Clinicians’ attitudes towards patient involvement in mental health research

Juliet Carmichael MBChB, BMedSci, Thomas Misselbrook BSc, Leah Marriner BSc, Alexandra Forrest MSc, Andrew Molodynski MBChB, MRCPsych

Mental health studies often recruit a low number of participants and Welcome Trust data have shown that less than a third of the trials successfully achieved their recruitment targets within the time frame given. The authors at the Oxford Health NHS Foundation Trust surveyed community staff to analyse the barriers to mental health research studies but also to uncover strategies for the future, which have the potential to shift the balance towards better patient recruitment into research and ultimately to secure future care informed by robust evidence.

Introduction

The NHS constitution pledges to inform patients of research that they may be eligible to participate in, and research and innovation are key targets for both the Department of Health and government overall.1 People with serious mental illness die up to 20 years earlier than the overall population average and this has been described as the ‘biggest health scandal of our time’.2 Mental health studies often recruit low numbers of participants and less than a third of the trials successfully achieved their recruitment targets within the timeframe given in one evaluation.3 Clinical trials are frequently terminated due to difficulties recruiting. This results in a considerable waste of time, resources and effort and raises ethical issues around participation and resource allocation.4,5,6

In a recent survey 95% of the general public agreed that it is important that the NHS carries out clinical research and 89% indicated that they would be willing to take part.7,8 A recent study of 736 patients with depression and schizophrenia across seven European countries (including the UK) found that 91% of patients asked were willing to participate in some form of research. Rates varied across different methods of research but were, in all categories, overwhelmingly positive; for example, over 50% of patients indicated that they would be willing to participate in medication trials.9 We could find no evidence of similar large scale surveys of staff in the existing literature so decided to collect this evidence to inform our local practice. The views of clinicians on research are important for several reasons. Most important is the effect that such attitudes have upon behaviour. Positive attitudes of staff are likely to impact positively on research recruitment; the converse of this is also likely to be true. Other studies have reported a feeling among staff of needing to ‘protect’ patients, which can act as a barrier to recruitment.10,11 In order to increase patient participation in research, it is important to ensure that clinicians feel confident and empowered to operate their brokerage roles effectively.

Method

Survey instrument

We designed a questionnaire (see Box 1) to capture the attitudes of mental health clinicians across the Oxford Health NHS Foundation Trust (OHFT) toward patient involvement in research. The instrument was based upon that used by Schafer et al.9 to allow for comparison between patients and clinicians. A brief six-question survey was finalised and piloted among mental health workers in one community mental health team prior to wider distribution. The questions focused on: (1) Staff position, (2) awareness of local research opportunities, (3) current staff practice, (4) attitudes towards patient involvement in research, (5) attitudes towards different types of research and (6) possible improvements. Questions 2-5 were assessed on a five-point Likert scale, whilst question 6 asked participants to select relevant possible improvements. There was a free-text box at the end of the questionnaire to allow for the collection of novel ideas or suggestions.

Distribution

The survey was distributed among large numbers of clinical staff in community mental health services in OHFT over an eight-week period. Research assistants recruited participants at team meetings, on an individual basis, and via email to maximise the response rate. A total of 134 responses were collected from 357 eligible staff members. Our sample therefore represented 38% of the staff group.
and the vast majority of staff approached agreed to complete the survey. The majority of questionnaires were completed by clinical staff likely to be involved in recruiting patients for research, such as mental health nurses (n=50), doctors (n=24), social workers (n=23), support workers (n=13) and occupational therapists (n=12). A minority of questionnaires were completed by students (n=7) and psychologists (n=5). (See Figure 1.)

The numbers of professionals completing questionnaires reflected well the overall staff makeup in the service, with a slight overrepresentation of medical staff.

Statistical analysis
Given the nature of this service evaluation, only observational data are presented as no statistical analysis was undertaken.

Results
Awareness and attitudes of staff
Sixty-three per cent of respondents stated that they were fully aware of research opportunities for patients. This did not vary by profession. Sixty-two per cent reported that they were aware of how to access further information for patients. Fifty-seven per cent of staff reported that their ability to consider research was limited by time constraints, though 86% agreed that it was important to maintain and improve standards. Respondents were further asked to give their views regarding different forms of research. Eighty-three per cent of staff recognised the importance of involving patients in medication trials and 68% recognised the importance of placebo-based trials. Only 48% agreed that research funded by the pharmaceutical industry was important, however.

