

Research Priorities for Service User and Carer-Centred Mental Health Services

Overview Report

Samele C, Wallcraft J, Naylor C, Keating F & Greatley A

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Introduction

In 2005 the National Co-ordinating Centre for Service Delivery and Organisation (NCCSDO) commissioned the Sainsbury Centre for Mental Health, led by the Research Section, to conduct a literature synthesis and consultation exercise to identify the research priorities for service user and carer centred mental health services.

The overall aim of both elements of work was to advise the NCCSDO Programme on the key areas of research that would create more service user and carer focused mental health services. The main objectives included:

- An understanding of what is meant by service user and carer centred services
- Identifying the research needs to achieve service user and carer centred services and to examine a range of specific groups (i.e. young people, older people, Black and ethnic minorities, and other traditionally excluded groups)
- A synthesis of the relevant literature
- Gathering the views of key stakeholders in a consultation exercise

This overview draws together the key research priorities emerging from the literature synthesis and consultation exercise and must be read in conjunction with these respective reports. For the purposes of this overview report, however, we summarise the key research priorities gathered from the two projects. We then discuss the three additional cross-cutting themes that emerged from the consultation exercise, which we consider central to promoting service user and carer centred research in all the priority areas identified. These are:

- Research into practice and dissemination
- Research methodologies
- Measures of outcome

In the final section we list a series of recommendations for research in relation to patient and carer-centred mental health and social care services.

Overall aims

Our aims were to:

- Provide a synthesis of existing work on service user and carer-centred services in mental health and social care, and
- Identify research priorities in mental health and social care.
- Establish the research priorities for service user and carer centred mental health services allowing relevant stakeholders to contribute to the process.

Methodology

Literature synthesis

We employed The Centre for Reviews and Dissemination (NHS CRD, 2001) guidelines for producing systematic reviews. Our key questions for the purposes of the literature synthesis were: a) what is the available literature in terms of research priorities and developments of mental health services, and in particular service user and carer-centred services in mental health? b) what research has been done to promote service user and carer-centred services? c) what gaps exist in the research and policy literature in mental health and social care?

Key bibliographic databases, relevant websites were searched for published literature. Grey literature and policy documents were searched using relevant websites. We kept our search terms and literature selection inclusion criteria deliberately broad. These included: i) people with mental health problems from a range of groups; ii) relevance to mental health and social care services; iii) restricted to countries with similar health care services to the UK, e.g. Canada, Australia; iv) English language papers only; and v) any study design.

We extracted relevant data from selected literature and synthesised this using a narrative analysis, including a description of all included studies, and thematic analysis of the data based on the research questions for this review (Dixon-Woods et al, 2004).

Data synthesis of the research recommendations listed in policy documents or other relevant grey literature was performed, and given equal weighting to the data drawn from research papers.

Consultation exercise

Three broad stakeholder groups were included: mental health service users; carers; and professionals working in mental health or related professions. We used an adapted Delphi method to reach a consensus with diverse stakeholder groups. A three stage process was employed to:

1. **Explore** service users' and carers' views regarding how services could be more centred on them and their needs and aspirations
2. **Develop** research areas based on these views – aimed at professional stakeholders who work in mental health and related sectors
3. **Prioritise** the developed research areas – aimed at all stakeholders

Semi-structured questionnaires were distributed via NHS Trusts, Primary Care Trusts, National Institute for Mental Health in England (NIMHE) and voluntary organisations.

We also conducted a series of focus groups with service users and carers with groups whom we anticipated would be under-represented in the questionnaire-based component, e.g. young people, older people and people from Black and Minority Ethnic (BME) groups.

We also recruited an Expert Group who included representatives from all stakeholder groups. The group was consulted via meetings at key stages of the consultation, at which the proposed methodology and emergent findings were discussed.

Patient carer-centred research priorities

Understanding patient carer-centred services

Our initial task was to gain an understanding of what patient and carer centred services meant. The literature synthesis sought to shed some clarity on what service user and carer centred services signified. The literature was not only limited but tended to conflate service user and carer centred services with activities relating to service user and carer involvement. One definition of service user and care centred services in the general health literature described it as shared control of the consultation and decisions and consideration of the person as a whole rather than focusing only on the disease process (Lewin et al, 2001, p.127). Patient centredness is generally conceptualised in terms of the context of the contact between the patient/service user and the professional. Mead and Bower (2000) describe five elements of patient-centredness which include the sharing of power and responsibility and therapeutic alliance. Gillespie et al (2004) found that patient-centredness is often viewed differently by patients and professionals. For the former patient-carer centred services emphasised the social or whole person model of health. Professionals used a medical model to describe patient centred care and the need to inform patients and engender trust as a way of delivering treatment. The key dimensions of patient centred care thus concern the way professionals and patients perceive this and ultimately the way in which care or treatment decisions are made and subsequently delivered.

It is clear that there is a need to gain a further understanding of the concept of patient and carer-centred services and its effects on the relationship between patients and professionals. Furthermore there is a need to take account of the full spectrum of potential activities that constitute patient-centred care (Gillespie et al, 2004).

Models of patient and carer-centred services

The Government policy aimed at modernising health services, including mental health services, seeks to improve the quality of care by creating new teams, staff and services. The focus for mental health services is on social inclusion and recovery. Examples of relatively new services include assertive outreach, crisis resolution and early intervention. Despite some research to assess the impact of these services there remains a lack of evidence to make conclusive judgements about their effectiveness.

Self-help is a new development introduced into mental health care. This has been found to help restore a sense of coping for people with mental health problems attending a primary care clinic (Rogers et al, 2004). However, service users need to be informed and educated about the nature of these services. The evidence base for self help initiatives is also limited and there is a need to expand this in terms of further evaluations and the role they play in providing patient and carer-centred services.

The use of modern technologies such as the internet can provide a useful means of support through dissemination of information about mental illness, medication and services for service users and carers (Sa'adiah, 2002). Other forms of technology including mobile phones are being used to act as a prompt or reminder of appointments and computer programmes to assist with diagnosis and

management of depression. These initiatives also require further exploration in terms of their potential impact.

Overall research priorities

Table 1 lists the principle themes gathered from the literature synthesis and consultation exercise and categorised according to services and interventions and common themes that span across all service issues.

