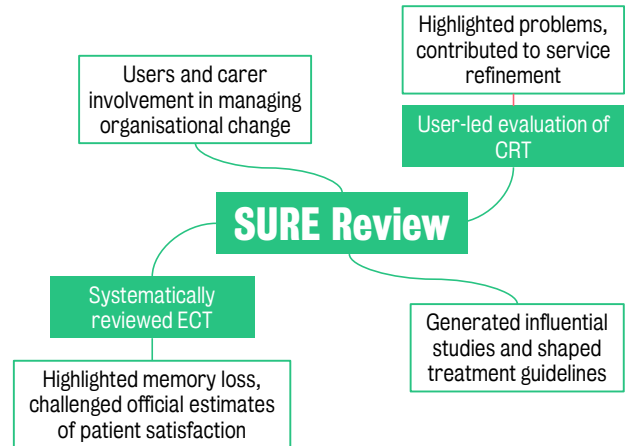# User involvement | Set of techniques rather than a single approach

SURE Research (at the IoPPN)

Tests the effectiveness of services/treatments from the perspective of those with mental health problems and their carers.

Service User Involvement

- Design
- Data collection
- Data analysis
- Results
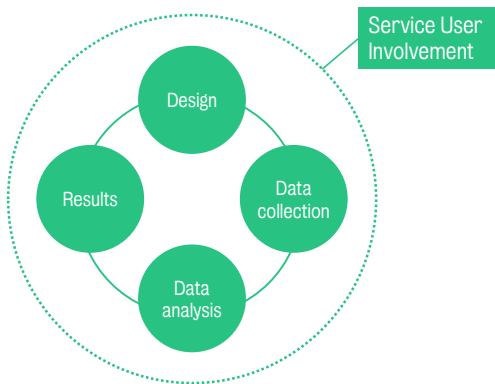
Also implements a **collaborative** management structure.

SURE Review

- Users and carer involvement in managing organisational change
- Highlighted problems, contributed to service refinement
- User-led evaluation of CRT
- Systematically reviewed ECT
- Highlighted memory loss, challenged official estimates of patient satisfaction
- Generated influential studies and shaped treatment guidelines

Rose et al. (2003, 2008)

Slide 2

Key methods and impacts

Translational research | Convert findings from basic research more efficiently into clinical practice.

Knowledge from the bedside must feed back into the laboratory to have real and lasting success.

- Bridge the translational gap
- Evaluating and enhancing the validity of outcome measures
- Assessing the acceptability and feasibility of proposed changes
- Improve organisational efficiency
- Highlighting areas of concern to service users
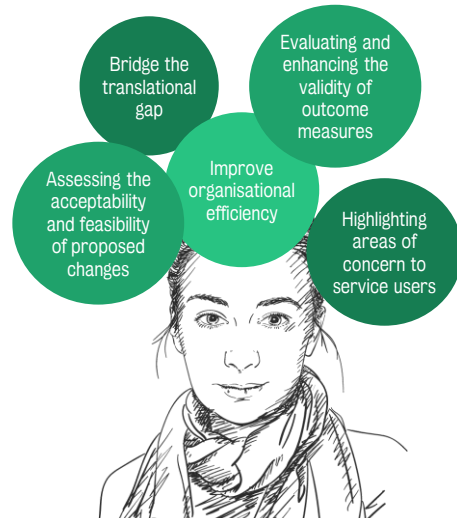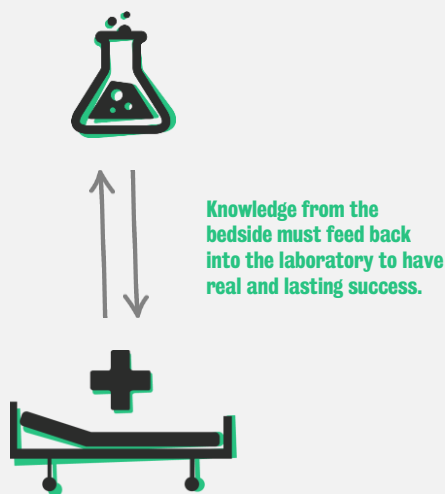
Benefits of service user generated knowledge

Consumer studies of ECT

Patient-centred Systematic Reviews

Exploring consumers' perspectives on ECT

Two main researchers had experienced ECT

Evidence collected:

Peer-reviewed literature

Testimonies sourced from video archive and the internet

Outcomes:

Conventional research showed much higher levels of satisfaction than this user research

New NICE guidelines on ECT developed, especially around information and consent, including risk of memory loss

User research can have a direct effect on national policy

Patient-reported Outcome Measures (PROMs)

SURE's method

Generated entirely from the service user perspective

- discussing medication side-effects
- discussing experience of inpatient care

Researchers are also service users

Discrete Choice Experiment

- inform drug developers of key side-effects to avoid

Focus Groups

Variety of topics and at different stages of research process

6-8 people, one facilitator with experience of in-patient care and also a service user

Expert Panel

One drawn from focus group members and one independent

Amending and refining the measure to make sure language and layout are appropriate/consistent

Feasibility study

Make sure a (new) measure is easy to complete

Groups of approximately ten

Challenges to user-led research and user-produced knowledge (1)

Marginalisation of 'experiential' knowledge pervaded other sectors…

Emphasis on: **Deficit**   **Pathology**

Served to **justify** the **segregation** and **institutionalisation** of the **ill** or **impaired**.