Attitudes towards patient involvement in research
Reassuringly only 9% of respondents reported that patients rarely

1. Staff position
   a. Do you work on a ward or in an AMHT?
   b. If a ward, which ward?
   c. If an AMHT, which AMHT?
   d. What is your job role within the team?

2. Awareness of local research opportunities
   a. I am aware of research opportunities for OHFT service users and I know how to access information for their participation.
   b. I am familiar with the process by which research is governed and ethically approved.
   (Assessed on a 5-point Likert scale ranging from ‘Strongly disagree’ to ‘Strongly agree’)

3. Current staff practice
   a. Have your service users been involved in research studies as a result of information you have given them?
   (Assessed on a 5-point Likert scale ranging from ‘Very likely’ to ‘Never’.)
   b. How likely are you to discuss research opportunities with service users when acutely unwell?
   c. How likely are you to discuss research opportunities with service users in the recovery phase?
   d. How likely are you to ask service users whether they would consent to be contacted by an approved researcher when acutely unwell?
   e. How likely are you to ask service users whether they would consent to be contacted by an approved researcher in the recovery phase?
   (Assessed on a 5-point Likert scale ranging from ‘Very likely’ to ‘Never’.)

4. Attitudes towards patient involvement in research
   a. Incorporating research into clinical practice is limited by time constraints.
   b. Most service users are not interested in participating in research.
   c. I do not have sufficient knowledge to comfortably discuss research opportunities with service users.
   d. Service users rarely fit the eligibility criteria for research studies.
   e. Most service users with a mental illness don’t have the capacity to consent for participation in research.
   f. Even when service users do have capacity, they are often too unwell to engage in discussions about research.
   g. Research is not in the best interest of service users and clinical care should take priority.
   h. Most research doesn’t provide information that is relevant to my clinical practice.
   i. Service users taking part in research have better outcomes than those in routine care.
   j. Research is important for improving patient care.
   (Assessed on a 5-point Likert scale ranging from ‘Strongly disagree’ to ‘Strongly agree’.)

5. Attitudes towards different types of research
   a. I recognise the importance of involving service users in research for drug treatments.
   b. I recognise the importance of involving service users in research funded by the pharmaceutical industry.
   c. I recognise the importance of involving service users in research using placebo drugs.
   (Assessed on a 5-point Likert scale ranging from ‘Strongly disagree’ to ‘Strongly agree’.)

6. Possible improvements
   a. What do you think would help you to introduce research to your service users?
      • Training on how to discuss research with service users.
      • Training on the principles of research methods and approval processes.
      • Readily accessible information on the intranet.
      • A dedicated R&D email address for enquires about research.
      • Simplifying the information provided on research, without extensive study details.
      • Signposting service users to readily accessible information about research at OHFT.
      • Involvement in Patient and Public engagement activities.
      • Access to professional development research events and training.
      • Access to information in a variety of formats to inform service users.
      • Other (please specify)
   (Respondents were asked to select all that apply.)

Box 1. Questionnaire
fit eligibility criteria for research and 8% reported that patients rarely had capacity to consent to research. The majority of staff felt that patients were receptive to discussions about research, with only 15% feeling that patients are often too unwell to engage in discussions about research. Overall, staff viewed research positively with 71% reporting that research was in patients’ best interests and only 8% reporting that research did not produce relevant information. However, only 24% of respondents believed that patients would have better outcomes by taking part.

Less than half of staff reported that patients were interested in research, with just 18% agreeing or strongly agreeing they would be.

**Barriers to recruitment**
Approximately one in three staff (34%) reported that they did not have the knowledge to comfortably discuss research opportunities with patients.

Only 7% of staff reported successfully recruiting patients frequently into research studies, though 47% had ‘sometimes’ achieved this. One in five (20%) staff reported never successfully recruiting into studies.