Table 1
Overall research priority areas* by services and interventions and common themes for service user & carer centred mental health services

<i>Services & interventions</i>	<i>Common themes relevant to all service issues</i>
Care pathways & transitions between services	Marginalised groups
GPs & primary care	Service user & carer involvement in service planning & delivery
Medication & side effects	Workforce issues
Mental health in the criminal justice system	
Non-medication based interventions	
Person-centred care planning	
Prevention & mental health promotion	
Services for people in crisis	
Service user & carer centred services	
Social inclusion & the role of mental health & social care services	

* Listed in alphabetical order

The key areas emerging from the literature synthesis included:

- Patient-carer centred care
- Service user involvement
- Carer-centred care, carer involvement and support

- Marginalised groups
- General priorities

The consultation identified 12 key areas which to some extent overlapped with those gathered by the literature synthesis, particularly where patient and carer-centred care and service user and carer involvement were concerned. The priority areas resulting from the consultation included:

- GPs & primary care
- Prevention & mental health promotion
- Non-medication based interventions
- Social inclusion & the role of mental health & social care services
- Services for people in crisis
- Person-centred care planning
- User & carer involvement in service planning & delivery
- Supporting & empowering family members & carers
- Medication & side effects
- Care pathways & transitions between services
- Workforce issues
- Mental health in the criminal justice system

The three additional themes cutting across each of the 12 priority areas were:

- Research into practice and dissemination
- Research methodologies
- Measures of outcome

The following sections bring together all research priorities identified from both projects. The priority areas found by the literature synthesis, including the 'General Priorities', have been incorporated into the main themes of the consultation given they coincide considerably.

Services and interventions

Care pathways and transitions between services

Research is needed to improve the acceptability and efficiency with which service users move between different parts of the mental health system. The research priorities include:

- Good practice in transition planning. Developing new tools and guidelines to allow teams to link up and plan for transitions.
- How services can move away from 'exclusion criteria' and reduce multiple referrals and rejections
- How can referral pathways from primary care and community-based organisations to secondary services be clarified?
- Qualitative research examining service users' and carers' experiences of care pathways
- Care pathways followed by people from marginalised groups
- Explore the most effective ways of improving access to appropriate care

GP & primary care

Research is needed to improve the support provided within primary care for people with mental health problems, and improve the early detection of mental health problems within primary care. The research priorities include:

- How GPs can detect mental health problems at the earliest possible stage, e.g. using routine screening tools
- Effectiveness of counselling/therapy and other interventions in primary care in reducing referral to specialist services
- How to meet the physical health needs of people with mental health problems within primary care
- The quality of support and extent of choice within primary care for those with 'common mental health problems'
- Evaluation of 'stepped care' as a model for increasing access to mental health support in primary care by providing lower intensity interventions

Medication & side effects

Research is needed to ensure that medication is used in the most effective and acceptable way, with particular regard to minimising side effects and maximising user choice and control. Respondents called for research into:

- Ways of giving people more choice & control over the type and amount of medication they use
- The role of mental health pharmacists in improving prescribing, giving people accurate information & assisting with medicines management
- Side effects of long-term medication use
- Tailoring prescription to individual metabolic profile / genetic markers

Mental health in the criminal justice system

Research is needed to improve the quality of mental health care available within the criminal justice system & other secure settings, and the ability of Police & other staff to deal competently with mental health issues. The research priorities include:

- Effectiveness of user-led training for Police and prison staff regarding mental health, substance abuse and cultural sensitivity
- Mental health assessment processes and support within prisons & asylum seeker detention centres
- How courts deal with mental health assessments
- Court diversion from prison to other settings
- Treatment of people from Black and Minority Ethnic groups with mental health problems by the courts
- Secure units – service user satisfaction and experiences
- Family support for people with family members in secure units
- Treatment of people diagnosed with a personality disorder in prisons and secure settings
- Care available for people with a mental health problem after being discharged from prison or secure units
- The extent of use of Anti-Social Behaviour Orders against people with mental health problems
- Attitudes amongst generic mental health teams to service users with a 'forensic' label

Non-medication based interventions

Research is needed to improve access to effective non-medication based interventions. The research priorities include:

- Adapting and evaluating psychological therapies & other interventions to make them suitable for all client groups
- Identification of the key processes common to effective therapies so that therapeutic input can be made more flexible whilst retaining effectiveness
- Effectiveness of approaches based on diet & exercise
- Effectiveness of self-management techniques
- Evaluations of self-help initiatives and the role they play in service user and carer centred services
- Examine how we can increase the psychological components of care
- Evaluate effectiveness of behavioural interventions, e.g., for schizophrenia, and depression

Person-centred care planning

Research is needed to enable services to adopt a flexible, collaborative approach in which people are involved in planning their own care. Respondents called for research into:

- How best to use CPA care plans, advance directives, direct payments, Wellness and Recovery Action Plans (WRAP) etc.
- How marginalised groups can be better involved in planning their care
- Attitudinal barriers to collaborative working
- The long-term impact of user-led training for staff in mental health services
- How to manage differences of opinion when working collaboratively
- Evaluate the role of the care programme approach in delivering patient and carer-centred care

Prevention & mental health

Research is needed to enable the development of preventative interventions for high-risk groups, and interventions which promote mental well-being in the general population. The research priorities include:

- Psychosocial risk factors – especially drug abuse – and interventions which aim to protect people from them
- Long-term effectiveness of initiatives to teach children skills for looking after their mental health
- Preventative interventions for children whose parents have mental health problems
- Targeting preventative work effectively – which groups should be focused on?
- Evaluate the efficacy of mental health promotion

Service user and carer centred services

More research is needed to better understand what service user centred services are and the models that can be applied into practice. The research priorities include:

- More conceptual work is needed to clarify what is meant by service user and carer-centred services, the dimensions of such services and the organisational determinants for service user and carer-centred services
- Which interventions constitutes patient and carer-centred care, and
- Reliable and appropriate tools/outcome measures to assess the effects of interventions to promote patient and carer-centred care
- Best ways of training professionals to adopt patient and carer-centred approaches in their practice
- Explore how a more holistic model of mental illness could promote patient and carer-centred services.