Service user testimony → Devalued / Omitted → **Psychiatric knowledge production**

There is a suggestion that

User-research | **Biased** | **Anecdotal** | **Over-involved**

Beresford (2002)
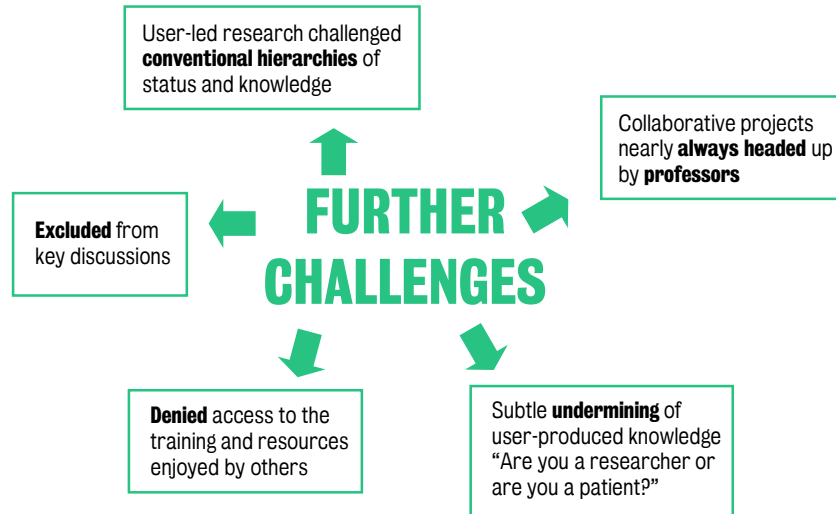
Challenges to user-led research and user-produced knowledge (2)

User-led research challenged **conventional hierarchies** of status and knowledge

Collaborative projects nearly **always headed** up by **professors**

Excluded from key discussions

FURTHER CHALLENGES

Denied access to the training and resources enjoyed by others

Subtle **undermining** of user-produced knowledge "Are you a researcher or are you a patient?"

Commonly due to **deficiencies** in research design

Rose (2003)

Hierarchies of evidence

Evidence-based medicine hierarchies rank study types based on:

Strength of their research methods

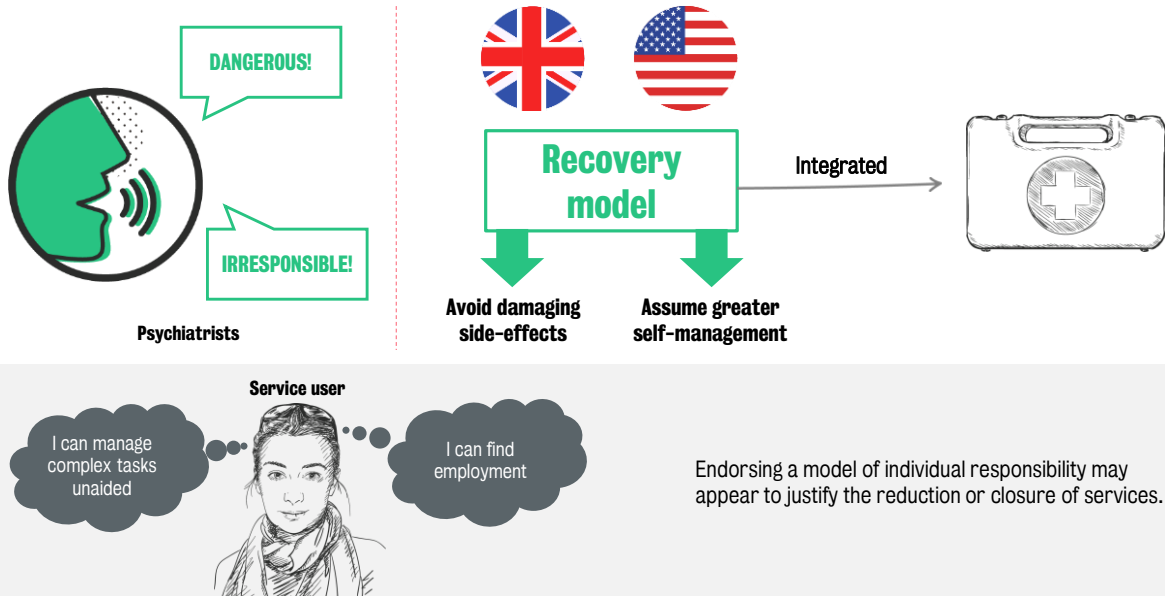**Precision of their research methods**

Systematic reviews and meta-analyses

Lay expert opinion, anecdotal experience

? Different **question types** = Different **hierarchies**

The concept of 'recovery'

DANGEROUS!

IRRESPONSIBLE!

Psychiatrists

Recovery model

Integrated

Avoid damaging side-effects

Assume greater self-management

Service user

I can manage complex tasks unaided

I can find employment

Endorsing a model of individual responsibility may appear to justify the reduction or closure of services.

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End of topic