Only 17% of staff felt that they would be likely to discuss research opportunities when a person was acutely unwell, but 68% reported that they would do so with someone in the ‘recovery phase’ of illness. Reflecting these findings only 20% of staff reported being ‘likely’ or ‘very likely’ to offer consent to contact (a declaration by a patient that they are happy to be asked about research in the future) in the acute phase. This rose to 70% in the recovery phase.

**Possible remedial factors**
We asked respondents to rate potential interventions that they believed could improve their ability and willingness to inform patients about research (see Figure 2). The three most common suggestions were:

- Readily accessible information on the intranet (71%)
- Access to information in a variety of formats to inform services users (66%)
- Signposting service users to readily accessible information (63%).

Over half of respondents (55%) also believed that simplifying the information provided was important and 60% felt that a dedicated R&D email as a means of gathering further information would be useful. A significant proportion of staff believed that training in this area was important, with 53% wanting access to training on discussing opportunities with patients, 44% wanting training on research principles and approval and 48% seeing the benefit of attending professional development courses in this area.

**Limitations**
This study used a convenient sample of community mental health workers in one Trust in southern England. Oxford Health NHSFT is an innovative and forward-thinking Trust that is relatively ‘research active’ so the issues identified here are likely to be even more pressing elsewhere. Our sample was large, however, and was representative of the service in terms of staff type. We believe as a result that the views expressed on this fairly general issue will be generalisable and reflected elsewhere.

**Discussion**
Recruitment to mental health studies remains a major barrier to the collection of high quality evidence to support and improve care. In the current system, clinicians nearly always are the ‘gatekeepers’ of access to patients for research participation. There is good evidence that patients understand research and its importance and want to be involved. We have shown that clinical staff are also generally positive about research but less so than those who would be taking part. While this is an issue across medicine (and indeed other areas of life) it appears particularly important in mental health care where patients may be seen as vulnerable or exploited. The fact that one in five staff report never having recruited someone into a research study is of concern given that research is a key NHS priority and a crucial factor in improving patient outcomes.

NHS trusts could play a more active role in developing such things as ‘consent to contact’ lists of patients who had opted to...
accept information about studies, but such schemes remain uncommon. One reason frequently cited for not doing this is ‘data protection’ – a concern that also often limits access to information about patient characteristics to allow for case finding. It is hoped that large data systems that are becoming available will transform this area but currently most NHS areas rely upon clinical staff entirely to identify and recruit participants, hence the importance of their attitudes.

We did not examine in detail why many clinical staff lacked the confidence to approach patients but experience suggests that it might be the fact that research is often managed separately and seen as ‘outside’ normal clinical practice. The suggestions made by staff appear to be ones which can be readily implemented and largely relate to increasing information for staff and patients and enhancing clinicians’ skills in introducing research to patients. In our service a video has been made to help inform staff regarding research and it includes a training scenario to enhance confidence. Most importantly, by embedding research staff in clinical teams we are striving to make research part of day-to-day care delivery and bring as many patients as possible to the point where it is them that say yes or no to research rather than others doing it on their behalf. Several large-scale studies have shown that the vast majority of patients support research and would consider taking part; this is now beyond debate. It is now time for services and those who run them to catch up and allow for that choice to be exercised. The barriers are significant in terms of organisational priorities, staff attitudes and training (as highlighted here), and the characteristics and use of information systems; however, they are not insurmountable.

Greater education and training will go some way towards the goal of empowering patient choice, and the embedding of research teams within clinical areas (as in specialties like oncology) will gradually change views and opinions so that they more closely reflect the reality. Better information systems and more innovative use of them (within all relevant safeguarding frameworks, of course) also have significant potential to shift the balance. If these factors together improve our ability to recruit to and successfully complete studies then future care will be better informed by robust evidence and as a result improve outcomes for patients.

Figure 2. Staff suggestions for improving participation in trials

Dr Carmichael is a first year Core Medical Trainee and Mr Misselbrook is a Clinical Research Assistant, both at Warneford Hospital, Oxford; Ms Marriner is a Research Assistant and Ms Forrest is a Research Implementation Manager, both at Oxford Health NHS Foundation Trust, and Dr Molodynski is a Consultant Psychiatrist at Oxford Health NHS Foundation Trust and Honorary Senior Clinical Lecturer at Oxford University.

Declaration of interests
No conflicts of interest were declared.

References