Carers

Research is needed to focus on specific groups of carers, (i.e. young carers, BME carers, etc.) and effectiveness of services for carers who care for people with specific mental health problems (i.e. depression, eating disorders, anxiety disorders, substance abuse, and those with dual diagnosis, etc.). The research priorities include:

- Assessments of the needs of long-term carers
- The link between providing support for carers, their ability to cope and the quality of life of the person being supported
- Understanding how different communities/cultures view the caring role and how care is provided in these communities

Services for people in crisis

Research is needed to improve the quality of services for people in crisis. Respondents called for research into:

- Crisis houses, home treatment teams & other alternatives to acute wards – their role, function and outcomes

- How acute inpatient wards can be better linked with teams in the community, so that the care strategy can be focused on preparing for return to the community, and so that admission can be used in a flexible, planned way
- How inpatient wards can improve socially inclusive outcomes - ensuring that jobs, tenancies, and family relationships do not break down during admission
- Evaluation of alternative crisis provision aimed at particular client groups e.g. people with a diagnosis of personality disorder
- Redesigning acute wards using models from therapeutic communities, psychology-led inpatient services and crisis houses
- How best to work with those detained and treated against their will for an effective and mutually acceptable outcome
- Evaluate the effectiveness of acute services and the efficacy of user-led alternatives to inpatient care

Social inclusion & the role of mental health & social care services

Research is needed to explore how various services (e.g. day centres, housing services, employment services) can help people who use mental health services to become more involved in wider society. Research priorities included:

- How day centres can be part of a system that actively promotes social integration
- Effectiveness of a range of social support interventions
- How mental health agencies can work more closely with housing associations / local authorities to increase the stability of tenure and improve the quality of housing available for people with mental health problems
- Effectiveness of models of supported housing (including floating support)
- A high quality experimental trial of employment support in the UK
- Effectiveness of interventions aiming to address stigma in the workplace and within 'hard' groups e.g. JobCentrePlus staff, housing officers
- Study the efficacy of support interventions for socially isolated and vulnerable groups

Common themes for services

Common themes relevant to each of the 'services and interventions' research areas included marginalised groups; service user & carer involvement in service planning & development; and workforce issues. The specific research priorities for each are listed below.

Marginalised groups

Young people

Research is needed to evaluate the effectiveness, accessibility and acceptability of community based services for families and children. The needs of children and young people from BME communities have been neglected, as have the mental health needs of young offenders. The research priorities include:

- Research is needed to explore ways of improving the transition from child and adolescent to adult services, for service users and carers
- Research is needed establish the long-term risks of childhood psychiatric medication and to define dosages more precisely
- How inpatient units can be made more suitable for children and young people
- Alternative models for young people – e.g. intensive home treatment models.
- How mental health services can work with schools and colleges to ensure young service users are not excluded from education
- Making therapies more effective, accessible and acceptable for young people e.g. using computerised self-help programmes, narrative therapies
- Effectiveness of dietary-based interventions for young people diagnosed with Attention Deficit and Hyperactivity Disorder
- Long-term effectiveness of interventions used by Child and Adolescent teams in preventing mental health problems in later life
- Development of effective initiatives to teach children skills for looking after their mental health
- The role school nurses can play in early diagnosis of medical/social difficulties which may lead to mental health problems
- Preventative interventions for children in the care system
- How young people can be meaningfully involved in decisions around their care?
- Experiences of young people and their families of care pathways and access to services, to inform decisions about the most appropriate care pathways
- Mental and physical health impact on young people of parent's mental health – and effectiveness of interventions to reduce this
- Models for working with families – respective roles/rights of parents & young people
- Improve the evidence base on practice, clinical outcomes and effectiveness of services for children and young people
- Understand how to best meet the needs of particular groups of young people, such young people from BME communities and young offenders

Older people

Research is needed to examine residential options and the development of appropriate services and treatments for older people with particular mental health problems and other impairments. The research priorities include:

- What are the effects and side-effects of medication on older people, particularly around the issue of 'polypharmacy' – interactions resulting from taking several medicines in combination
- How acute inpatient units can be made more suitable for older people, especially those with a dementia
- Evaluation of residential options for people with dementia– including enhanced care at home, live-in support workers, overnight respite, supported housing.
- Importance of vocational activity (e.g. volunteering) in maintaining older peoples' mental health.
- Making therapies more accessible for older people with cognitive impairment
- Improving the detection and treatment of depression, anxiety and *physical* health problems in older adults with a dementia – ensuring dementia does not 'overshadow' other, treatable problems
- How the transition from adult to older people's services can be improved
- How referral pathways from primary care to secondary services can be clarified for older people with dementia or depression
- How older people with cognitive impairment can be meaningfully involved in decisions around their care?
- Skills needed for staff on inpatient wards to meet the needs of older adults

Black & ethnic minority groups

There is a need for research to identify culturally relevant and evidence based styles of service delivery for BME communities. Innovative work in Black-led voluntary organisations has been carried out and there is a need to identify the ways this knowledge can be mainstreamed. The research priorities include:

- Large scale evaluation of the role of Black-led voluntary sector agencies to identify service philosophies, content of services and outcomes
- Research is needed to examine how best to work with those detained and treated against their will for an effective and mutually acceptable outcome
- Making therapies accessible and acceptable for people from BME groups
- Pathways through the mental health system followed by people from BME groups
- How people from BME groups can be better involved in decision about their care
- How to address attitudes within services regarding service users from BME groups, in order to promote collaborative working
- Examine progress in reducing the inequalities and disparities in services for BME communities

Refugees and Asylum seekers

Often refugees and asylum seekers drop out of services early and are more likely receive pharmacological interventions instead of psychological treatment. The research priorities include:

- Making psychological therapies more accessible for refugees and asylum seekers
- Study the extent of psychological need in refugee and asylum seeker communities and to determine the most desirable treatment approaches

Women

Women and mental health issues revolve around acute wards, medication and preventive mental health initiatives at the time of childbirth. The research priorities include:

- Gender differences in the experience of acute wards. Differences in the frequency and impact of violent incidents and implications for staffing approaches, skills mix etc
- Effects and side effects of medication on women – this not always tested systematically
- Preventative interventions and mental health promotion initiatives for women around the time of childbirth
- Determine the effectiveness of treatment interventions in women and service evaluation
- Service evaluation and research should include gender as a key variable in analysis and presentation

People with learning difficulties and autistic spectrum disorders

Research is needed to improve the quality of mental health care available for people with learning difficulties and/or autistic spectrum disorders (ASD). The research priorities include:

- Research is needed to clarify the respective roles of mental health and learning disability services and under what circumstances people with learning disabilities should use each service
- Study the experiences of people with learning disabilities of mental health services,
- Measuring met and unmet mental health needs
- Effectiveness of alternative models of service provision
- Capacity and willingness of mainstream mental health services to meet the needs of individuals with learning difficulties / ASD
- Improving detection of mental health problems, particularly within primary care rather than being 'overshadowed' by learning difficulty / ASD
- Inappropriate prescription of anti-psychotics for people with learning difficulties / ASD
- How people with learning difficulties / ASD can be meaningfully involved in decision about their care
- Generic vs. specialist inpatient units – experimental evaluation looking at differences in outcomes/length of stay/readmissions
- Making therapies accessible for people with learning difficulties / ASD
- Carer support - effectiveness of informal carer interventions and role-modelling, and provision and uptake of respite services

People with a dual diagnosis

Service models for dual diagnosis are at an earlier stage of development. Research is needed to identify the most active and important ingredients of successful therapy for people with a mental health problem and substance misuse. The research priorities include:

- Epidemiological studies to assess the nature and extent of the problem, further development of interventions and service models and evaluations of their effectiveness
- Set up clinical trials to identify the most important ingredients of successful therapy for people with dual diagnosis
- Study the impact of different service models to meet the needs of people with dual diagnosis

Homeless people

Mental health in the criminal justice system emerged as a key priority for people who had experience of rough sleeping or living without stable accommodation. For some of them, mental health problems, offending and homelessness formed a “vicious circle”. Other research priorities includes:

- How services would need to be organised in order to be accessible to homeless people
- Preventative interventions targeted at the children living without stable accommodation
- Housing options – how homeless people with mental health needs can be supported into independent accommodation

Lesbian, Gay, Bisexual & Transgender people

Sexual minority groups often fail to register alongside other forms of minorities despite significant mental health needs. Research priorities include:

- Mental health needs of these groups
- Staff attitudes towards service users from these groups – the impact of prejudice

Deaf people

Deafness poses a particular challenge to mental health services. Research priorities include.

- Adapting psychological therapies for deaf people
- Ways of enabling deaf people to participate in planning their treatment
- Segregated Vs mainstream provision. Models of good practice in supporting this client group
- Good practice in joint working between mental health services and specialist voluntary/independent sector providers

Service user & carer involvement in service planning & development

Service user involvement

Research is needed to enable meaningful and representative involvement of service users and carers in planning and delivering services, including through user-led services. The research priorities included:

- Models of support that enable service users and carers to be involved in the most meaningful way, particularly in acute care settings
- Involving marginalised groups so that all people are represented
- How trusts can support and promote user-led services and user organisations
- Feedback/complaints systems within services – accessibility & effectiveness
- Effectiveness of training/interventions to promote positive attitudes and behaviour regarding user/carers involvement amongst staff
- The development and evaluations of outcomes for advocacy
- Evaluation of models that translate service user and carer involvement into practice
- Evaluation of the effects of service user involvement on the use of services, the quality of care, satisfaction with care

- Evaluate how service user involvement can be translated into patient-centred care
- Evaluate to whether participatory approaches, such as action research and observational studies contribute to the knowledge base on patient and carer-centred mental health services

Carer involvement

Research is needed to:

- Evaluate how carer involvement can be improved and how this can be translated into carer-centred services
- Study the long term impact of caring
- Identify the needs of specific groups of carers such as young carers, carers from BME communities, and those who support someone with a dual diagnosis
- Examine the links between providing support for carers, their ability to cope and the quality of life of the person being supported
- Differentiate between the effectiveness of interventions for specific groups of carers, e.g., spouse and non spouse carers, female and male carers, etc.

Workforce Issues

Research is needed to clarify the workforce, skill mix and team working arrangements required to allow services to become more user & carer-centred.

Respondents called for research into:

- Workforce requirements to make inpatient wards more therapeutic environments
- Workforce requirements in crisis teams to minimise the need for hospital admission
- Workforce requirements to allow community teams to become more responsive to people's needs
- Combating stress and low morale within the workforce, and thereby increasing continuity of care
- Training and supervision arrangements required for therapies to remain effective
- Role of non-medical professionals in mental health teams – how can their experience be better harnessed?

Cross-cutting issues

Three additional themes emerged from the consultation that were relevant to all of the priority areas listed above. We considered these themes to be highly important and worthy of particular attention. These were:

- a) putting research into practice and dissemination,
- b) research methodology, and
- c) measures of outcomes

Research into practice & dissemination

The current mechanisms for putting research into practice were deemed inadequate by many respondents to the consultation, and that this inadequacy “devalues research”. Respondents stated that in the case of some of service users’ and carers’ priority areas (e.g. psychological therapies) adequate research had already been conducted, but not acted upon.

Respondents described four separate failings, at different levels of the health system, including the failure to:

- (i) make research relevant to real practice
- (ii) base policy on research evidence
- (iii) base management decisions on research evidence
- (iv) change practice on the basis of messages from research and policy

Respondents also described potential solutions to these failures:

- More practice-based research would improve clinical relevance
- Increasing the role of service users and carers in research and the use of ‘action research’ approaches would ensure that the research conducted is the research people want
- Improving the links between researchers and providers of professional training
- Establishing clear channels for sharing research findings with all stakeholders, including service users and carers
- Examining the processes by which Local Implementation Teams (LITs) implement policy guidance
- Developing active strategies for anticipating and overcoming resistance to developmental change
- Research exploring the implementation and impact of NICE guidelines
- Establishing a process for deciding how new research knowledge is prioritised for implementation

An underlying principle implicit within the above solutions is to conduct research that is more applicable to practice. Effectively this would prevent any further generation of the gap between research and practice. This may have already started with the current overhaul in health research funding by the Department of Health. Best Research for Best Health (2006) seeks to establish Research Centres within leading NHS and University partnerships to drive progress on innovation and translational research in biomedicine and NHS service quality and safety. The infrastructure by which to achieve this was the creation of the National Institute for Health Research (NIHR). Programme Grants for Applied Research have been introduced.

Research in this instance would have the role of assessing whether the current changes in funding health research lead to a more direct adoption of research, but there should also be further investment and exploration in less complex methods of: a) making research findings more accessible to practitioners, b) exploring how practitioners can be made more receptive to implementing research findings, and c) evaluating whether this makes a difference to practice and outcomes.

Dissemination of research findings to service users and carers :

Knowledge and understanding of the benefits of research as a means to improving health services varied dramatically among the different stakeholder groups consulted. Mental health service users and carers were the least well informed of all the stakeholder groups regarding past and present research evidence. This was apparent on two levels. The first concerned the difficulty service users and carers had in expressing what sort of research ought to be conducted. We found service users and carers were more adept at describing their experiences of mental health services and the improvements they considered to be important to implement. Some of these improvements listed in the stage one priority areas have already received considerable research attention and pointed out in stage two by professional stakeholders (such as employment and psychological therapies). This highlighted two issues 1) the lack of implementation of research into practice, and 2) the lack of dissemination of research findings to service users and carers.

The latter issue is unsurprising given the limited access these groups have to such evidence, and even where available the inappropriate format by which it is provided. Very often the evidence base is targeted almost exclusively at academics, and to a lesser extent, health professionals. How then can service users and carers gain access to and benefit from the current research base, thereby using this knowledge to improve their quality of life? At present there are few effective systems in place to transfer research evidence directly to service users and carers. What systems are available are mostly through the voluntary sector and DH websites. However, ensuring a wider dissemination of the evidence to service users and carers could be via the health practitioner. That, however, requires the practitioner to be well informed of the evidence base, (which has received some investment), to explain effective treatment/care options in a way that service users and carers find useful. This neatly links in with the current policy agenda on Choice and the provision of information to enable service users make meaningful choices (CSIP 2006). A further advantage of having this knowledge would be to enable service users and carers to lobby government in an effort to change policy.

In adopting a broader dissemination of research findings to service users and carers research would be needed to:

- Develop models for the effective dissemination of research findings to service users and carers
- Evaluations to assess whether service users and carers with access to and understanding of the evidence base have improved outcomes, including quality of life.

Research methodologies

A key theme from the literature was the importance of user-led research. Research is needed to seek new research methodologies to allow for the effective participation of service users and carers in research. This would include:

- Exploration of participatory approaches
- Adaptations of existing research methods for better involvement of service users and carers.
- Evaluations of the benefits of that involvement
- What are the most effective ways to develop and commission user-led research
- What new research methodologies are needed to allow for effective participation of service users and carers in research
- How can a 'multi-perspectives' paradigm be used to integrate various sources of evidence

The emphasis placed by respondents to the consultation argued that research areas generated by service users and carers would be more amenable to qualitative approaches than Randomised Controlled Trials (RCTs) or other quantitative techniques.

Research is needed to explore how:

- Accounts gathered from personal narrative research can lead to greater insights into the causes of mental health problems
- Preventative interventions can be developed using narrative approaches
- The demand for high quality qualitative research can be met
- The development of adequate training in these qualitative methodologies can be made more efficient and accessible for service user and carer involvement in research
- The outputs from qualitative research can be more readily accepted by the academic and policy communities

The latter priority requires a policy shift in the Research Councils and the National Institute for Clinical Excellence towards a greater valuing of qualitative methods, especially in relation to human services and particularly in mental health where so much depends on a quality experience/relationship between service user and practitioner. This might lead to greater investment in a) developing and refining qualitative methodology in mental health b) more large-scale qualitative research studies being run by prestigious institutions and commissioned by PCTs and Trusts and c) more readiness by practitioners to value and implement the results of qualitative research. In the meantime, 'grey' literature such as qualitative studies carried out by leading mental health charities should be valued more highly as indicative of the priorities of service users and carers and the meanings and values they attach to certain forms of intervention.

Outcome measures

The final cross cutting theme concerned the need to develop improved measures of service user and carer-centred outcomes. Respondents argued these outcome measures would better reflect the life goals considered important by the service user, rather than reduction in symptoms. This theme therefore is critical to any evaluations assessing the effectiveness of interventions in any of the priority

areas covered above. The importance of service user based outcomes is stressed in a critical review by Gilbody et al (2003). This review verifies the dominance of measuring psychiatric symptoms, and also points out that psychiatrists in the UK rarely use outcome measures. These authors state a number of research priorities. These include research to:

- Support the potential for routine outcomes measures to improve the quality of mental healthcare
- Assess the suitability and value of service user based outcomes measure in research and practice

Developing service user and carer centred outcome measures for research cannot be overestimated. Thus far there has been insufficient attention given to how to develop this kind of measures, especially in the area of Randomised Control Trials and clinical trials generally. Service user and carer involvement in developing outcome measures would be crucial to their validity in measuring items of agreed importance to service users and carers. What is needed is a policy agenda that a) directs resources to the urgent development and testing of such measures and b) ensures that all mental health research studies demonstrate that they have used valid and reliable outcome measures (i.e. those considered to be valid by service user and carers) reliability would emerge in testing the measures.

Research priorities by different stakeholder groups

We carried out a series of analyses to look at the differences between stakeholder groups and the research areas they prioritised. Interestingly, there was a fair degree of similarity between the three main groups we initially examined – service users, carers and professional. All three main stakeholder groups rated 'GPs and primary care', 'Prevention and promotion', 'Non-medication based interventions' and 'Social inclusion' quite highly. Hence, there were more similarities between the three groups than differences. Further comparisons between these groups found service users rated 'Crisis services' as their top priority, more so than carers and professionals. For carers 'Carer support and empowerment' was rated their highest priority area. Professionals rated 'Prevention and promotion' highly.

Other interesting differences were found between professional groups. Academics, senior health service professionals and social care workers rated 'Social inclusion' very highly. Practitioners, however, rated this area lower by comparison. Also for senior health professionals 'Service user/carer involvement' took high priority.

We also analysed responses to uncover groups or clusters of participants. We identified three clusters of people. One group (Cluster 2) accounted for 49% of our total sample (n=292) and consistently rated all research areas highly, with emphasis on 'GPs and primary care', 'care pathways' and 'medication and side effects'. The other two groups (clusters 1 and 3) were more difficult to interpret as their ratings pattern differed. Cluster 1 (n=151) had a 'service focus' and prioritised 'GPs and primary care', 'care pathways' and 'medication and side effects'. Whereas Cluster 3 (n=154) focused on social inclusion and service user empowerment by rating these areas highly.

We looked at the composition of each cluster by three stakeholder groups (service user, carer and professional). This revealed the heterogeneity of each cluster. In other words, no particular stakeholder group appeared to predominate in any one cluster. Each cluster comprised of a relatively even number of all three stakeholder groups. We were unable to pinpoint, with the limited demographic data we had on respondents (i.e. age, gender, ethnicity and location), what factors influenced the way each cluster group rated areas more highly than others.

Recommendations

Here we list our main recommendations for research derived from both the literature synthesis and consultation reports and subdivided by potential target audience – research funding agencies, policy makers and local research and developments groups.

Recommendations for research funding agencies

- Research needs to be funded in all 12 of the areas identified by the consultation, and in particular the 4 areas where the strongest consensus exists between service users, carers and professionals:
 - Primary care
 - Prevention and promotion
 - Non-medication based interventions
 - Social inclusion
- The most important issue for service users is the quality of care available for people in crisis. This includes inpatient care and community alternatives. This area must receive further research attention if we are to claim that our mental health services are in any way 'patient centred'.
- Stakeholders identified a "shameful" lack of research attention to the mental health needs of children and young people, older people (particularly those with a dementia), women and people with learning difficulties.
- Mechanisms for putting research into practice and disseminating findings to stakeholders (including service users and carers) need to be improved. Participants in the consultation observed that the failure to implement research findings "devalues research".
- There is a need to develop researchers' skills in qualitative methodologies and to strengthen connections between health researchers and disciplines with a stronger tradition of qualitative methodologies e.g. sociology.
- The use of user-centred outcome measures needs to be encouraged in all trials of mental health interventions and services.
- Understanding how patient and carer-centred services can be better conceptualised and thus developed into service models is key to ensuring the implementation of patient and carer centred services.

Recommendations for policy makers

- The consultation reaffirms the existence of several of the research gaps identified by The National Service Framework – Five Years On (DH 2004). In particular:
 - Mental health promotion
 - Services for carers
 - Inpatient care
 - Forensic services
- A policy focus on primary care, early intervention, prevention and promotion would be particularly likely to receive wide support from service users, carers and professionals alike.
- There is wide support for many of the concepts predominant in recent policy documents – e.g. patient-centred care, social inclusion, user

involvement – but also a pressing need to define these concepts more precisely and establish how they can be implemented effectively.

- A strong consensus exists behind the need to develop a mental health system which is not reliant on medication but which also provides access to psychological therapies and approaches based on diet, exercise and self-management. This concurs with the agenda currently being promoted by Professor Lord Layard concerning the expansion of access to psychological therapies.
- Mechanisms for putting research into practice and disseminating findings to stakeholders (including service users and carers) need to be improved. Participants in the consultation observed that the failure to implement research findings “devalues research”.
- Despite policy attempts to address the needs of marginalised groups there remains a lack of evidence to demonstrate how best to meet the needs of certain groups, particularly Black and Ethnic Minority groups, carers, younger people and young offenders.

Recommendations for R&D groups in local services

- Several of the research areas identified by the consultation will need to be pursued at least in part at a local level. In particular:
 - Research is needed to clarify the workforce, skill mix and team working arrangements required to allow services to become more user & carer-centred
 - Research is needed to improve the acceptability and efficiency with which service users move between different parts of the mental health system e.g. from child and adolescent to adult services
- Mechanisms for putting research into practice and disseminating findings to stakeholders (including service users and carers) need to be improved. Local R&D groups could play a vital role in improving connections between practitioners and service users locally and the national research community.
- The consultation suggested that differences of perspective between different types of professionals were as great as those between service users and professionals generally. In particular, there was evidence that practitioners may have less enthusiasm for concepts such as user involvement and social inclusion than people working in research, management and policy roles.
- It is useful for local services to gain an understanding of the potential attitudinal barriers when implementing policy and how these can be surmounted.
- The literature synthesis identified a gap in how service user and carer involvement can fail to translate into practice to generate more patient and carer-centred services. Local evaluations can help to assist with this translation process.

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Appendices

Appendix A – Priorities by research type

Priorities for health services research

GPs and primary care

- How to meet the physical health needs of people with mental health problems within primary care
- The quality of support and extent of choice within primary care for those with 'common mental health problems'
- How primary care can forge good links with secondary teams
- Evaluation of 'stepped care' as a model for increasing access to mental health support in primary care by providing lower intensity interventions
- Effective means of delivering primary mental health care to refugees and asylum seekers
- Improving detection of mental health problems, particularly within primary care rather than being 'overshadowed' by learning difficulty / ASD

Social inclusion

- How day centres can be part of a system that actively promotes social integration
- Practical steps and methodologies for services and agencies to implement the principles of social inclusion
- How mental health services can work with schools and colleges to ensure young service users are not excluded from education

Crisis services

- Crisis houses, home treatment teams & other alternatives to acute wards – their role, function and outcomes
- How acute inpatient wards can be better linked with teams in the community, so that the care strategy can be focused on preparing for return to the community, and so that admission can be used in a flexible, planned way
- How inpatient wards can improve socially inclusive outcomes - ensuring that jobs, tenancies, and family relationships do not break down during admission
- Evaluation of alternative crisis provision aimed at particular client groups e.g. people with a diagnosis of personality disorder
- Redesigning acute wards using models from therapeutic communities, psychology-led inpatient services and crisis houses
- How inpatient units can be made more suitable for young people
- Alternative models for young people – e.g. intensive home treatment models
- How acute inpatient units can be made more suitable for older people, especially those with a dementia
- Gender differences in the experience of acute wards. Differences in the frequency and impact of violent incidents and implications for staffing approaches, skills mix etc

- Generic Vs specialist inpatient units for people with LD – experimental evaluation looking at differences in outcomes/length of stay/readmissions
- How inpatient units can be made more suitable for children and young people
- Evaluate the effectiveness of acute services and the efficacy of user-led alternatives to inpatient care
- Alternative models for young people – e.g. intensive home treatment models.

Service user and carer-centred care

Research is needed to identify:

- What patient and carer-centred care means
- What its key dimensions are
- Which interventions constitutes patient and carer-centred care
- reliable and appropriate tools/outcome measures to assess the effects of interventions to promote patient and carer-centred care
- Best ways of training professionals to adopt patient and carer-centred approaches in their practice
- Explore how a more holistic model of mental illness could promote patient and carer-centred services
- Evaluate the role of the care programme approach in delivering patient and carer-centred care
- Segregated Vs mainstream provision. Models of good practice in supporting deaf people
- Good practice in joint working between mental health services and specialist voluntary/independent sector providers for deaf people

Person centred care planning

- Attitudinal barriers to collaborative working
- The long-term impact of user-led training for staff in mental health services
- How to address attitudes within services regarding service users from BME groups, in order to promote collaborative working
- More conceptual work is needed to clarify what is meant by patient and carer-centred services, the dimensions of such services and the organisational determinants for patient and carer-centred services.
- How can services be encouraged to move from a disease management model and use more a more person-centred approach that takes into account their needs, lives and health concerns
- How young people can be meaningfully involved in decisions around their care?
- How older people with cognitive impairment can be meaningfully involved in decisions around their care?
- How people from BME groups can be better involved in decision about their care
- Ways of enabling deaf people to participate in planning their treatment

Medication

- The role of mental health pharmacists in improving prescribing, giving people accurate information & assisting with medicines management

User/carers involvement & carer support

- Models of support that enable service users and carers to be involved in the most meaningful way
- Involving marginalised groups so that all people are represented
- Outcomes of involvement work

- How trusts can support and promote user-led services and user organisations
- Feedback/complaints systems within services – accessibility & effectiveness
- Effectiveness of training/interventions to promote positive attitudes and behaviour regarding user/carer involvement amongst staff
- Evaluate how service user involvement can be translated into patient-centred care
- Models for working with families – respective roles/rights of parents & young people
- How to address attitudes within services regarding service users from BME groups, in order to promote collaborative working
- Evaluate to whether participatory approaches, such as action research and observational studies contribute to the knowledge base on patient and carer-centred mental health services
- Evaluate how carer involvement can be improved and how this can be translated into carer-centred services
- study the long term impact of caring
- Identify the needs of specific groups of carers such as young carers, carers from BME communities, and those who support someone with a dual diagnosis
- Examine the links between providing support for carers, their ability to cope and the quality of life of the person being supported
- Differentiate between the effectiveness of interventions for specific groups of carers, e.g., spouse and non spouse carers, female and male carers, etc.
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Marginalised groups

- Study the experiences of people with learning disabilities of mental health services
- Measuring met and unmet mental health needs in people with learning disabilities
- Study the impact of different service models to meet the needs of people with dual diagnosis
- Understand how to best meet the needs of particular groups of young people, such young people from BME communities and young offenders,
- Service evaluation and research should include gender as a key variable in analysis and presentation.
- Examine progress in reducing the inequalities and disparities in services for BME communities
- Research is needed to explore ways of improving the transition from child and adolescent to adult services, for service users and carers
- How mental health services can work with schools and colleges to ensure young service users are not excluded from education
- Evaluation of residential options for people with dementia– including enhanced care at home, live-in support workers, overnight respite, supported housing
- Large scale evaluation of the role of Black-led voluntary sector agencies to identify service philosophies, content of services and outcomes
- Research is needed to clarify the respective roles of mental health and learning disability services and under what circumstances people with learning disabilities should use each service
- Effectiveness of alternative models of service provision for people with learning disabilities
- Capacity and willingness of mainstream mental health services to meet the needs of individuals with learning difficulties / ASD

- How services would need to be organised in order to be accessible to homeless people
- Staff attitudes towards service users from lesbian, gay, bisexual and transgender groups – the impact of prejudice

Workforce issues

- Workforce requirements to make inpatient wards more therapeutic environments
- Workforce requirements in crisis teams to minimise the need for hospital admission
- Workforce requirements to allow community teams to become more responsive to people's needs
- Combating stress and low morale within the workforce, and thereby increasing continuity of care
- Ethnic diversity within the mental health workforce
- Skills needed for staff on inpatient wards / residential units to meet the needs of older adults e.g. relating to dementia and physical health

Care pathways and transitions

- Good practice in transition planning. Developing new tools and guidelines to allow teams to link up and plan for transitions.
- How services can move away from 'exclusion criteria' and reduce multiple referrals and rejections
- How can referral pathways from primary care and community-based organisations to secondary services be clarified?
- Qualitative research examining service users' and carers' experiences of care pathways
- Care pathways followed by people from marginalised groups
- How to improve the transition from child and adolescent to adult services, for service users and carers
- Experiences of young people and their families of care pathways and access to services, to inform decisions about the most appropriate care pathways
- How the transition from adult to older people's services can be improved
- How referral pathways from primary care to secondary services can be clarified for older people with dementia or depression
- Explore the most effective ways of improving access to appropriate care
- Experiences of young people and their families of care pathways and access to services, to inform decisions about the most appropriate care pathways
- How the transition from adult to older people's services can be improved
- How referral pathways from primary care to secondary services can be clarified for older people with dementia or depression
- Pathways through the mental health system followed by people from BME groups

Criminal justice system

- Mental health assessment processes and support within prisons
- Court diversion from prison to other settings
- Secure units – service user satisfaction and experiences
- Family support for people with family members in secure units and prisons
- Treatment of people diagnosed with a personality disorder in prisons and secure settings
- Care available for people with a mental health problem after being discharged from prison or secure units

- Attitudes amongst generic mental health teams to service users with a 'forensic' label

Dissemination of research to service users & carers

- Develop models for the effective dissemination of research findings to service users and carers
- Evaluations to assess whether service users and carers with access to and understanding of the evidence base have improved outcomes, including quality of life.

Research methodologies

- Accounts gathered from personal narrative research can lead to greater insights into the causes of mental health problems
- Preventative interventions can be developed using narrative approaches
- The demand for high quality qualitative research can be met
- The development of adequate training in these qualitative methodologies can be made more efficient and accessible for service user and carer involvement in research
- The outputs from qualitative research can be more readily accepted by the academic and policy communities
- Exploration of participatory approaches that enhance service user and carer-led research
- Adaptations of existing research methods for better involvement of service users and carers. Finding the most effective of supporting service user and carer involvement in research
- Evaluations of the benefits of that involvement

Outcome measures

- Support the potential for routine outcomes measures to improve the quality of mental healthcare
- Assess the suitability and value of service user based outcomes measure in research and practice
- What new research methodologies are needed to allow for effective participation of service users and carers in research
- How can a 'multi-perspectives' paradigm be use to integrate various sources of evidence

Priorities for public health research

Prevention and promotion

- The role school nurses can play in early diagnosis of medical/social difficulties which may lead to mental health problems
- Long-term effectiveness of initiatives to teach children skills for looking after their mental health
- Preventative interventions for children whose parents have mental health problems
- Long-term effectiveness of interventions used by Child and Adolescent teams in preventing mental health problems in later life
- Preventative interventions for children in the care system
- Preventative interventions and mental health promotion initiatives for women around the time of childbirth
- Mental health promotion strategies for people with learning difficulties
- Evaluate the efficacy of mental health promotion
- Development of effective initiatives to teach children skills for looking after their mental health
- The role school nurses can play in early diagnosis of medical/social difficulties which may lead to mental health problems
- Preventative interventions for children in the care system
- Preventative interventions targeted at the children living without stable accommodation

Priorities for medical and clinical research

GPs and primary care

- How GPs can detect mental health problems at the earliest possible stage, e.g. using routine screening tools
- Effectiveness of counselling/therapy and other interventions in primary care in reducing referral to specialist services
- Improving the detection and treatment of depression and anxiety in older adults with a dementia – ensuring dementia does not ‘overshadow’ other, treatable problems
- Improving detection of mental health problems within primary care – ensuring learning difficulties / ASD do not ‘overshadow’ these
- Improving the detection and treatment of depression, anxiety and *physical* health problems in older adults with a dementia – ensuring dementia does not ‘overshadow’ other, treatable problems

Non-medication based interventions

- Adapting and evaluating psychological therapies & other interventions to make them suitable for all client groups
- Identification of the key processes common to effective therapies so that therapeutic input can be made more flexible whilst retaining effectiveness
- How to make psychological therapies more person-centred by giving clients greater information and control over the process
- Effectiveness of approaches based on diet & exercise
- Effectiveness of self-management techniques
- Examine how we can increase the psychological components of care
- Evaluate effectiveness of behavioural interventions, e.g., for schizophrenia, and depression
- Making therapies more effective, accessible and acceptable for young people e.g. using computerised self-help programmes, narrative therapies

- Effectiveness of dietary-based interventions for young people diagnosed with Attention Deficit and Hyperactivity Disorder
- Making therapies accessible and acceptable for people from BME groups, for refugees and asylum seekers and people with learning disabilities
- Making therapies more accessible for older people with cognitive impairment
- Adapting psychological therapies for deaf people

Crisis services

- How best to work with those detained and treated against their will for an effective and mutually acceptable outcome
- How acute inpatient units can be made more suitable for older people, especially those with a dementia
- Generic vs. specialist inpatient units – experimental evaluation looking at differences in outcomes/length of stay/readmissions for people with learning disabilities

Person centred care planning

- How best to use CPA care plans, advance directives, direct payments, Wellness and Recovery Action Plans (WRAP) etc.
- How marginalised groups can be meaningfully involved in planning their care, including those with a learning disability
- How to manage differences of opinion when working collaboratively

Medication

- Ways of giving people more choice & control over the type and amount of medication they use
- Inappropriate prescription of anti-psychotics for people with learning difficulties / ASD
- Research is needed establish the long-term risks of childhood psychiatric medication and to define dosages more precisely
- What are the effects and side-effects of medication on older people, particularly around the issue of 'polypharmacy' – interactions resulting from taking several medicines in combination
- Effects and side effects of medication on women – this not always tested systematically
- Inappropriate prescription of anti-psychotics for people with learning difficulties / ASD

Carer support and empowerment

- Carer support/education programs – e.g. for families immediately after a person is discharged from an inpatient unit
- Effectiveness of interventions to reduce the mental and physical health impact of caring –especially for young children with a parent or older sibling who uses services, and older carers
- Models for working with families from family-based therapies & the voluntary sector
- Evaluation of the carers assessment process inc. comparison of those conducted by carer support workers Vs professionals involved with the service user
- Evaluation of respite procedures – which models work best, for whom, in what circumstances?
- The link between providing support for carers, their ability to cope and the quality of life of the person being supported

- Assessments of the needs of long-term carers
- Carer support - effectiveness of informal carer interventions and role-modelling, and provision and uptake of respite services for those caring for people with learning disabilities

Workforce issues

- Training and supervision arrangements required for therapies to remain effective
- Role of non-medical professionals in mental health teams – how can their experience be better harnessed?

Marginalised groups

- Mental and physical health impact on young people of parent's mental health – and effectiveness of interventions to reduce this
- An exploration of psychological need to determine the most appropriate treatment options for this group
- Determine the effectiveness of treatment interventions in women and service evaluation
- Service evaluation and research should include gender as a key variable in analysis and presentation
- Epidemiological studies to assess the nature and extent of the problem, further development of interventions and service models and evaluations of their effectiveness
- Set up clinical trials to identify the most important ingredients of successful therapy for people with dual diagnosis
- Study the impact of different service models to meet the needs of people with dual diagnosis
- Mental health needs of Lesbian, Gay, Bisexual & Transgender people

Priorities for social research

Prevention and promotion

- Psychosocial risk factors – especially drug abuse – and interventions which aim to protect people from them
- Targeting preventative work effectively – which groups should be focused on?

Social inclusion

- How mental health agencies can work more closely with housing associations / local authorities to increase the stability of tenure and improve the quality of housing available for people with mental health problems
- Effectiveness of models of supported housing (including floating support)
- A high quality experimental trial of employment support in the UK
- Effectiveness of interventions aiming to address stigma in schools, the workplace and within 'hard' groups e.g. JobCentrePlus staff, housing officers
- Effectiveness of vocational activity (e.g. volunteering) in maintaining older peoples' mental health.
- Evaluation of residential options for people with dementia– including enhanced care at home, live-in support workers, overnight respite, supported housing.
- Effectiveness and efficacy of social support interventions, particularly for socially isolated and vulnerable groups

- Importance of vocational activity (e.g. volunteering) in maintaining older peoples' mental health
- Housing options – how homeless people with mental health needs can be supported into independent accommodation

Criminal justice system

- Effectiveness of user-led training for Police and prison staff regarding mental health, substance abuse and cultural sensitivity
- Treatment of people from Black and Minority Ethnic groups with mental health problems by the courts
- How courts deal with mental health assessments

Carer support and empowerment

- Cultural issues impacting on the involvement of families and carers within BME groups
- Understanding how different communities/cultures view the caring role and how care is provided in these communities

Marginalised groups

- Improve the evidence base on practice, clinical outcomes and effectiveness of services for children and young people
- Set up clinical trials to identify the most important ingredients of successful therapy for people with dual diagnosis
- Study the extent of psychological need in refugee and asylum seeker communities and to determine the most desirable treatment approaches
- Determine the effectiveness of treatment interventions for women